A practical guide to tests and treatments

# UNDERSTANDING CHEMOTHERAPY





# About this booklet

This booklet is about chemotherapy, which is a treatment for cancer. We explain how chemotherapy works and how it's given. There is also information about common side effects, how they can be treated and what you can do to manage them.

Your cancer doctor or specialist nurse will talk to you about the chemotherapy recommended for your situation and answer any questions you have.

We have more information about particular chemotherapy drugs and many commonly used combinations of drugs. If you would like any of this information, please contact us or download it from our website at macmillan.org.uk

In this booklet we've included quotes from people who have had chemotherapy, which you might find helpful. They are from people who have chosen to share their experience on our online community website community.macmillan.org.uk Some names have been changed. Some quotes are from Kate, who is on the front of this booklet. She has chosen to share her story with us.

#### To find out more

If you'd like to discuss the information in this booklet, call the Macmillan Support Line free on 0808 808 00 00, Monday-Friday, 9am-8pm. If you're hard of hearing, you can use textphone 0808 808 0121, or Text Relay. For non-English speakers, interpreters are available. Or, visit macmillan.org.uk.

Turn to pages 111–115 for some useful addresses and helpful websites. You'll find a useful table on pages 116-117 where you can make notes about your own chemotherapy treatment. There's also a list of questions you may want to ask your cancer doctor or specialist nurse on pages 118-119.

Macmillan has an easy to use app called My Organiser that you can download for free on your mobile phone from the Apple App Store or Google Play. This can help you organise and record things that are important to you. It helps you to remember when appointments are coming up, when to take medication and links you to information and support to help you through treatment.

If you find this booklet helpful, you could pass it on to your family and friends. They may want information to help them support you. We also have a website called The Source which has comments and advice from people who have had cancer or been affected in some way (source.macmillan.org.uk). Family and friends can find valuable information to help them know what to say or do when someone they care about has cancer. You can also share your own tips.

# **Contents**

What is chemotherapy?

Having chemotherapy

Side effects of chemotherapy

Life during chemotherapy

After treatment

Further information

5

19

47

85

97

105



# WHAT IS CHEMOTHERAPY?

What is cancer?	6
Chemotherapy	9
How chemotherapy drugs work	11
When chemotherapy is used	13
Planning chemotherapy	14

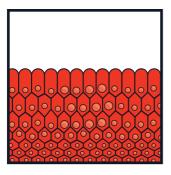
# What is cancer?

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

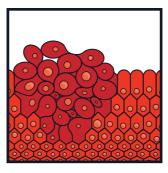
Cancer starts in cells in our body. Cells are tiny building blocks that make up the organs and tissues of our bodies. They divide to make new cells in a controlled way. This is how our bodies grow, heal and repair. Cells receive signals from the body telling them when to divide and grow and when to stop 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 (see below).

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

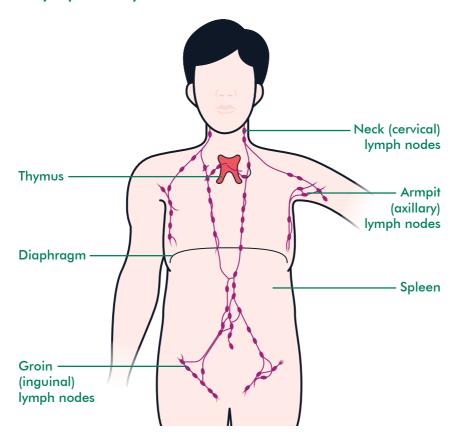
## The lymphatic system

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 bone marrow, the 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. You may have some lymph nodes removed during surgery. If they contain cancer cells, your doctor may talk to you about having further 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. 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 (or biological) therapies.

'To many people the chemo word is almost as scary as cancer, but it is just medicine. I had three cycles of chemo, including Cisplatin, and whilst it wasn't fun, nor was it unbearable. The overriding memory for me was boredom and some tiredness.

Mark

# Chemotherapy drugs

Not all cancers are treated with the same chemotherapy drugs or in the same way. There are many different chemotherapy drugs and new drugs are being developed all the time.

Research that's already been done will help your cancer specialist decide the most effective drugs to treat the type of cancer you have. You may have one drug or a combination of different drugs.

# Other anti-cancer drugs

Other anti-cancer drugs are used to treat cancer but they're not usually known as chemotherapy. For example, newer drugs called targeted (biological) 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 chemotherapy drugs, combinations of chemotherapy drugs and individual targeted therapy drugs. Call us on 0808 808 00 00 to order free copies.

# How chemotherapy drugs work

Chemotherapy drugs work by stopping cancer cells reproducing. 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 that they can reach cancer cells anywhere in the body. But chemotherapy can be given in different ways (see page 27). It depends on the type of cancer being treated and the chemotherapy drugs being used.

Chemotherapy drugs also affect some healthy cells. These healthy cells can usually recover from damage caused by chemotherapy but cancer cells can't and eventually die.

#### Side effects

The effect chemotherapy drugs have on some of the healthy cells in your body can cause side effects. Most side effects will go away when treatment is over.

Healthy cells in certain parts of the body, such as the bone marrow (which makes blood cells) and the digestive system, are more sensitive to chemotherapy drugs. This is why certain side effects, such as risk of infection or feeling sick, are more common. There is information on side effects and how they can be reduced and managed on pages 48-83.

# 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 a cancer can be felt or is visible, your doctor will be able to tell if it's 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 treatments of chemotherapy to see if the cancer is getting smaller. If you're having chemotherapy to reduce the risk of cancer coming back after surgery (adjuvant chemotherapy), you won't usually need scans to check whether it's working.
- With some cancers, blood tests can be used to check if treatment is working. These cancers release proteins in 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 hasn't responded well enough, your doctor may decide to give you 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 (called neo-adjuvant chemotherapy)
- after surgery or radiotherapy to reduce the risk of cancer coming back by treating any remaining cells (called adjuvant chemotherapy)
- at the same time as radiotherapy to make it work better (called chemoradiation)
- to treat cancer that has spread into surrounding areas (locally advanced) or to other parts of the body (advanced). This may cure certain cancers but, more commonly, the aim is to shrink and control a cancer to try to prolong life, and to relieve symptoms. Chemotherapy to relieve symptoms is called palliative chemotherapy.

Your cancer doctor or chemotherapy specialist nurse will explain why chemotherapy is being advised for you. You can read more about this in our next section 'Planning chemotherapy' (see pages 14-17).

# Planning chemotherapy

Your treatment is planned by your cancer doctor (oncologist) who 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 be introduced to a chemotherapy nurse specialist and also 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, and the benefits and disadvantages to you.

## Giving your consent

Before you have any treatment, your cancer doctor or nurse specialist will explain its aims. They will 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. You can use pages 118-119 at the back of this booklet to write your questions down.

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 able 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. Call our cancer support specialists on **0808 808 00 00** to order a free copy.

'I know we all have a choice whether to accept chemo, but I feel that really there is no choice but to try and drag myself through this to try and beat this horrid thing. If there is anything I have to go through to give myself a chance of survival, then I will.'

**Natty** 

#### Research - clinical trials

You may be offered chemotherapy as part of a cancer research trial. These trials are carried out to find new and better treatments for cancer. Trials are carried out to test new chemotherapy drugs or new combinations of drugs. Trials may also look at different ways of giving chemotherapy to make it more effective or to reduce side effects

Trials are the only reliable way to find out if a different chemotherapy treatment is better than what is already available. But sometimes treatments are later found to be not as good as existing treatments, or to have more side effects than benefits.

If you are unsure about taking part in a trial, it can help to talk to your cancer doctor or nurse so that they can give you the best advice. If you decide not to take part in a trial, you don't have to give a reason. There will be no change in the way that you're treated and you'll be offered the standard treatment for your situation.

Our booklet, Understanding cancer research trials (clinical trials) describes clinical trials in more detail. Or you can read more about trials on our website macmillan.org.uk/clinicaltrials

## 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, and the number of 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'll have a better idea of what you can plan for, 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's given, and how long your course takes depends on:

- the type of cancer you have
- the chemotherapy drugs you're having, and how the cancer responds to the drugs
- how the side effects are affecting you.

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

Chemotherapy is sometimes given continuously by an infusion pump (see pages 37-39) for several days or several weeks. If you're having chemotherapy as tablets or capsules (see pages 41–42), you may have them daily for several weeks or months before a rest period.



# HAVING CHEMOTHERAPY

Preparing for chemotherapy	20
Where chemotherapy is given	24
How chemotherapy is given	27
Chemotherapy into a vein	28
Other ways of having chemotherapy	41

# Preparing for chemotherapy

Having information about the chemotherapy treatment and its side effects can help you to 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's very important to talk to your cancer doctor before treatment starts. Sometimes your fertility can be preserved by storing sperm or eggs before chemotherapy begins (see pages 79-81).

#### Getting a wig

If the chemotherapy drugs cause hair loss or thinning you might decide to have a wig fitted. You can have the wig fitted before your hair falls out. You can then match it to your own colour and style (see page 58).

#### **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 over-the-counter drugs, vitamins or supplements you're taking or plan to take. Some vitamins or supplements may interact with chemotherapy drugs and make treatment less effective.

#### Work or education

It's a good idea to talk to your employer (see page 92) or tutors, so they can make arrangements to support you and organise your time off during treatment.

#### Help at home

Chemotherapy makes you tired so you may need help with day-to-day chores. 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 see 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 can usually organise a rota to help. It's also useful to know who you can contact at short notice to look after your children. We have more information on childcare when you have cancer.

Our website The Source has information for family and friends. It has advice on what to say or do to help when someone you care about has cancer. You can search for tips or share your own. Visit source.macmillan.org.uk

#### Tests and scans

Your cancer doctor or specialist nurse will talk to you about any tests, scans or check-ups you may 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're 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 sound waves 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 checks 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'll have a blood test before each cycle of chemotherapy. To save time, your blood may be checked a day or two before chemotherapy. This can be done at the hospital where you're having chemotherapy, or by your GP, practice nurse or a hospital closer to home. The results will be ready for you when you go to have your chemotherapy.

#### **Pregnancy test**

Women may be offered a pregnancy test before starting treatment.



# 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 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 help with drinks or snacks when you need them. Some units also have complementary therapists who provide therapies such as massage and reflexology (see page 101).

Having the chemotherapy drugs may take from half an hour to a few hours. But you may also have to wait for blood results, your chemotherapy drugs to be made up by the pharmacy, or to see your cancer doctor. The nurses will try to keep any waiting to a minimum.

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.

After you've 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 complex or take longer and 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 (see pages 37-39), the nurses can come and disconnect the pump when it's finished. This means that you don't 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 telephone numbers to contact the hospital if you have a temperature (see pages 50-51), feel unwell or 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 (see page 112).

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

- in your phone
- in your My Organiser
- in the 'Your chemotherapy' section at the end of this book (pages 116-117).

'The nurses were always prepared to answer the phone 24 hours a day, if you had cancer-related side effects or symptoms that you didn't understand or you couldn't cope with. They were really very helpful.'

Rob

# How chemotherapy is given

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

These methods are described in more detail in the following pages.

# 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 (see page 29)
- a central line a long thin tube inserted into a vein in your chest (see pages 30-31)
- a PICC (peripherally inserted central venous catheter) line put into a vein in the arm and threaded through to a vein in the chest (see pages 32-33)
- an implantable port (portacath) put into a vein and has an opening (port) under the skin on your chest or arm (see page 34).

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. There's more information about this on pages 37–39.

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 shouldn't take long and any pain soon wears off.

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, let your nurse or doctor know immediately.

# 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 and it can be left in until your course of chemotherapy is over. This means you won't 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's in place, the nurses will show you how to look after it (see pages 35-36).

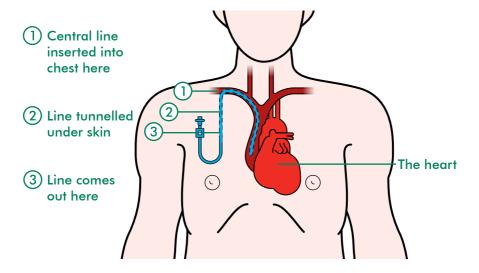
When your course of treatment is over, the line or port will be taken out. A doctor or nurse will do this for you, usually in the outpatients department.

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

#### Central line

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

#### A central line



#### How it's put in

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

Your doctor 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'll have a chest x-ray to make sure it's in the right position.

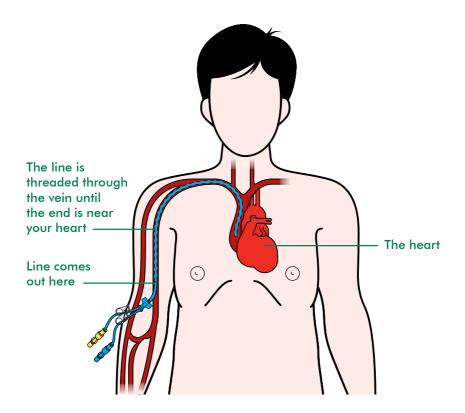
Around the central line there's a small 'cuff' you can feel just under the skin. The tissue under your skin grows around this cuff over about three weeks and holds the line in place. Until this happens, you'll have a stitch holding the line in place.

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

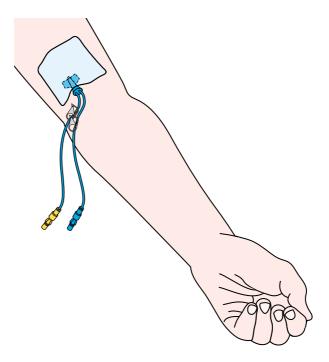
# PICC (peripherally inserted central venous catheter) line

A PICC line is a long, thin, hollow tube that a nurse or doctor puts into a vein near the bend in your elbow. You'll be given a local anaesthetic to numb the area before the line is put in. They gently thread it along the vein until the tip sits in a large vein in your chest. The end of the line comes out near your elbow. Once it's 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 near the crook of your elbow



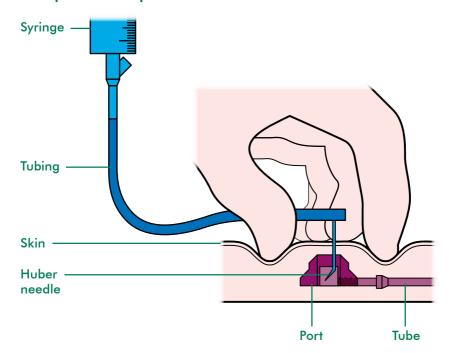
We have more information about PICC lines that we can send you. You can also watch an animation on our website about having a PICC line put in. You can watch it at macmillan.org.uk/ havingapiccline

# Implantable port (portacath)

An implantable port is a thin, soft plastic tube with a rubber disc (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's 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 don't feel any discomfort. We have more information about implantable ports that we can send you.

#### 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 relative or friend how to do it or arrange for a district nurse to visit you. The main things 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
- notice quickly if there's a problem with your line or port and phone the number you have been given for advice.



#### What to look out for

Most people won't 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
- a feeling of being 'shivery' or unwell after your line or port has been flushed
- a high temperature. Most hospitals say that a temperature above 38°C (100.4°F) is high, but some use a lower or higher temperature. The cancer doctors and nurses at your hospital will advise you on this.

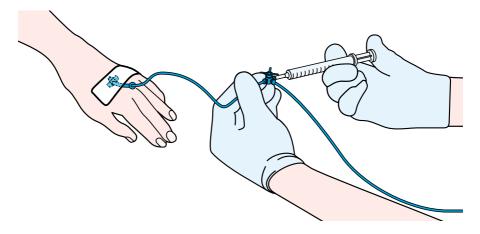
# Having intravenous chemotherapy

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 vour 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 20 minutes to several hours. depending on the chemotherapy you're 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's 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 relative 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're washing. There are also disposable pumps that are operated by a balloon mechanism or spring control.

Your nurse or pharmacist will explain how to look after the pump and who to contact if you have any problems.

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.

# If a chemotherapy drug leaks

If a drug leaks into the area around the vein while being given, it's called extravasation. This is uncommon but can happen if a cannula dislodges and isn't in the correct position in the vein. Extravasation rarely happens with a central line.

Your nurse will be very careful to prevent extravasation when giving your chemotherapy. Some chemotherapy drugs can damage the tissues so it's 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

This section is about other ways you can have chemotherapy (apart from intravenously). Your chemotherapy nurse or cancer doctor will explain more about this.

# By mouth (oral chemotherapy)

Some chemotherapy drugs are taken 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'll be told when to take your chemotherapy tablets or capsules and given other instructions, such as whether or not to take them with food.

#### It's very important to:

- read the labels on the boxes before you leave the hospital and if instructions are unclear, ask your nurse, doctor or pharmacist
- 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 immediately for advice if you can't take your medicines for any reason or are sick after taking them.

Chemotherapy by mouth can cause side effects, just like chemotherapy into a vein, and it's 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 45.

# Injection into a muscle or skin

Some chemotherapy drugs are given by injection into a muscle of 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 can't reach these cancer cells.

The doctor numbs an area of skin over your spine with local anaesthetic. After a few minutes, they will 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 need to lie flat for a few hours afterwards and drink plenty of fluids.

We have information about intrathecal chemotherapy and lumbar punctures. Call us on 0808 808 00 00 to order free copies.



# Into a body space (intracavitary)

Chemotherapy drugs can be given into a space (cavity) in the body, such as the bladder. This can cause irritation or inflammation in the area the drugs are given but it doesn't 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 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's over. Our booklet Understanding non-invasive bladder cancer has more information about this treatment.
- Into the abdominal cavity (intraperitoneal chemotherapy) - This is very occasionally used to treat ovarian cancer or mesothelioma in the abdomen (peritoneal mesothelioma).
- Between the two layers of the pleura (tissue that covers) the outside of the lungs) - Chemotherapy is sometimes put in between the two 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 isolated limb perfusion which we can send you.

# **Chemotherapy creams**

Chemotherapy creams are used to treat some types of skin cancer. You put the cream on the affected skin in a thin layer 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 won't cause side effects in other parts of the body.

# Chemotherapy at home

If you're 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 hare hands
- All drugs must be stored out of the reach of children as they could cause serious harm if taken by accident.
- If you're 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 immediately.
- If you feel unwell at any time of the day or night, use the contact numbers you've been given to get advice.



# SIDE EFFECTS OF CHEMOTHERAPY

Possible side effects	48
Changes to your treatment plan	72
Effects on sex life and fertility	75
Late offects of chamotherapy	9.5

# Possible side effects

The side effects you get will depend on the chemotherapy drugs you're 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 gradually go away when chemotherapy is over. Although the side effects can be unpleasant, the benefits of chemotherapy usually outweigh this.

> 'I think most of us feel like backing out before it starts. It's just the uncertainty when they tell you what side effects you might get. But many people get very few side effects, some get none at all. So just think of this as a short period of treatment to make things better in the long run! I know it's not easy."

Mark

If you're 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.



We can send you information about the different side effects of chemotherapy.

#### 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 that develop into the different types of blood cells:

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

You'll have regular blood samples taken to check the number of these cells in your blood. This test is called a full blood count.

#### Risk of infection

If the number of your white blood cells is low, you're 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 at its lowest 7–14 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 your white blood cell count is low can sometimes be a serious complication of chemotherapy.

Although this may sound scary, most people don't have any serious problems with infection. Some chemotherapy treatments are more likely than others to reduce your white blood cell count. 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 count 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. Most hospitals consider a temperature above 38°C (100.4°F) to be high, although some hospitals use a lower temperature.

You can have an infection without showing 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've been given and speak to a nurse or doctor if:

- your temperature goes over 37.5°C (99.5°F) or over 38°C (100.4°F), depending on the advice given by your chemotherapy team
- 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 GCSF 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 that we can send you.



## Helpful hints – 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, which we can send you.

#### 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 lightheaded. 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's more common to have a blood transfusion for angemia.

We have more information about blood transfusions and erythropoietin.

#### 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 small cuts or grazes.

Tell your cancer doctor or specialist 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.



#### Helpful hints - avoiding injuries

- 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 don't floss.

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

We can send you more information about platelet transfusions.



#### 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 don't 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.



#### Helpful hints – 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.
- Don't perm or colour your hair if it's 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 (do a strand test first), and 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 can only be used with certain drugs and types of cancer and doesn't always prevent hair loss. You can ask your doctor or nurse whether one would be useful for you.

### 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.

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.



#### Helpful hints - coping with hair loss

- Cutting 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 once you've finished treatment. It will be very fine at first and may be a slightly different colour or texture than before. You'll probably have a full head of hair after 3-6 months. To begin with, you should try to look after the condition of your hair.



'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 three or four months being
totally bald and really happy.'

Kate

#### 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're not entitled to a free wia, you can get one from the NHS at a subsidised price.
- You may want to buy a wig privately. You shouldn't have to pay VAT on your wig if your hair loss is caused by cancer.

Our booklet Coping with hair loss has more information and helpful advice.

'I thought a wig was a thing that you put on your head and it was all hot and horrible. But there was lots of choice and she was brilliant, and she cut it 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 and vomiting

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.

#### Anti-sickness drugs

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

Contact your doctor or nurse at the hospital if:

- the anti-sickness drugs don't stop you feeling or being sick other drugs can be prescribed
- you're being sick and aren't able to drink enough fluids
- the anti-sickness drugs make you constipated.

If you can't 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're managing to eat well in between treatments, don't worry if you can't eat much for a couple of days after chemotherapy.



# Helpful hints - 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.
- Sipping a fizzy drink can help try mineral water, ginger beer or ale, lemonade or soda water and sip 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 (see page 101), 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.

We can send you more information about controlling sickness and vomitina.

#### Diarrhoea

Some chemotherapy drugs can cause diarrhoea, usually in the first few days. Let your nurse or doctor know if this happens as they can prescribe medicine to reduce this.

Make sure you drink plenty of liquid (up to two litres a day) to replace fluid you're losing with diarrhoea. Eat less fibre (cereals, raw vegetables and fruits) until the diarrhoea improves.

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

#### **Constipation**

Some chemotherapy drugs, anti-sickness drugs and painkillers can cause constipation. Let your nurse or doctor know 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's important to try to eat well during your treatment. If you're having problems, ask your nurse for advice and 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. Our booklet The building**up diet** has more information.



#### Taste changes

Chemotherapy can affect your sense of taste. You might find food lacks flavour or tastes more salty, bitter or metallic. This will return to normal after chemotherapy finishes.



#### Helpful hints - changes to sense of taste

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

Our booklet on **Eating problems and cancer** has more information. We can send you a free copy.

#### 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 5-10 days after they're 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 liquid medicines or tablets. Some people are prescribed these 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's a good idea to see your dentist before you start treatment. Routine dental treatment may need to be delayed during chemotherapy because of the risk of infection and a sore mouth.

We have more information about mouth care during chemotherapy. Call **0808 808 00 00** for a free copy.





#### Helpful hints – 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 one teaspoon of bicarbonate of soda dissolved in a pint (570mls) 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.

#### Helpful hints - if your mouth is sore

- Try to drink at least 3 pints (1.5 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.

# Other possible side effects

#### **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 don't 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 couple of days after. Some people may need extra childcare help and a social worker can usually arrange this for you. We have information about childcare that we can send you.

Make sure you get plenty of rest. But try to take some gentle exercise, such as 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.

> 'The tiredness gets to me, and I find it very hard to accept that I can't do what I used to. I try very hard not to let it impact too much on my day. The occasional cat-nap in the early afternoon helps a lot.'

Paul

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

If you're having difficulty sleeping, we have information about managing sleep problems.

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

Our booklet Coping with fatigue has helpful tips on dealing with tiredness during chemotherapy.

Our website The Source (source.macmillan.org.uk) can help family and friends know what to say or how to help when someone they care about has cancer. You can also share your own tips and ideas.

# Skin and nail changes

#### Your skin

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

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



# Helpful hints – 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're also having radiotherapy.
- If you're out in the sun, wear a high sun protection factor (SPF) suncream of at least SPF 30.

#### Your nails

Chemotherapy may make your nails grow more slowly or become brittle or flaky. You may notice white lines appearing across them, or changes in the shape or colour of your nails. They should go back to normal after chemotherapy.

Protect your nails and hands by keeping them well moisturised. Wear gloves to protect them when doing chores in the house or garden. It's fine to wear nail varnish, but don't wear false nails during chemotherapy. 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's important to let your doctor or nurse know if this happens. The dose of the chemotherapy drug may need to be changed if it aets worse. Usually, peripheral neuropathy gradually gets better when chemotherapy is over but sometimes it's permanent. We can send you more information about peripheral neuropathy.

#### 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's important to let your cancer doctor or nurses know. 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 mild cognitive impairment (MCI), but it's more usually known as 'chemo-brain' or 'chemo-fog'.

If this happens, it's 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 mild cognitive impairment.

### 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 fluid 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 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 lose the ability to hear some high-pitched sounds. Very occasionally, your sense of balance may be affected. Any hearing loss and changes in balance may be permanent. Tinnitus usually improves when treatment ends.

Tell your cancer doctor or nurse if you notice any of these 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's important to tell your doctor straight away if you have any of these symptoms. However, 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.

'I do like to think that the side effects are an indication that the chemo was doing its job and killing the bad as well as some of the good! So try and remain positive that the chemo will help you.'

Mark

### 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're 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.

Occasionally, 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're 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 2-3 days.

We have more information about steroids that we can send you.

# 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 on the cancer itself. Sometimes changes are made to suit your personal circumstances. Depending on the reason, your doctor may delay your chemotherapy for a short while, reduce the dose or put you on a different chemotherapy drug.

### Delaying your chemotherapy

The most common reason for delaying chemotherapy is a low number of white blood cells or neutrophils. This isn't unusual, so try not to worry too much about it. Once 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 won't usually be a problem. Your cancer doctor or specialist nurse will 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 others drugs may affect your hearing.

Depending on the problem, 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 page 12).

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



# Effects on sex life and fertility

Having chemotherapy can affect your sex life, although not everyone finds this. 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's no medical reason to stop having sex during chemotherapy. But if you have low platelets, or a low white blood cell count, your doctor may advise you to avoid penetrative sex until your blood count improves.

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's 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 don't feel like having sex.

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



### **Protecting your partner**

If you have sex in the first couple of 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 won't make the cancer worse.

### **Contraception**

It's 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.

It's usually best to use 'barrier' methods of contraception during treatment. For example, condoms, the cap or the coil (non-hormonal 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, let your cancer doctor or nurse know 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.

### 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, which you cannot keep or use, so that 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 such as 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 the age of 45.

You may be able to have hormone replacement therapy (HRT) to replace the hormones your ovaries are no longer producing. It can improve some symptoms of the 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. We can send you information about managing menopausal symptoms for women with breast cancer.

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

### Managing menopausal symptoms

If your doctor doesn't advise you to take HRT or if you don't 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 affect fertility (your ability to become pregnant or to father a child).

It's important to discuss your risk of infertility with your cancer doctor before you start chemotherapy. If you have a partner, it's a good idea to include them in 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 (see page 76).

#### Women

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 may return to normal. It may take a few months or up to two years for your periods to come back. 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 (see page 78).

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 with you possible options to help preserve your fertility, such as storing embryos (fertilised eggs) or eggs.

#### Men

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 won't 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'll usually be asked to produce several sperm samples over one or two weeks. These will be frozen and stored. This means they can be used later to try to fertilise an egg and make your partner preanant.

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 in our booklets about fertility. We have a booklet for women, and one for men. Call us on 0808 808 00 00 to order a free copy.

### 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 or you can contact the organisations on page 111-113 for more information. Our cancer support specialists on freephone **0808 808 00 00** can also provide support.



# Late effects of chemotherapy

Some people may have late effects from the chemotherapy. These are side effects you still have six months after chemotherapy, or side effects that begin years later. Late effects aren't 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 78)
- infertility (see pages 79–81)
- peripheral neuropathy (see page 68).

### 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 about this on pages 100-103.

Our booklet Heart health and cancer treatment has helpful tips on looking after your heart and how late effects can be monitored and managed.

### 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 weigh up the small increase in risk of this happening, against the benefit of the chemotherapy in treating your cancer.



'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



# LIFE DURING CHEMOTHERAPY

Effects on everyday life	86
Your feelings	89
Work	92
Financial help and benefits	93

# 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're having.

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

Some people are able to go to work with time off and shorter working hours (see page 92).

#### Social life

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

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

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 shouldn't affect your chemotherapy treatment. But it's best to check with your cancer doctor or specialist nurse first.

#### Vaccinations

Vaccinations can reduce your chance of getting certain infections. If you've 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're going abroad on holiday during chemotherapy treatment, it's important to remember that you should not have any 'live' travel vaccines. The vaccinations you may need will depend on where you're going. Before booking a holiday, ask your doctor if you need any vaccines and whether it's safe for you to have them.

## Holidays and travel insurance

Sometimes people who have cancer can find it difficult to get travel insurance. It's best to look for travel insurance as early as possible. Ideally, you should start looking before booking a holiday.

We can send you booklets about travelling and finding travel insurance. This information is also on our website. Visit macmillan.org.uk/travel



# Your feelings

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

Sometimes these feelings can be triggered 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's 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're likely to face. It's often helpful to talk over your feelings with your family or close friends.

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

Kate

You can also talk to your cancer doctor, specialist nurse or a social worker about how you're feeling. It's important to let them know if you're 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 doesn't mean being cheerful and happy all the time. When you're coping with a serious illness, it's normal to feel worried and low sometimes. Accepting that you'll have days when you don't feel positive is part of coping with cancer.

Our booklet How are you feeling? The emotional effects of cancer may help you cope with your feelings and emotions.

### **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 don't understand the explanations given to you by your doctors or nurses, then 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.

As your journal develops, you may find it encouraging to look back at 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 can't express in any other way.

You can create your own blog, chat to people and watch videos on our online community. Visit macmillan.org.uk/community

# Work

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

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

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

### **Employment rights**

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

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

# Financial help and benefits

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

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

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

There are two different types of ESA:

- **contributory** you can get this if you have made enough national insurance contributions
- **income-related** you can get this if your income and savings are below a certain level.

Since October 2013, a new benefit called Universal Credit has started replacing income-related ESA in England, Scotland and Wales. This benefit is for people who are looking for work or on a low income.

Personal Independence Payment (PIP) is a new benefit for people under 65 who find it difficult to walk or look after themselves (or both). You must have had these difficulties for at least three months, and they should be expected to last for the next nine months. Since April 2013, PIP has started to replace a similar older benefit called Disability Living Allowance (DLA) in England, Scotland and Wales.

Attendance Allowance (AA) is for people aged 65 or over who find it difficult to look after themselves. You may qualify if you need help with things like getting out of bed, having a bath or dressing yourself. You don't need to have a carer, but you must have needed care for at least six months.

If you are terminally ill, you can apply for PIP, DLA or AA under the 'special rules'. This means your claim will be dealt with quickly and you will get the benefit you applied for at the highest rate.

### **Help for carers**

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

#### More information

The benefits system can be hard to understand, so it's a good idea to talk to an experienced welfare rights adviser. You can speak to one by calling the Macmillan Support Line on 0808 808 **00 00**. We've just listed some benefits here, but there may be others you can get.

You can find out about state benefits and apply for them online at **gov.uk** (England, Wales and Scotland) and **nidirect.gov.** uk (Northern Ireland). These websites have information about financial support, your rights, employment and independent living. You can also get information about these issues from the relevant Department for Work and Pensions helplines (see page 114) or Citizens Advice (see page 114). In Northern Ireland, you can call the Benefit Enquiry Line Northern Ireland on 0800 220 674.

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

#### Insurance

People who have, or have had, cancer may find it hard to get certain types of insurance, including life and travel insurance. A financial adviser can help you look at your needs and find the best deal for you. You can find a financial adviser by contacting one of the organisations on pages 113-114.

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





# AFTER TREATMENT

Follow-up  Beginning to recover  How you can help yourself	98
	99
	100

# Follow-up

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

Many people find that they get very anxious before their appointments. This is natural. It may help to get support from family, friends, or one of the organisations on pages 111–115 during this time.

Follow-ups are a good opportunity to discuss any problems or worries you have. It may help to make a list of questions beforehand so you don't forget anything important.

If you have any problems, or notice any new symptoms in between your appointments, let your GP or cancer doctor know as soon as possible. Don't 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's anything they're worried about.



# Beginning to recover

Coming to the end of your chemotherapy treatment can be a time of mixed emotions. You'll probably feel relieved, but may feel anxious or uncertain about the future. Many people find that they feel very low and 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 confidence and to come to terms with what you've been through. It may also take time to recover from treatment. You may feel tired for a while and you may have emotional or physical changes to deal with. It's important to give yourself time to adjust.

Support is available from the organisations listed on pages 111–115. You can also ask your healthcare team for the details of local support groups that may be able to help you.

# 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 be more focused 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 – we have a booklet called **Physical** activity and cancer treatment, which has tips on how to be more active. Our booklet Heart health and cancer treatment has helpful tips on looking after your heart and how late effects can be monitored and managed
- Keeping to a healthy weight and eating healthily is good for your heart and bones. We have booklets called **Healthy** eating and cancer and Managing your weight after cancer treatment, which you may find useful.
- 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. Smoking is the main cause of lung cancer and a major risk factor for other cancers. Our booklet **Giving up smoking** has information and tips to help you stop.

### Complementary therapies

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

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

We have a booklet about complementary therapies, with information on how to contact registered practitioners.

### How others 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. You can talk to them on **0808 808 00 00**.

Our booklet Talking about your cancer will also help you to find ways of discussing your cancer.

### Family and friends

Family and friends often want to help you. However, they may find it difficult to understand exactly what you're going through. Good communication is really important. Just at a time when you feel your friends and family should be helping, they may stand back and wait for you to make the first move. This is often because they're worried they may say the wrong thing, or they think you may want to cope alone. They may also be feeling guite emotional themselves.

Try to be open and honest about how your treatment is going and how you feel about it. Misunderstandings can then be avoided and family and friends are given the chance to show their love and support.

'I think a lot of people are afraid to address cancer and talk about it directly, but actually that's the worst thing. I'd much rather have it out in the open and for it to be discussed because, at the end of the day, that's the only way that people are going to become more comfortable going to the doctor.'

Kate

Our booklet called Lost for words: how to talk to someone with cancer was written for relatives and friends of people with cancer. It looks at the difficulties people may have when talking about cancer.

Our website The Source (source.macmillan.org.uk) has valuable information to help family and friends know what to say or do when someone they care about has cancer. For further information and advice on medication, call the Macmillan Support Line free on 0808 808 00 00 or visit macmillan.org.uk





# FURTHER INFORMATION

About our information	106
Other ways we can help you	108
Other useful organisations	111
Your chemotherapy	116
Chemotherapy – questions you could ask	118
Your notes and auestions	120

# **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.

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

#### Other formats

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

- audiobooks
- Braille
- British Sign Language
- Easy Read booklets
- ebooks
- large print
- translations.

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

## Help us improve our information

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

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

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



# Other ways we can help you

At Macmillan, we know how a cancer diagnosis can affect everything, and we're here to support you. No one should face cancer alone.

#### 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-Friday, 9am-8pm. Our cancer support specialists can:

- help with any medical questions you have about your cancer or treatment
- help you access benefits and give you financial advice
- 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 advice

Our financial auidance team can give you advice 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/ financial support 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

Macmillan's My Organiser app This 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

79 Acton Lane, London NW10 8UT Tel 020 8961 4151 **Email** 

info@cancerblackcare.org.uk

www.cancerblackcare.org.uk Offers information and support for people with cancer from ethnic communities, their friends, carers and families.

## **Cancer Focus Northern Ireland**

40-44 Eglantine Avenue, Belfast BT9 6DX **Tel** 0800 783 3339 (Mon-Fri, 9am-1pm) **Email** 

hello@cancerfocusni.org

www.cancerfocusni.org

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

## Cancer Research UK

Angel Building, 407 St John Street. London EC1V 4AD Tel 0300 123 1022

# www.cancerhelp.org.uk

Has patient information on all types of cancer and has a clinical trials database.

# **Cancer Support Scotland**

The Calman Centre, 75 Shelley Road, Glasgow G12 0ZE Tel 0800 652 4531 **Email** info@ cancersupportscotland.org

# www.cancersupport scotland.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**

PO Box 183. Rossendale BB4 6W7

#### **Email**

daisy@daisynetwork.org.uk www.daisynetwork.org.uk

A support group for women who have early ovarian failure. The website gives information about premature menopause and related issues. Also has a mailing list for subscribers and details of other helpful groups. Membership fee of £20 a year.

#### Look Good...Feel Better

West Hill House. 32 West Hill, Epsom, Surrey KT19 8JD **Tel** 01372 747 500 Email info@lafb.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

2<sup>nd</sup> Floor Palace Wharf, Rainville Road, London W6 9HN Tel 0300 123 1801

# **Email**

enquiries@maggiescentres.org www.maggiescentres.org Provides information about cancer, benefits advice, and emotional or psychological support.

# National Cancer Treatment **Helpline (Scotland)** Helpline 0800 9177711

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

### **Penny Brohn Cancer Care**

Chapel Pill Lane, Pill, Bristol BS20 0HH Tel 01275 371 100 (Mon-Fri, 9.30am-5pm)

#### **Fmail**

helpline@pennybrohn.org

# www.pennybrohn cancercare.org

Offers a combination of physical, emotional and spiritual support, using complementary therapies and self-help techniques.

# Riprap

Att. Pauline Hutchinson. University of Sheffield, Sykes House office, St Luke's Hospice, Little Common Lane, Sheffield S11 9NF www.riprap.org.uk Developed especially for teenagers who have a parent with cancer.

#### **Tenovus**

Head Office, Gleider House, Ty Glas Road, Cardiff CF14 5BD Tel 0808 808 1010 (Mon-Sun, 8am-8pm) www.tenovus.org.uk Aims to help everyone get equal access to cancer treatment and support. Funds research and provides support such as mobile cancer support units, a free helpline, an 'Ask the nurse' service on the website and benefits advice.

## Financial or legal advice and information

**Benefit Enquiry Line** Northern Ireland Tel 0800 220 674 (Mon-Wed and Fri, 9am-5pm, Thu, 10am-5pm) **Textphone** 0800 243 787 www.nidirect.gov.uk/ money-tax-and-bfits Provides information and advice about disability benefits and carers' benefits.

#### Citizens Advice

Provides advice on a variety of issues including financial, legal, housing and employment issues. Find details for your local office in the phone book or on one of these websites:

- **England and Wales** www.citizensadvice.org.uk
- Scotland www.cas.org.uk
- Northern Ireland www.citizensadvice.co.uk

You can also find advice online in a range of languages at advicequide.org.uk

**Department for Work** and Pensions (DWP) **Disability Living Allowance** Helpline 0345 712 3456 **Textphone** 0345 722 4433 **Personal Independence Payment Helpline** 0345 850 3322 **Textphone** 0345 601 6677 Carer's Allowance Unit 0345 608 4321 **Textphone** 0345 604 5312 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 comprehensive information about social security benefits and public services.

**Personal Finance Society –** 'Find an Adviser' service www.findanadviser.ora Use the website to find qualified financial advisers in your area.

# Support for carers

**Carers Trust (Princess Royal Trust for Carers in Scotland)** 

32-36 Loman Street. London SE1 0FH

Tel (England)

0844 800 4361

Tel (Scotland)

0300 123 2008

Tel (Wales)

0292 009 0087

Email info@carers.org www.carers.org and

www.youngcarers.net

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 Tel (England, Scotland, Wales) 0808 808 7777 Tel (Northern Ireland) 028 9043 9843

(Wed-Thu, 10am-12pm and 2-4pm)

**Email** 

advice@carersuk.org

www.carersuk.org

Offers information and support to carers across the UK. Can put people in contact with support groups for carers in their area.

You can search for more organisations on our website at macmillan.org/organisations, or call us on 0808 808 00 00.

# Your chemotherapy

Drug names	Dose	When do I take it?		
Number of courses	s planned:			
Dates:				
Treatment will be i	reviewed on:			

How do I take it? (injection, liquid, tablet)	Any special instructions ega with food/empt stomach	
If there are a	ıny problems, co	ntact:
In clinic hours:	_	
At other times:	_	
Tell the doctor	or nurse:	
• Your name	_	
<ul> <li>Your hospital r</li> </ul>	number	
<ul> <li>Your diagnosis</li> </ul>	_	
Your chemother	erapy treatment	
• The name of y	our doctor	

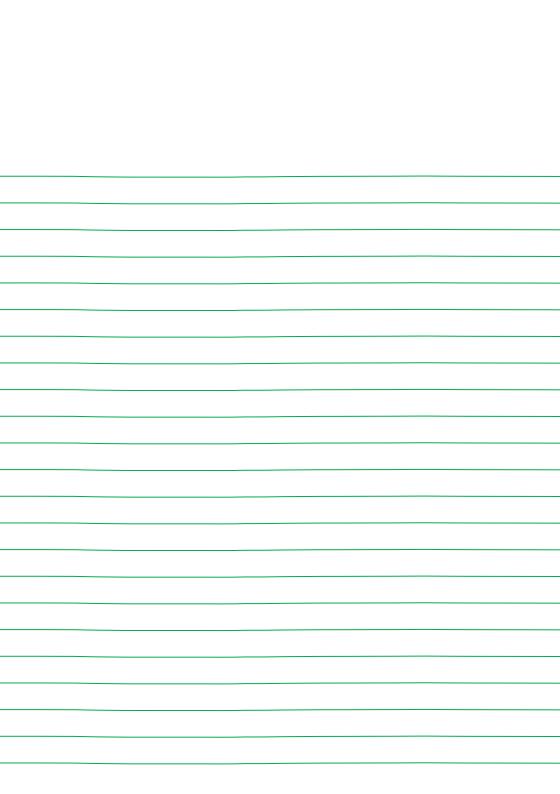
# Chemotherapy – questions you could ask

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

to if I have problems during the night?				
How long will my whole course of chemotherapy take?				
How many cycles will I have?				
Will I have to stay in hospital?				
Will I need any tests before or after chemotherapy?				

What are the likely side effects of my 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:				

# YOUR NOTES AND QUESTIONS



## **Disclaimer**

We make every effort to ensure that the information we provide is accurate and up to date but it should not be relied upon as a substitute for specialist professional advice tailored to your situation. So far as is permitted by law, Macmillan does not accept liability in relation to the use of any information contained in this publication, or third-party information or websites included or referred to in it. Some photographs 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, Macmillan Consultant Medical Oncologist. With thanks to: Paik Hang Ooi, Senior Pharmacist; Jenny King, Chemotherapy Clinical Nurse Specialist; Danny Lynch, Clinical Oncology Nurse; and Natalie Singer, Advanced Haematology Clinical Nurse Specialist. Thanks also to the people affected by cancer who reviewed this edition, and those who shared their stories.

#### Sources

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

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# Can you do something to help?

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

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



#### Share your cancer experience

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

### Campaign for change

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

#### Help someone in your community

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

#### Raise money

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

#### Give money

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

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

#### Please fill in your personal details keep your money Mr/Mrs/Miss/Other Do you pay tax? If so, your gift will be worth 25% more to us – at no Name extra cost to you. All you have to Surname do is tick the box below, and the tax office will give 25p for every Address pound you give. Postcode I am a UK taxpayer and I would like Macmillan Cancer Phone Support to treat all donations **Email** I have made for the four years prior to this year, and all Please accept my gift of £ donations I make in the future, (Please delete as appropriate) as Gift Aid donations, until I I enclose a cheque / postal order / notify you otherwise. Charity Voucher made payable to Macmillan Cancer Support I confirm I have paid or will pay an amount of Income Tax and/or Capital Gains Tax in each OR debit my: tax year, that is at least equal to the tax that Visa / MasterCard / CAF Charity Charities & CASCs I donate to will reclaim on my aifts. I understand that other taxes such as Card / Switch / Maestro VAT and Council Tax do not qualify and that Macmillan Cancer Support will reclaim 25p of Card number tax on every £1 that I give. Macmillan Cancer Support and our trading companies would like to hold your details in order to contact you about our fundraising, Valid from Expiry date 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. Security number Issue no In order to carry out our work we may need to pass your details to agents or partners who act on our behalf. Signature

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Date

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

More than one in three of us will get cancer. For most of us it will be the toughest fight we ever face. And the feelings of isolation and loneliness that so many people experience make it even harder. But you don't have to go through it alone. The Macmillan team is with you every step of the way.

We are the nurses and therapists helping you through treatment. The experts on the end of the phone. The advisers telling you which benefits you're entitled to. The volunteers giving you a hand with the everyday things. The campaigners improving cancer care. The community there for you online, any time. The supporters who make it all possible.

Together, we are all Macmillan Cancer Support.

For cancer support every step of the way, call Macmillan on 0808 808 00 00 (Mon–Fri, 9am–8pm) or visit macmillan.org.uk

Hard of hearing? Use textphone 0808 808 0121, or Text Relay. Non-English speaker? Interpreters available. Braille and large print versions on request.

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