

A guide for young people

A young man with a shaved head is the central figure, smiling broadly and winking at the camera. He is wearing a white t-shirt. In the background, several other young people are visible but out of focus, suggesting a social gathering or event.

CANCER AND TREATMENT



CONTENTS

Where do I start?	4
What is cancer?	6
Diagnosis and tests	9
Your care team	15
Treatment	19
Surgery	23
Chemotherapy	26
Radiotherapy	32
Cancer and blood	36
Neutropenia, infections and staying well	38
Steroid treatment	44
Stem cell transplant	46
Handling side effects	49
Helping with research	53
After treatment	54
How CLIC Sargent can help	57
Useful organisations	58

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Thank you also to Sarah Palmer for allowing us to adapt copy from *Fighting the Big C*

WHERE DO I START?

Finding out you have cancer can be a big shock, leaving you with lots of questions and wondering what will happen next.

There will be many professionals helping you and it may feel like you are getting a lot of information all at once. Sometimes, it can be overwhelming and difficult to take everything in.

It's easier to make decisions and feel more in control when you have some knowledge. That's why we've put together this booklet, which gives you the basics about cancer, treatment and its side effects. The booklet has been written with the help of cancer experts and young people who, like you, have experienced cancer themselves.

You can read it all in one go, or just dip into different sections when you need to – whatever works best for you.

Cancer is a complex subject and there is not room here for all of the details. Each type of cancer is different, and so is everyone's experience. So, whatever your cancer diagnosis, it's important to know that there are lots of professionals who will help you understand your type of cancer, its treatment and side effects, and support you through your cancer journey.

You can also find out more about the main types of cancer affecting young people at **www.clicsargent.org.uk/foryoungpeople**

Every year in the UK, around 2,000 young people aged 16 to 24 are diagnosed with cancer.

You'll find information about the support CLIC Sargent offers at the back of this booklet. Just after that, we've included a list of other useful organisations which offer information and one-to-one support.

Along with this booklet, you may also have received a practical guide called *Making sense of it all*, which has been written especially for 16 to 24-year-olds. If not, you can order it free of charge from www.clicsargent.org.uk. Or, if you have a CLIC Sargent Young People's Social Worker or Community Worker, you can ask them for a copy.



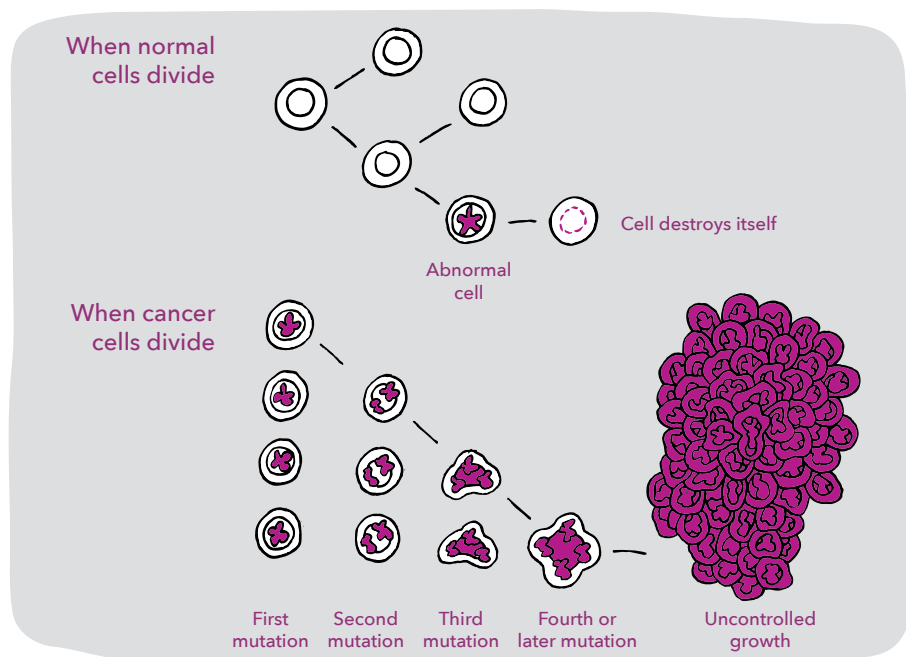
WHAT IS CANCER?

Your body is made up of millions of cells. There are about 200 different types, each with its own unique structure and function. For example, a muscle cell is very different to a brain cell, and so on.

Throughout your life, your cells continue to divide and make copies of themselves. These new cells help you grow or they replace older cells. However, if something goes wrong when the cells are dividing, an abnormal cell may be produced. When this happens, the cell usually destroys itself.

But, sometimes, abnormal cells continue to divide, producing more abnormal cells. In some cases, they divide and grow faster than normal cells. Cancer is the name given to an abnormal growth of malignant cells. 'Malignant' means that the abnormal cells have the potential to spread to other parts of the body if they are not treated. You may also hear the word 'malignant' being used to mean cancer.

When normal cells become cancer cells



Malignant cells are cancerous and can spread through the body. 'Benign' means a lump is not cancer, but you might still need treatment to prevent further growth.

Cancer is not actually just one disease – it's more of an umbrella term. There are more than 200 different types of cancer.

"When the test results came back and I was given the diagnosis, I felt so shocked. I wondered if I had done anything to cause the condition, but the consultants at the hospital said that it had developed naturally and it wasn't my fault."

Anais, diagnosed with a brain tumour at 16

Why did this happen to me?

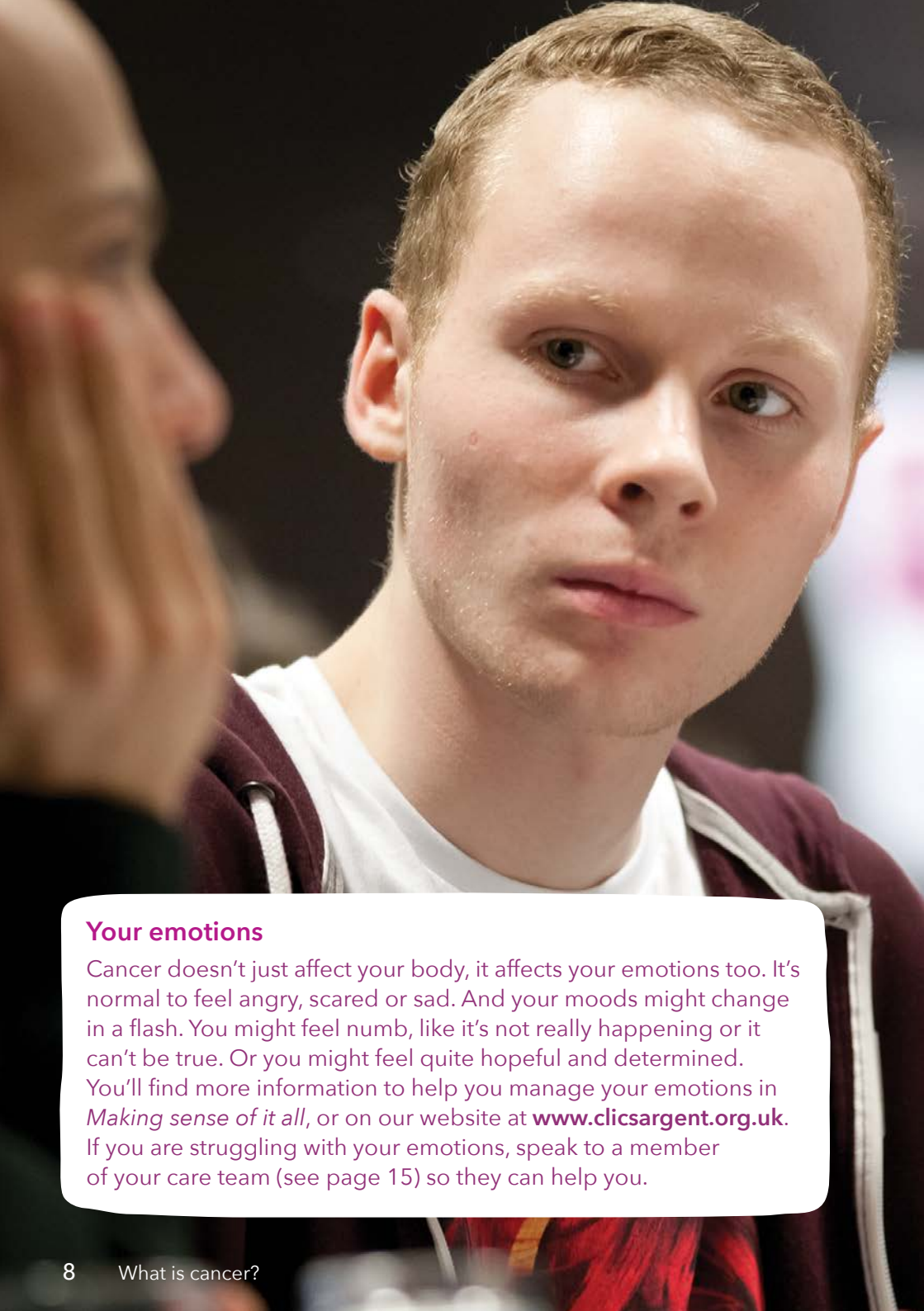
Most of the time, we simply don't know why one young person gets cancer and another young person doesn't. We do know that cancer isn't contagious though. You don't catch it from people, and you can't pass it on to others.

For a few cancers, there might be a genetic link (meaning a higher risk of cancer runs in the family). For others, a viral infection may increase the risk of developing cancer.

It's possible that some cancers start before you are born, when your cells are dividing rapidly while you are still in the womb. Cancers such as bone tumours in young people may also be related to periods of fast growth when the cells are dividing rapidly, but their exact cause is not known.

You've probably heard that smoking or a poor diet increases your risk of cancer. While this may be true in middle-aged or older people, it's very unlikely that any lifestyle choices have caused your cancer.

So you've no need to feel guilty, or to blame yourself or anyone else.



Your emotions

Cancer doesn't just affect your body, it affects your emotions too. It's normal to feel angry, scared or sad. And your moods might change in a flash. You might feel numb, like it's not really happening or it can't be true. Or you might feel quite hopeful and determined. You'll find more information to help you manage your emotions in *Making sense of it all*, or on our website at www.clicsargent.org.uk. If you are struggling with your emotions, speak to a member of your care team (see page 15) so they can help you.

DIAGNOSIS AND TESTS

If you have symptoms that could be linked to cancer, your doctor will usually refer you to a specialist at a hospital for further tests.

If cancer is suspected, you will need additional tests to work out the type of cancer you have and whether it has spread. Your doctors will also need to learn more about your general health.

Waiting for the results can be stressful, but your care team needs to have as much information as possible so they can work out the best treatment plan for you.

Here are some of the most common tests that are used to diagnose cancer. If you are unsure about why you need a particular test, or if you have any questions about how it will be carried out, don't hesitate to ask your doctor or nurse.

Biopsy

A biopsy involves removing a small part of a lump or tumour, either with a specially-designed needle (needle biopsy) or during a small operation (open biopsy). The sample is then examined and tested in a laboratory to find out what type of tumour it is. Most suspected tumours will be biopsied.

Blood tests

Blood tests are usually done before, during and after treatment. Some of the reasons for blood tests include:

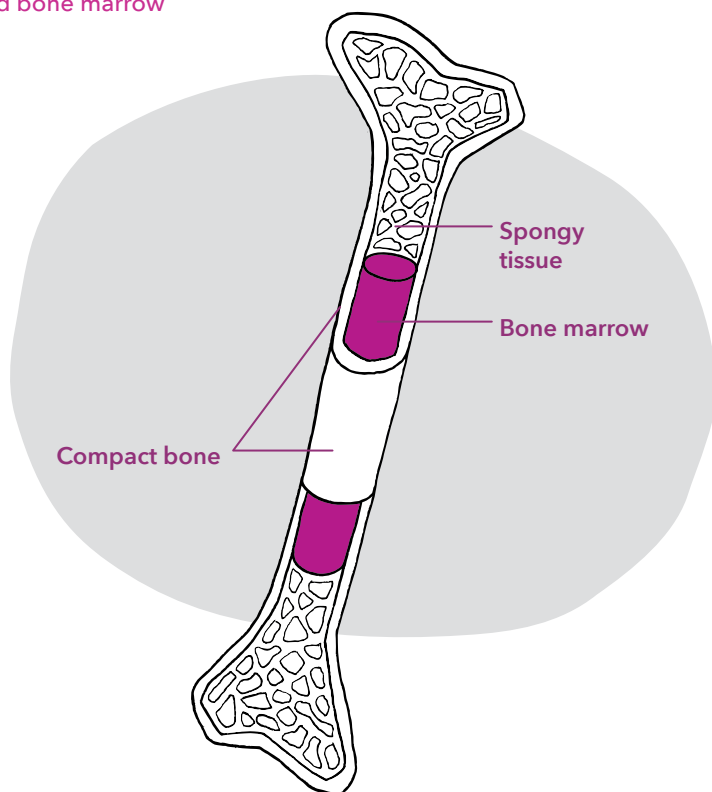
- Detecting cancer
- Checking for infection
- Monitoring how well treatment is working
- Monitoring the side effects of treatment
- Making sure your body's systems (such as your liver or kidneys) are still working properly
- Matching your blood with a donor's if you need a transfusion
- Monitoring your blood count (the number of red and white blood cells and platelets in your blood).

A reduction in the total number of blood cells is a common side effect of treatment, and can increase your risk of infection. You can learn more about how cancer affects your blood on page 36.

Bone marrow tests

Bone marrow is the spongy tissue found inside certain bones. It contains stem cells, which develop into blood cells (see page 37 for more details). Leukaemia and other cancers can affect the bone marrow.

Bone and bone marrow

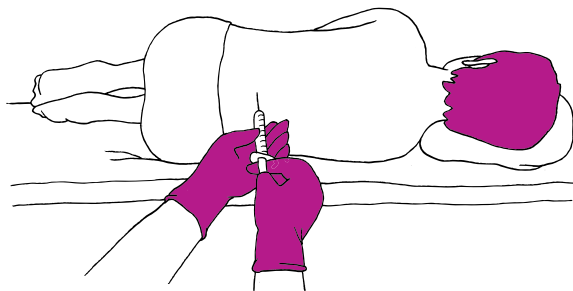


In a bone marrow test, a needle is inserted into the bone to collect some of the bone marrow. You may have a sedative to make you drowsy, or a general anaesthetic to make you sleep. If you are not having a general anaesthetic, the area will be numbed first using local anaesthetic. The bone marrow sample is checked in a lab to see if there are any abnormal changes that suggest cancer. This test might also be repeated to monitor your condition once you have a diagnosis.

Lumbar puncture

A lumbar puncture is used to test the fluid around your spinal cord (called the cerebrospinal fluid) to see if it contains cancer cells. A needle is inserted between the bones in your lower spine, and a few drops of the fluid are drawn out for testing in the lab. You will have a local or general anaesthetic before the test. As some people have a headache afterwards, once you have had the test you will be asked to lie flat for a while to try and prevent a headache coming on.

A lumbar puncture is used when leukaemia, lymphoma and some solid tumours are suspected or confirmed. It tests whether the cancer has spread to this fluid from elsewhere in the body.

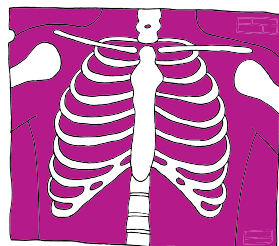


If you might be pregnant

Tell your doctor and the technician doing your tests if you are pregnant, or think you might be. They can take steps to protect your baby, especially if you are having X-rays or scans. This is also important during treatment, so let people know.

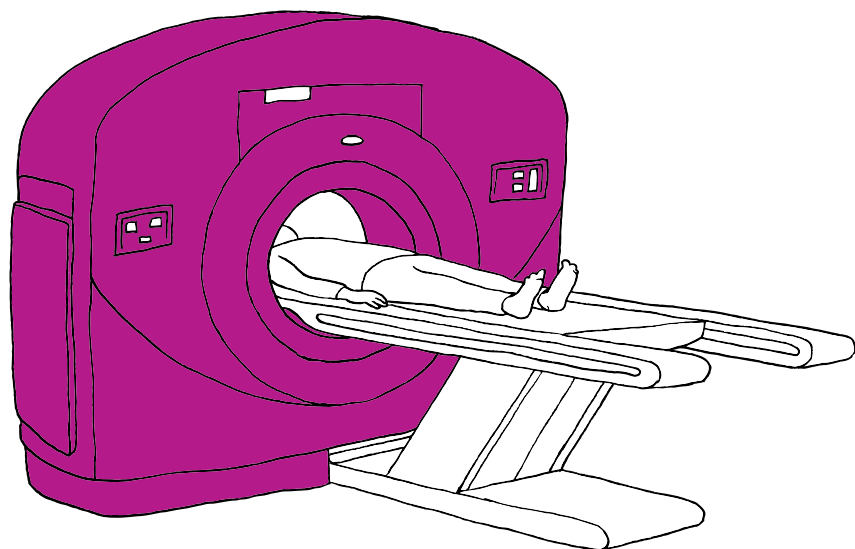
X-rays

X-rays can help to diagnose a suspected tumour in your chest or bones. X-rays are also used at other times, for example to check for a chest infection if you have a temperature. Sometimes tumour tissue can look very different to healthy tissue on an X-ray, but this isn't always the case. If the tumour tissue is not obvious on an X-ray, the specialists may need to use different scans to get a more detailed picture.



CT (computerised tomography) scan

This scan uses X-rays to produce images of the inside of your body. You will need to lie very still during the scan, but it only takes a few minutes. Sometimes an injection is also given with the scan to help different areas of your body show up more clearly.



MRI (magnetic resonance imaging) scan

An MRI scan involves lying in a narrow tunnel within the machine as the scan takes place. The scanner uses magnetic waves to create a detailed image of the inside of your body. The machine can be loud, so you will usually wear headphones to help reduce the noise.

The scanner may be fitted with a music or DVD player so ask in advance if you can bring something to keep you occupied. The scan will usually last between 20 and 60 minutes, depending on the parts of your body that need scanning, and you will need to lie very still. Sometimes you will be given an injection during the scan to show up parts of your body more clearly.

Ultrasound scan

An ultrasound scan uses sound waves to look at different organs inside your body, especially your heart, liver or kidneys. It can show the presence of unhealthy tissue. The person doing your scan will put some gel on your skin, which may feel a little cold. They will then move a hand-held ultrasound wand around, pressing it over the part of your body that is being scanned.



Bone scan

A bone scan highlights areas of your bone that are growing or changing rapidly. It starts with a small amount of radioactive fluid being injected into your vein (called a tracer), which after a few hours will travel to your bones. You then have a scan of your whole skeleton and the tracer shows up. The results can help to tell if cancer is affecting any of your bones.

PET (positron emission tomography) scan

PET scans are able to measure how much glucose (sugar) parts of the body are using. This can show where cancer cells are, because they often use more sugar than normal cells.

Having a PET scan is very similar to having a CT scan. As when having a CT scan, you need to lie still on a bed which moves through the tunnel on the machine.

Before the scan, you have an injection of a sugar solution with a small amount of radioactivity. After the injection you have to lie still for up to an hour while the radioactive glucose gets into your tumour cells. Lying still stops the sugar solution going to your muscles, which can make it harder to understand what the scan shows. It's also important to stay nice and warm while waiting for the scan.

The scanner then moves over your body, and picks up areas where the radioactive sugar is more concentrated. After the scan, your body quickly eliminates the radiation. You can ask the people at the scan centre to give you more information about this.

About staging and grading

One of the big questions on your mind may be how far your cancer has advanced. Answering this question is one of the main reasons for all the tests. It's also important information for your doctors, as it influences the choice of treatment. There are two general concepts to understand:

Staging 🕒 The stage describes how big the tumour is, and how far it has spread from the location where it started

Grading 🕒 This tells how much your cancerous cells have changed, compared to a normal cell.

These test results can be difficult to understand, so ask your care team to explain how staging and grading work for your type of cancer, and what your test results mean.

YOUR CARE TEAM

During your cancer treatment, you'll meet many different people who all work together to provide you with the best possible care.

In this booklet we use the term 'care team' to cover the range of professionals who will care for you during this time. Some of their roles are explained below.

The exact make-up of your team will depend on your age, the type of cancer you have and the hospital you are at.

Consultant

A senior doctor will take the lead in your diagnosis and treatment. They may be known as a specialist, a consultant or have some other title. They will usually specialise in the type of cancer that you have been diagnosed with. You may not see this person every time you visit the hospital – sometimes you might see other doctors on the consultant's team who are at different levels of their specialist training. There are several different types of consultants you may meet:

Oncologist

A doctor who treats people with cancer. There are three types of oncologist. Clinical oncologists treat patients of all ages with radiotherapy, and adults with drug treatments. Medical oncologists treat adult patients with drug treatments. Paediatric oncologists treat children with drug treatments.

Haematologist

A doctor who specialises in blood disorders, including leukaemia and lymphoma.

Surgeon

A doctor who specialises in the type of surgery related to your condition.

Hospital multi-disciplinary team (MDT)

The group of healthcare professionals, led by a consultant, who make decisions together about your care.

Teenage and young adult multi-disciplinary team (TYA MDT)

A team of health and social care professionals who specialise in the treatment of young people with cancer. They are available to advise hospital MDTs of 16 to 24-year-olds to help ensure you get the most appropriate treatment, care and support.

Specialist nurses

They have had extra training in certain areas of care and are a really important contact for you and your family, as they can talk you through any questions or worries. The type of specialist nurse may vary between hospital teams. They could include:

- ◉ Paediatric specialist nurses who support children with cancer and leukaemia
- ◉ Teenage and young adult specialist nurses who support young people up to the age of 24
- ◉ Cancer site specific nurses who support people with a specific type of cancer, such as a lymphoma nurse specialist or a sarcoma nurse specialist
- ◉ Late effects nurse specialists who support children and young people through any long-term effects of their treatment.

Ward nurse

They carry out day-to-day care and provide ongoing treatment, including giving injections and taking blood samples.

Community or district nurse

These nurses provide care at home and any medication you may need.

Ward doctor

These doctors, under the supervision of the oncologist, will do most of your tests and treatments.

GP

They care for you when you're back at home. Your consultant will keep the GP informed about your treatment.

Oncology pharmacist

They specialise in the drugs used to treat cancer. They can give advice about the side effects of a particular drug and can help your doctors with prescribing drugs to control things like pain or nausea.

Pain control team

They can help you with any pain or other symptoms, such as nausea or loss of appetite caused by your cancer or its treatment.

Therapeutic radiographer

The person who operates the machine that gives you radiotherapy treatment.

Radiologist

A doctor who specialises in interpreting X-rays or scans to help with your diagnosis or treatment.

Diagnostic radiographer

The person who operates the machines that take your X-rays or scans.

Dietitian

They will provide you with nutritional advice to help you deal with your treatment and any side effects.

Physiotherapist

A specialist in using exercise and activities to help you during your treatment and also to help you recover physically afterwards.

Occupational therapist

They can help you maintain the physical and psychological skills that you need to continue with your day-to-day life.

Psychologist

They may be available at your treatment hospital to help you deal with your diagnosis, treatment and beyond.

Social care professionals

You may have a CLIC Sargent Young People's Social Worker or Community Worker in your area who can provide emotional support as well as practical help with financial issues, education, employment and training.



TREATMENT

There isn't one type of cancer treatment that works for everybody. Just as there are lots of different types of cancer, there are different ways to treat them. Your multi-disciplinary team will put together an individual treatment plan for you that takes into account:

- The type of cancer you have
- Its stage (such as how big the tumour is or how far it has spread)
- Your general health.

The three main ways to treat cancer – surgery, chemotherapy and radiotherapy – are explained in this booklet. There is also information about bone marrow transplants, high-dose chemotherapy with stem cell support and clinical trials.

Your treatment plan (sometimes called a 'protocol', 'regimen' or 'regime') may include just one of these treatments, or a combination of them.

Before treatment

Before your treatment plan is put into action, your doctor will discuss with you exactly what is going to happen and the benefits, risks and potential side effects of the treatments they are recommending.

Your doctor or nurse will also be happy to answer any questions you have and repeat the information as often as you need. It might help to write down your questions before each appointment, so you don't forget anything you wanted to ask about.

Other drugs and therapies

When you are receiving treatment for cancer, it's best not to take any other medications or start any complementary therapies without first speaking to your doctor. You also need to let your care team know if you've been using any recreational drugs, such as marijuana. If you are taking steroids for bodybuilding, they need to know about this too. These drugs may affect your treatment or some blood test results, so it's important to be honest with your hospital team.

What about side effects?

Whatever type of treatment you're having, the main aim will be to prevent further growth and, where possible, rid your body of the cancer. But your treatment may also cause side effects. Although treatments target cancer cells, they can affect other healthy cells that divide and reproduce quickly, such as the cells found in the stomach, skin, mouth, hair and bone marrow. It depends on your type of treatment but common side effects include hair loss, increased risk of infection, changes to your weight, tiredness, problems with concentration and thinking, and issues with eating and digestion.

If you're having problems because of your treatment, always ask your care team for help. And try to remember that, although the side effects of cancer treatment can be worrying and difficult to deal with, most of them are only short-term and will gradually disappear once your treatment is complete.

Some types of cancer treatment, such as radiotherapy and chemotherapy, can increase the risk of later developing another type of cancer. However, this is a rare occurrence – the risk is small compared to the risk of leaving your original cancer untreated.

You can read more about side effects on page 49.

Will I still be able to have children?

We know this question is a concern for many young people diagnosed with cancer. Everyone is different, and the possible effect on your fertility will depend on lots of factors – where your cancer is, the type of treatment you have and whether you're male or female.

Your doctor, or potentially the fertility team at your hospital or nearest fertility centre, should discuss any risks you're facing and your options before your treatment starts. If they haven't mentioned it already, don't be afraid to ask about it, or any other questions you have about sex and contraception. It's something they will have discussed many times before.

It might be possible to preserve your sperm or eggs for the future. In some instances, using IVF (in vitro fertilisation)

to make and freeze an embryo might be an option. These steps must happen before treatment starts. However, sometimes there isn't time if your treatment has to start urgently to stop the cancer developing further.

If you've already spoken to someone about fertility or sex, and are still unsure about what you've been told or what you should do, ask to speak to your doctor again. Or you can speak to another member of your care team if you prefer.

Where to have treatment

One of the biggest decisions that needs to be made is where you will be treated. It may be that due to your type of cancer, your place of treatment is determined for you. If this decision hasn't been made, it's important you ask your consultant about your options.

Where you will be treated is likely to be influenced by where you live, recommendations from your consultant and your age.

- If you're aged between 16 and 18, NHS guidance says your treatment should be at a Principal Treatment Centre (PTC) for young people. These are hospitals that have been recognised as specialist experts in teenage and young adult cancer
- If you're 19 or older, NHS guidance says you should have the option of having your treatment at a PTC, or at a teenage and young adult cancer designated unit working in partnership with the PTC.

Speak with your consultant or nurse about what options may be available to you. Your individual circumstances and the best clinical care will be important factors.

Some of your treatment may be on an outpatient basis – that is, you will turn up to the hospital clinic for your treatment and then go home the same day. Other times you may need to stay in hospital for a while as an inpatient.

For more information, visit www.nhs.uk/young-cancer-care, which clearly explains some of your possible choices. The site includes a checklist that helps you think through what is important for you, and gives you the chance to print a list of things to discuss with your consultant or nurse.

Transition

This can be a big issue for young people with cancer. If you start out in a children's cancer hospital, you may need to move on to an adult hospital as you get older, or you may be offered inpatient treatment in a specialist unit for teenagers and young adults. It might be daunting to enter new territory, but it can also ensure you get the best possible care.

Ideally:

- ◉ You will have a chance to talk to your doctors and nurses without your parents, if you want this. Even if you are under 18, health professionals will help you understand your options for where you can be treated
- ◉ You should get clear information about what to expect
- ◉ The paediatric and adult teams should have clear communications about your case, with a gradual handover.

Each hospital has its own policy about this, and some have services especially for young people. So ask your doctor or nurse how it's likely to work for you.



SURGERY

If you have been diagnosed with a solid tumour, you are likely to need surgery to remove your tumour and any surrounding tissue at some point during your treatment.

When you are first diagnosed, you may have an operation called a biopsy. This is where a small piece of the tumour is removed and examined to find out whether or not it contains cancer cells.

When is surgery used?

Depending on the size of the tumour, you might have surgery to remove the tumour in the first or second stage of treatment.

If your tumour is removed by surgery and is found to be benign (non-cancerous), then this operation may be the only treatment you need. However, some benign tumours do also need treatment with chemotherapy and radiotherapy.

If it's found to be a cancerous tumour, then you may also need chemotherapy or radiotherapy to kill any cancer cells that might be elsewhere in your body.

If your tumour is large, or if removing it might damage any surrounding tissue, you may first be given chemotherapy or radiotherapy to shrink the tumour and increase the chances of successful surgery.

How is surgery done?

Surgery is usually done in an operating theatre at a hospital. Biopsies may be done under local anaesthetic, but most other operations will require a general anaesthetic which sends you to sleep while the operation takes place. When you wake up, the operation will be finished. Sometimes you will be able to go home the same day, but for bigger operations you will need to stay in hospital for a while.

After your surgery, you will probably need to have some painkillers to help with the discomfort. If you are still uncomfortable, or in pain, tell the nurses as they can help with this.

What are the side effects?

The side effects associated with surgery will depend on the type of surgery you have.

Your surgeon will explain what to expect before you have the operation and check that you understand the effects. Sometimes the extent of your surgery will depend on what they find during the operation, when they can see the cancer. Ask as many questions as you need to. You can talk to other people on your care team too.

When you have surgery for cancer, it might leave you with permanent changes to your body. This depends on what kind of cancer you have and what your operation involved. Having a scar is common.

Here are a few tips:

- Remember, scars always look worse straight after surgery when they are red and obvious. They often fade with time
- Scarring can be difficult to accept and adjust to. If you feel low in confidence about your appearance because of scarring, think about speaking to a psychologist or counsellor (speak to your care team about this)
- Skin camouflage products and services to help cover up scars are available. Speak to a member of your care team about how to access them, or contact the organisation listed on page 25.

Sometimes the lasting effects of surgery might be really hard to come to terms with. You will get lots of support from your care team before and after your operation. There are also some organisations listed on page 58 that can provide practical advice.

Help with body changes

If you have body changes after surgery and need emotional or practical support, you may find it helpful to contact the charity Changing Faces.

www.changingfaces.org.uk

0300 0120 275

The website has useful information and booklets about scarring, as well as details of their skin camouflage service.

If you've lost a limb through surgery, you may want to contact the Limbless Association.

www.limbless-association.org

0800 644 0185

Pain and infection

You may experience some pain in the area that was operated on, but you should be given painkillers to reduce this. Talk to somebody in your care team if you are still uncomfortable.

You may also be given antibiotics to prevent infection to the wound, and be taught breathing and leg exercises to reduce the risk of chest infections and blood clots.

CHEMOTHERAPY

Chemotherapy is the name given to medicine which is used to kill cancer cells.

These anti-cancer drugs are sometimes known as 'cytotoxic drugs'. They are carried through the bloodstream and can reach the cancer cells wherever they are in your body. They work by disrupting the growth of these cells.

There are more than 50 chemotherapy drugs, and the choice depends on the type of cancer you have and how advanced it is. You may need several different drugs to treat your cancer. Once your specialist has decided on your treatment plan, they will let you know what drugs you will need and their particular side effects.

When is chemotherapy used?

For some cancer types, chemotherapy on its own is the main treatment.

Chemotherapy is also used to:

- ◉ **Shrink the tumour before surgery or radiotherapy (known as neoadjuvant therapy)**
- ◉ **Reduce the risk of the cancer coming back after surgery or radiotherapy (adjuvant therapy).**

Some cancers, such as leukaemia, need chemotherapy because the cancer cells are in the blood and therefore all over the body. In other cases, when a solid tumour is removed with surgery, specialists may also prescribe chemotherapy to target any cancer cells that might be left.

Biological therapies

You might hear different names for biological therapies such as immunotherapy, biologic agents or monoclonal antibodies. These treatments work by boosting your immune system, or by interrupting the growth of cancer cells. Sometimes they are used to manage the side effects of other treatments.

Hormonal therapies

Hormones are chemicals that your body produces naturally. You can think of them as messengers that give your body instructions. Some cancers, such as breast cancer, are affected by hormones. Hormone therapy modifies these chemicals or their effects and helps to control the cancer.

How is chemotherapy given?

Not everyone has chemotherapy. If you do, it's common to have intravenous chemotherapy (this means given directly into a vein). This can take a few hours or even several days. Chemotherapy can also be given as a liquid or tablet to take by mouth, or by injection into the muscle or under the skin. You might just have tablets, or you might have a combination of intravenous chemotherapy followed by tablets.

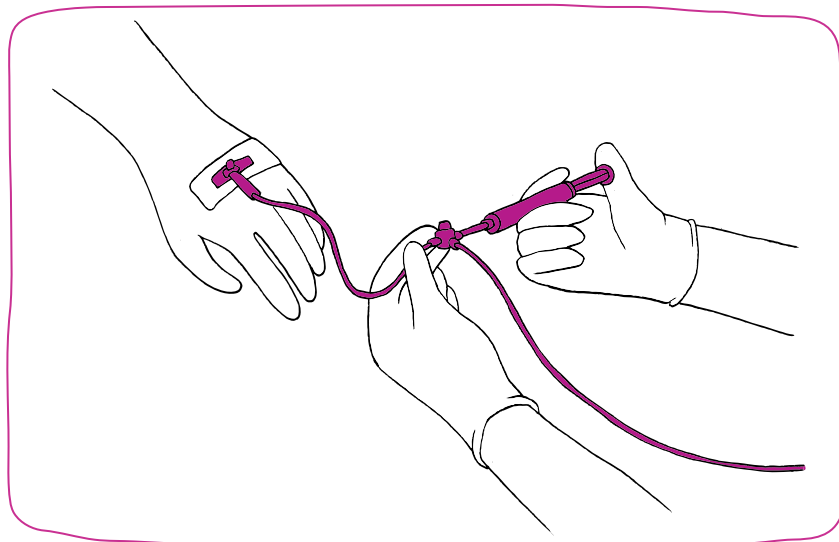
With some types of chemotherapy, you can go to the clinic, have your treatment, and then go home. Some chemotherapy can also be given at home. Other times, you have to stay in hospital.

Ways to have intravenous chemotherapy

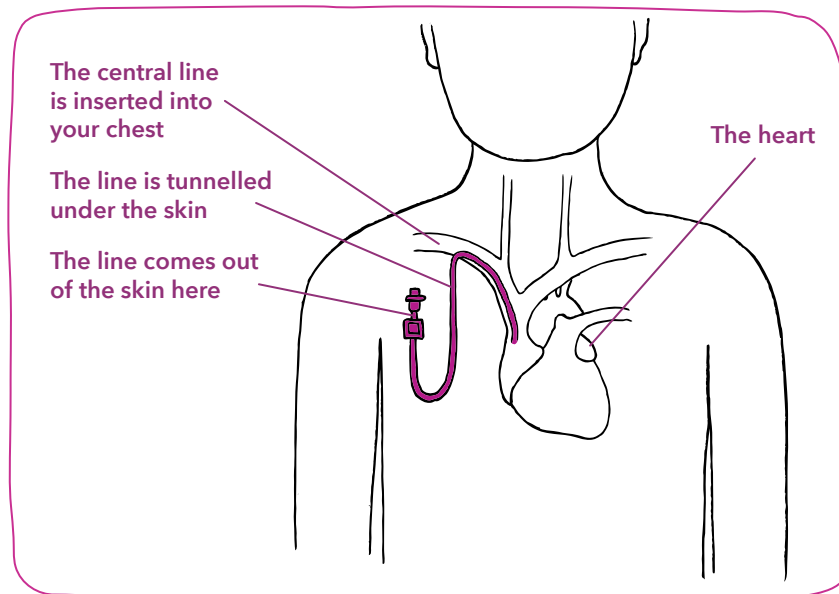
Intravenous chemotherapy always involves inserting a thin tube (or 'line') into your vein, but this can be done in different ways:

- Using a normal cannula, which is put into a vein in your hand or arm. These are usually put in specifically for each treatment, then removed immediately afterwards
- Through a PICC line (peripherally inserted central catheter). This is inserted into one of the veins of your arm, then slid into the vein until the tip sits in a large vein just above the heart
- Using a central line, which is a tube placed into a vein in your chest, usually the one that lies just under your collarbone. There are different types of central line. With a Hickman or Broviac line, the end of the tube is on the outside of your chest and is sealed with a cap. A portacath is located under your skin and accessed with a needle when it's needed. The central line is put in place while you are under anaesthetic and can stay in place for weeks or months if necessary.

Chemotherapy being given by injection into a cannula

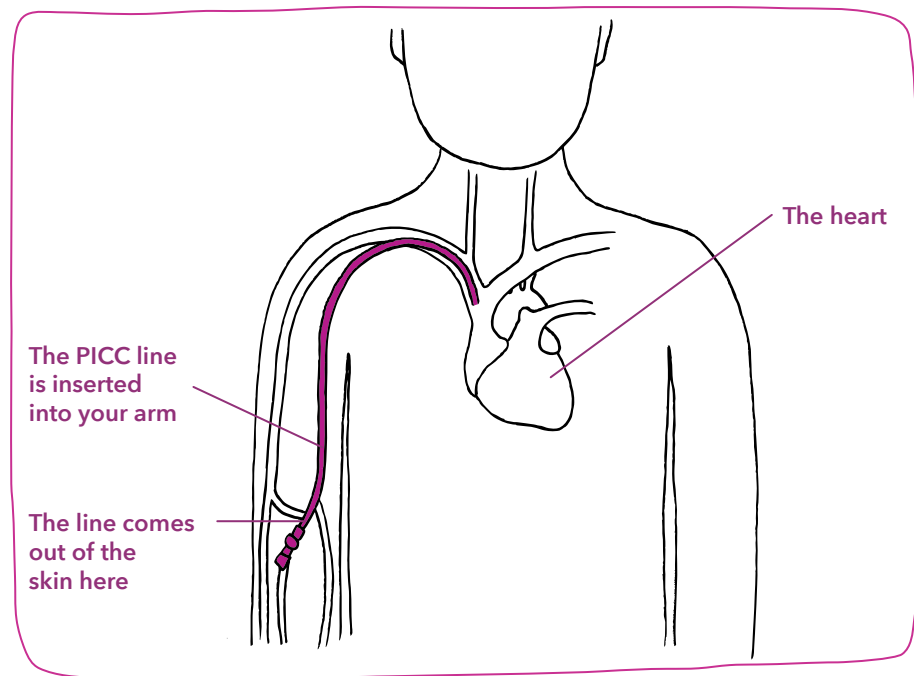


A central line

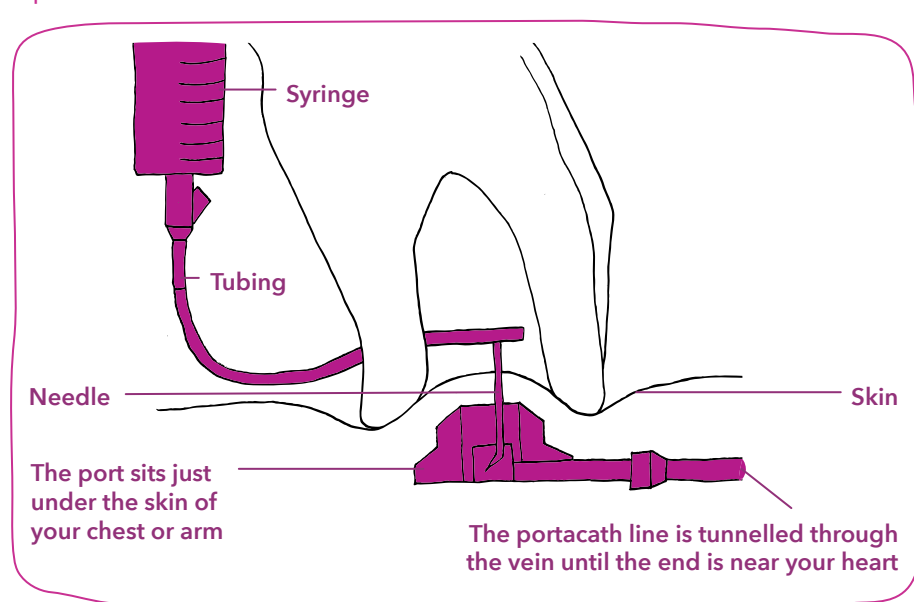


Intravenous chemotherapy – see page 27.

A PICC line



A portacath



Chemotherapy is usually given in cycles. This means you have several days or weeks of treatment, then a rest period, then more treatment. The number of chemotherapy cycles you need will depend on your individual circumstances, such as the type of cancer you have, and how well it's responding to treatment. Some people just have one cycle, while other people can have many.

What are the common side effects?

One drawback is that chemotherapy can also affect healthy cells, which is why side effects can happen.

Some people don't have many problems with chemotherapy. But if you don't have side effects, it doesn't mean the treatment isn't working.

Some of the most common side effects are:

- ◉ **Fatigue.** Many people feel really tired
- ◉ **Feeling sick and vomiting.** This happens to about half of people and it depends on the chemotherapy you have
- ◉ **Diarrhoea or constipation**
- ◉ **Hair loss.** But don't worry – it grows back when treatment stops
- ◉ **Getting infections**
- ◉ **Losing weight, or gaining it**
- ◉ **Changes in appetite or your sense of taste**
- ◉ **Sore mouth and gums**
- ◉ **Skin problems**
- ◉ **Concentration and memory problems**
- ◉ **Sleep problems.**

Many of these side effects are temporary, and should gradually improve once you complete your treatment. However, some individual drugs may cause particular longer term effects on your heart, renal system, hearing or other organs. If these drugs are used, your doctor will monitor you throughout your treatment to see what effect they are having on your body, and may alter the treatments or dosage if necessary.

For more information about the potential side effects of your treatment and how to deal with them, talk to your specialist. In many cases it's possible to reduce or treat side effects, so make sure you let your care team know how you are getting on with your treatment.

Chemotherapy and contraception

If you are on the pill or use an implant, either for contraception or to control periods, discuss this with your care team as some methods of contraception may be less effective due to chemotherapy side effects (eg diarrhoea). It's important not to become pregnant, or make someone pregnant, if you are having chemotherapy as it can affect an unborn baby.



RADIOTHERAPY

Radiotherapy uses controlled doses of high-energy X-rays to destroy the cancer cells while trying to do as little harm as possible to your normal cells.

When is radiotherapy used?

Not everyone with cancer will need radiotherapy. Whether or not it's part of your treatment plan will depend on the type of cancer you have and where it is in your body.

Radiotherapy is sometimes given in combination with other treatments, such as chemotherapy. It's also sometimes given before, or alongside, surgery to remove a tumour.

How is radiotherapy given?

There are two types of radiotherapy: external radiotherapy and internal radiotherapy. A member of your care team will explain the procedure and help you prepare for it.

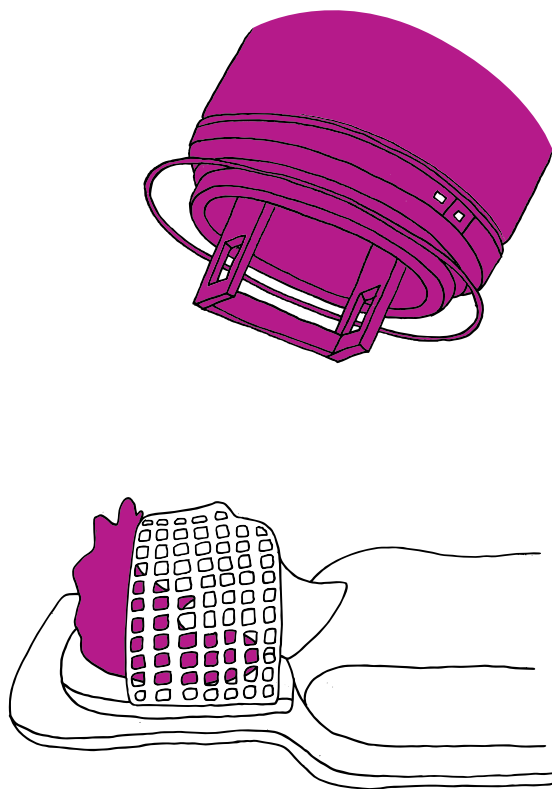
External radiotherapy

External radiotherapy is done from outside the body. Having external radiotherapy is a bit like having an X-ray. It's not painful and will only last a few minutes. The longest part is setting up the machine for your treatment.

It's important to stay very still during the treatment. You may also need a plastic mould, called an immobilisation device, to help prevent movement in the part of your body that's being treated.

Radiotherapy is usually given Monday to Friday, with breaks at the weekends and bank holidays. Each day's dose is called a fraction. Giving the treatment in fractions means that less damage is done to your normal cells. A course of radiotherapy may last anything between one day and seven weeks.

An example of radiotherapy to the head



Internal radiotherapy

Internal radiotherapy works from inside the body. It's based on the idea that cancer cells take up some radioactive substances faster than normal cells do, so can target cancer cells while having less effect on normal cells.

To have this treatment, you might take a radioactive drink or tablet, or it might be given as an injection into your vein or inserted into your body as radioactive wires or pellets.

You will need to stay in hospital until the radioactivity has left your body. During this time you might need to be kept isolated from other people. How long you are in hospital for will depend on your treatment, and it could be just a few hours or up to a few days.



What are the side effects?

Radiotherapy affects people in different ways, so it's not possible to predict exactly how you will respond to the treatment.

Some side effects depend on which part of your body is being treated, so ask your doctor or nurse what to expect. In general, people having radiotherapy might have the following side effects:

- Tiredness (fatigue)
- Feeling sick
- Changes in appetite
- Skin irritation – your skin can become sore, itchy or change colour
- Sensitive skin – so protect your skin from sun and cold wind
- Hair loss – but this only happens to the area that's being treated. Depending on the type of radiotherapy you have, it may or may not grow back
- Fertility problems – if your ovaries or testicles are within your radiotherapy treatment area, it may affect your ability to have children. Talk to your care team about your options before beginning treatment. You may be able to store eggs or sperm before your treatment starts, to use if you want to have children later.

Your care team can help you manage these, and other, side effects. You can also find more information about handling side effects on page 49.

High-energy proton beam therapy

This is a new type of treatment that isn't available in the UK yet. It uses small parts of atoms called protons, which are different from other forms of radiotherapy. Although the research evidence is still limited, it's possible that proton beam therapy may reduce the risk of long-term side effects. If your doctor thinks it's right for you, they will refer your case to a panel of experts. If the referral is approved, the NHS will pay for treatment, flights and accommodation abroad, usually in the USA. Only a few young people qualify for this treatment, which is especially useful for rare cancers affecting the base of the skull and the spine.

You can find out more about proton beam therapy at www.clicsargent.org.uk

CANCER AND BLOOD

You've probably never given your blood much thought. But while you are having treatment for cancer, your blood is like a dashboard that provides all kinds of information about your diagnosis, how treatment is progressing and your overall state of health.

Some background knowledge about blood will help you understand the results from lab tests, and explanations about what's happening with your cancer and treatment.

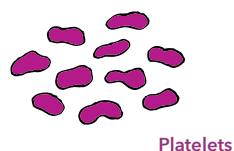
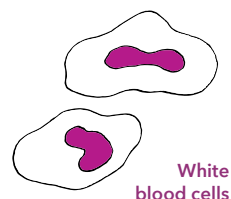
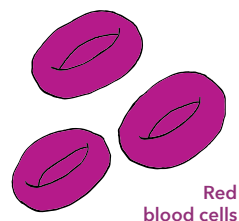
What your blood does

Blood carries oxygen around the body. It also collects carbon dioxide, which is a waste by-product of your body's metabolism. Blood plays a vital role in fighting infection and it keeps your body temperature steady.

What your blood is made up of

Your blood is only about half liquid. This rich fluid, called plasma, is composed of water, salts, sugars and fats. The plasma is packed with different types of cells, which make up the rest of your blood. The main types of blood cells are:

- **Red blood cells (RBCs), to carry oxygen.**
When you don't have enough RBCs you become anaemic, and start feeling tired and breathless
- **White blood cells (WBCs), to fight infection.**
When these are low, you are vulnerable to infection
- **Platelets, to form clots and stop bleeding**
when you are injured. A low platelet count can cause symptoms like bruising or nosebleeds, or increase the risk of serious bleeding.



It's a good idea to read the next section on neutropenia (a low WBC count) and preventing infection. This is important information for anyone having cancer treatment.

Bone marrow and your blood

Inside the hard outer layer of your bones is a spongy core called the bone marrow. This is like the factory for your blood. As old blood cells die off, the bone marrow constantly makes new ones. Because these cells are produced rapidly, they are more vulnerable to the effects of chemotherapy and radiotherapy. These treatments can temporarily damage your bone marrow, an effect that is called myelosuppression. This short-term effect decreases your body's ability to make blood cells, lowering your levels of RBCs, WBCs and platelets.

Some of the cancers that are more common in young people also affect the bone marrow. For example, leukaemia causes the bone marrow to produce abnormal WBCs. Some solid tumours can spread to the bone marrow, and also affect the production of WBCs.

If you are having bone marrow biopsies, you can find out about this on page 10. There is also a section on stem cell transplants on page 46.

NEUTROPENIA, INFECTIONS AND STAYING WELL

When you're having treatment for cancer, you are more vulnerable to infections. This is because chemotherapy and some other treatments reduce your supply of white blood cells (WBCs), which fight off bacteria and viruses. Even something like a cold, which would normally be trivial, can be dangerous when your WBC count is low.

A low level of white blood cells is called neutropenia. You can read more about the different types of blood cells on page 36.

A week or so after chemotherapy, your WBC count is likely to be at its lowest (when you are 'neutropenic'). Your care team will tell you more precisely when this is and will remind you to be extra careful at these times.

You can do a lot to protect yourself against infections:

- Wash your hands any time they might have picked up germs: after using the loo or changing a nappy, before cooking and eating, after handling a pet, after housework or clearing up rubbish
- Don't be afraid to remind other people to wash their hands before touching you, including doctors and nurses
- Have good personal hygiene, taking a bath or shower every day



- ◉ Make sure your clothes, towels and bed linen are washed regularly
- ◉ Take good care of your teeth and gums (see page 41)
- ◉ Use a condom if you have sex. This protects you from infection, provides contraception and, if you are having chemotherapy, it also stops your partner from coming into contact with drugs that might be in your system
- ◉ Stay away from people who have common illnesses like colds, flu or tummy bugs. It's not easy but this means friends, family and children too
- ◉ Avoiding crowded places is important too, especially during times when you are neutropenic. It might mean staying away from lectures, work, or unfortunately from places like concerts or cinemas. You might have to put off swimming. It's only for a while though. Ask your care team for specific advice for your individual situation.

Know the signs of infection

It's important to stay alert because what would normally be a minor illness could be extremely serious when your immunity is low. Watch out for the following signs and, if you develop them, call the department or ward number you have been given right away so they can tell you what to do.

- ◉ Fever – call immediately, even if it's the middle of the night
- ◉ Shivering or sweats
- ◉ A cough that is new or getting worse
- ◉ Cold symptoms – sore throat, stuffy nose
- ◉ Burning or pain when you pass urine, or in your genital area
- ◉ Diarrhoea and vomiting – tell your care team as they will be able to tell whether it's due to side effects or an infection
- ◉ Bleeding mouth or gums
- ◉ Blood in your urine or when you have a bowel movement
- ◉ Redness or soreness anywhere on your body, especially around your Hickman or PICC line, or your portacath
- ◉ Abdominal pain
- ◉ Stiff neck.

We can't cover everything here so if you are at all unsure, call the department or ward on the numbers they have given you. Do it right away to be on the safe side. They won't mind – they would rather talk to you and reassure you than see you get ill because you were worried about making a fuss.

Taking your temperature

It's important to get a digital or ear thermometer to keep at home, and make sure you know how to use it. You can ask your pharmacist or nurse to show you how.

Your care team will give you written information that explains when to get medical advice for a fever, including a phone number to call.

Chickenpox, shingles and measles

Any infection is bad news when you are having cancer treatment, but these are a few that are really important to avoid.

Chickenpox ● Try to stay away from children with chickenpox and tell your doctor right away if you have been around someone with chickenpox

Shingles ● The shingles virus is related to chickenpox. Sometimes it flares up many years after you've had chickenpox because the virus can lie dormant in your body for years. The main symptoms are pain and a rash, sometimes with a fever. Your doctor may give you medication to suppress the virus and manage the symptoms. If you have had shingles, it's common to get it again

Measles ● You can catch measles if you have not had it before, or if you were not immunised as a child. Symptoms are similar to a cold, with a high fever, red and painful eyes, and a sore throat. You usually will not need any specific medication to treat measles but if you get really ill from it, you might need to stay in hospital while you recover.

If you know you are not up-to-date on your jabs (immunisations), mention it to your care team so they can advise you what to do.

Mouth, teeth and gums

It's important that your dental treatment is up-to-date before your cancer treatment starts, if this is possible. Otherwise, see your dentist as soon as you can after starting treatment. This is because cancer treatments can damage the lining in your mouth, a condition called mucositis. It's painful and causes mouth ulcers (sores).

Either your own dentist, or a dentist who specialises in working with people with cancer, will advise you on ways to reduce the risk, and help you look after your mouth, teeth and gums. If you don't have a dentist it's important to let your care team know.

Mouth sores provide a way in for infections, so good oral hygiene is essential, not only to protect your teeth, but to keep you well. Clean your teeth gently but do it often, after every meal and before going to bed. Use a toothbrush with extra-soft bristles, like a child's toothbrush. Your care team will advise about using mouth wash, but do rinse your mouth often with water to keep it moist. They will also advise you about whether or not to floss your teeth.

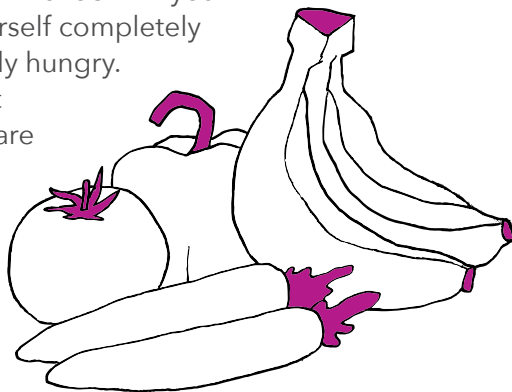
A sore mouth can make it painful to eat. Cold drinks, ice lollies or ice cubes can help with the pain. If your mouth is sore, try going for soft foods, and avoid things that are crunchy, hard or spicy. Aim for food at a medium temperature and not too hot. Tell your nurse or doctor if your mouth is sore and ask about painkillers or medication to help with the symptoms.



Eating and drinking during treatment

Cancer and treatment can wreak havoc with your appetite, whether you find yourself completely turned off by food or ravenously hungry.

Mouth problems might make it difficult to eat, even when you are hungry. At the same time, good nutrition is important in supporting your immune system and to keep up your strength. Try to make the most of the times when you feel hungry, and remember that the small snacks and



drinks that you can manage during the day all make a difference. Aim for a balance of different foods from all the food groups and concentrate on choosing the foods and drinks that you enjoy.

It's really important to drink plenty of fluids during treatment. This helps clear medication from your system and helps you avoid bladder infections.

If you want to drink alcohol, check with your care team whether this is okay.

You'll find more information and tips for managing side effects to do with eating and digestion on our website at www.clicsargent.org.uk

Avoiding injuries

This might not be obvious but when you're having cancer treatment, you need to be extra careful to avoid injuries. This is because of the changes that cancer or treatment can cause to your blood cells:

- If your white blood cell count is low, you are not able to fight off infections very well. So even a minor scrape could cause you problems
- If your platelet count is low, your body's ability to stop bleeding is reduced. A bump could leave you looking bruised and a cut might take longer to stop bleeding.

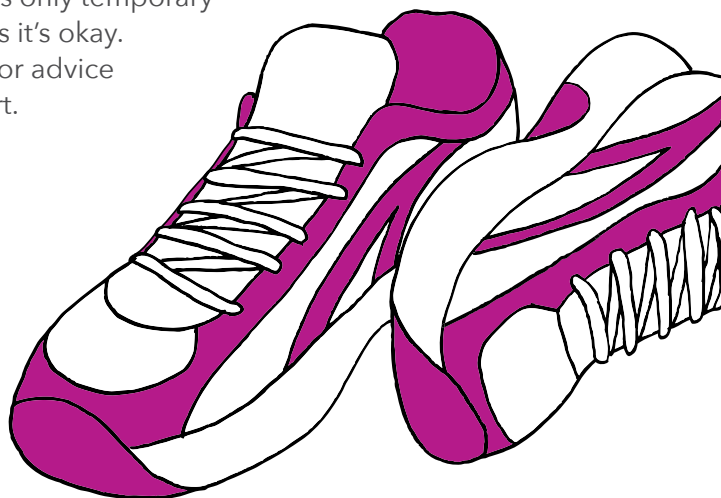
But this does not mean you have to spend your time wrapped in cotton wool. It's not the time to take risks but you can also get on with your life and enjoy yourself.

Exercise and sport

If you're keen on sport, having cancer treatment does not mean you have to give it up. You might need to take a break from your usual sport, but you could see this as an opportunity to try something new. If you're not usually into sport, this is a good time to take up gentle exercise because of all the health and emotional benefits. In general, it's well known that regular exercise helps prevent all kinds of health problems, like diabetes and heart disease. Exercise lifts your mood and can also help you cope with pain.

Although cancer treatments can be tiring, exercising regularly during treatment can actually improve the fatigue.

You might have to avoid some kinds of sport while you're having treatment. For example, contact sports where there's a risk of injury, or swimming while you have a central line, are too much of a risk. But it's only temporary until your doctor says it's okay. Ask your care team for advice on exercise and sport.



STEROID TREATMENT

There are different kinds of steroids. The full name for the type used to treat cancer and side effects is corticosteroids.

When are steroids used?

Steroids occur naturally in the body, and have a number of important functions. Extra steroids can be given as part of your cancer treatment for a number of reasons.

You might have them to:

- Reduce swelling around the cancer – this is particularly useful for people with brain tumours
- Treat the cancer itself, often alongside chemotherapy treatment
- Reduce inflammation
- Reduce your immune system's response to a transplant
- Help relieve sickness when having chemotherapy
- Help increase your appetite.

Most people who take steroids as part of their cancer treatment only need them for a few days or weeks.

If your disease or treatment stops your own steroid production, you may also be given replacement steroids to stop you feeling unwell. In this situation, low doses are used and you should not get any of the side effects described below.

How are steroids taken?

There are a number of different ways to take steroids, such as:

- A tablet that you swallow
- A syrup or tablet that dissolves
- An injection into a vein or muscle (usually your leg or buttock muscle) or into the fat under the skin.

If you're taking steroids for a while, you will get a steroid card to carry in your pocket, purse or wallet. This is important information if you need any kind of medical treatment.

At the end of a long course or high dose of steroids, your doctor will gradually reduce your dose rather than stopping them suddenly, as you would be very unwell if the steroids were suddenly stopped. This is because the medication affects your natural production of steroids and your body needs time to readjust.

Side effects

You might not experience all of these side effects and not everyone has them. It depends on the dose you take, how long you take them for, and whether or not you are also on any other medication. Ask your doctor or nurse about side effects of the specific steroid you are taking.

In general, some of the more common side effects include:

- Increased appetite and weight gain
- Swollen hands, feet or ankles from water retention
- Increased risk of infection
- Changes in blood sugar levels
- Changes in mood and behaviour
- Difficulty sleeping.

Your care team can help you manage these side effects. Advice from a dietitian can be especially helpful if you are worried about gaining weight while you're taking steroids.

It's not advisable to become pregnant, or father a child, while you are taking steroids as they can harm the developing baby. If you are concerned that you or your partner may become pregnant, talk to your specialist about contraception before starting treatment.

STEM CELL TRANSPLANT

You might hear different names for this treatment approach, including:

- ◉ High-dose treatment with stem cell support
- ◉ Peripheral blood stem cell transplant
- ◉ Bone marrow transplant.

But, essentially, they all involve having high-dose treatment with chemotherapy and/or radiotherapy which destroys your stem cells, and then replacing the stem cells afterwards. The replacements might be:

- ◉ Your own stem cells, which have been removed and saved before the high-dose treatment (called an autologous transplant), or
- ◉ Stem cells taken from someone else (a donor – this is called an allogenic transplant).

What is a stem cell?

Stem cells are made in your bone marrow, and some can also be found circulating in your blood. They are 'starter' blood cells that are not fully developed yet. All of your mature blood cells – whether they are WBCs, RBCs or platelets – evolve from these stem cells. To learn more about your blood and bone marrow see page 37.

When is it used?

Stem cell transplants can be used for a number of different cancers, including some types of lymphoma and leukaemia. It depends on your situation but the aims of treatment might be to:

- ◉ Destroy any cancer cells that might remain after your initial treatment
- ◉ Stop the cancer from coming back (keeping it in remission)
- ◉ Treat cancer that has not responded to ordinary therapy.

How is it done?

This treatment takes several weeks and you will need to stay in hospital during this time. It's a complex procedure, and your doctors and nurses will explain everything that will happen. They will also discuss the possible benefits and drawbacks. Here are the basic steps:

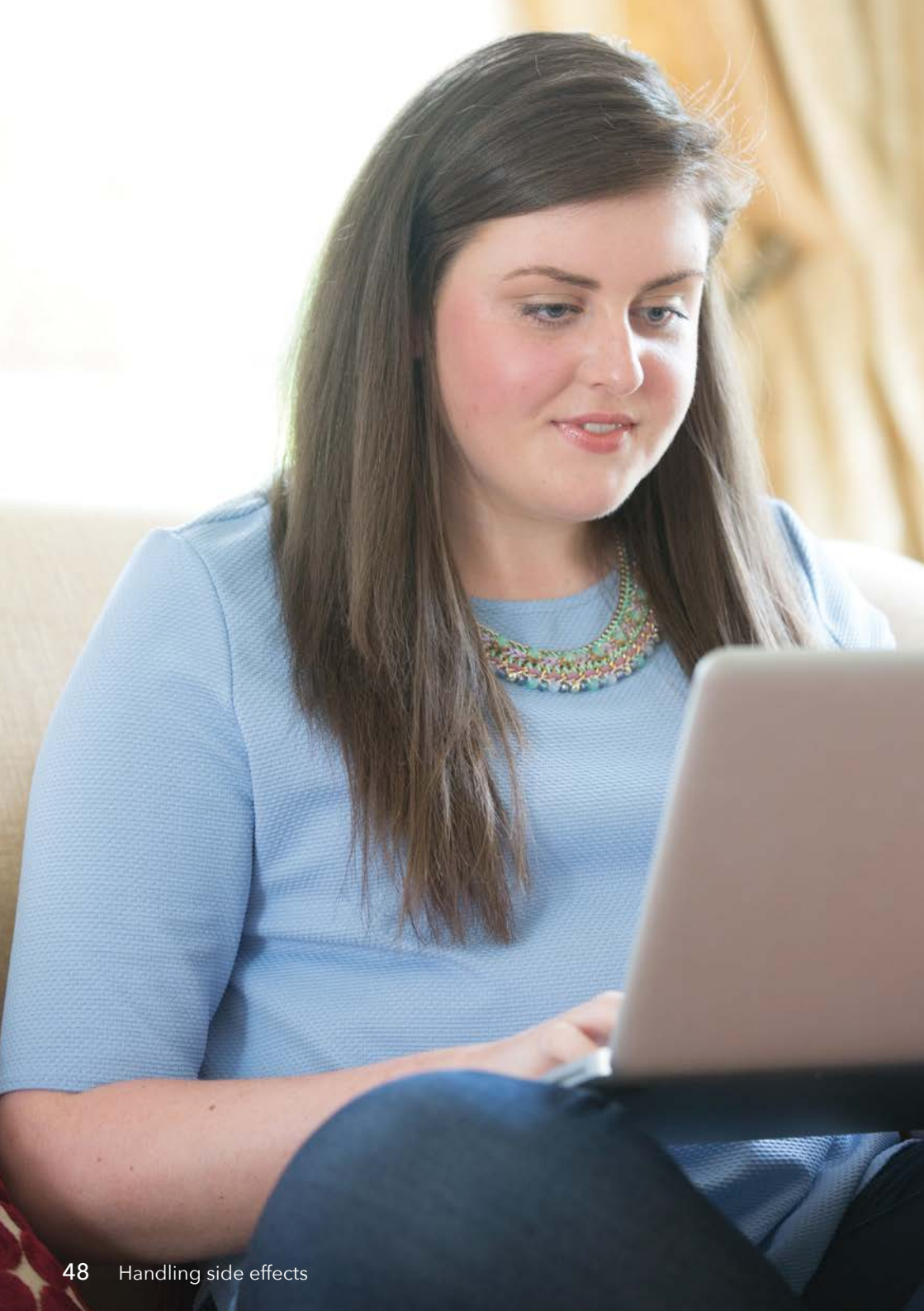
- Stem cells are collected from your blood or bone marrow, or from the donor's
- You then have the high-dose treatment, which destroys your remaining stem cells
- After the high-dose treatment, your stem cells that have been stored, or new stem cells from a donor, are put into your body through a drip into your vein.

While the transplanted stem cells are taking hold, and starting to produce new blood cells again, your immunity will be really low and you will be vulnerable to serious infections. So you will probably have a hospital room to yourself. Visitors might be limited, too, to protect you from infection.

It can be a lonely time, so think about how you could stay in touch with family and friends by phone, email or through social networks. Talking to people who have been through it themselves can help. And, remember, you can always speak to your care team if you are struggling or feeling low.

When are donor stem cell transplants used?

A donor stem cell transplant can be used to increase the chances of curing cancers that affect the bone marrow, such as leukaemia and lymphoma. Your specialist may suggest using donor stem cells because they do not contain any cancer cells, and because the healthy cells may attack and destroy any cancer cells remaining in your body. You may also receive a donor stem cell transplant to help keep your cancer in remission for as long as possible. Your specialist or transplant coordinator will need to find a donor with a tissue type close to your own. This increases the chance of the transplant being successful.



HANDLING SIDE EFFECTS

All treatments for cancer have potential side effects. Everyone has a different experience and it's hard to predict exactly what will happen. This can be both a good and a bad thing. The uncertainty can make it hard to decide about treatment and plan your life around it for a while. On the other hand, just because someone you know had a lot of problems with side effects, it does not necessarily mean this will happen to you.

"I'm one of the lucky ones. The side effects I experienced were extremely minimal and I haven't been affected long-term by the illness, which is great." Louise, diagnosed with acute myeloid leukaemia and now off treatment

The other good news is there's a lot your medical team can do to help with side effects of treatment. There are also steps you can take to help yourself feel better.

In this section we explain some common side effects and how they can be managed. Your medical team may give you medication before the side effects make themselves felt. But if you are struggling with side effects at any point, don't hesitate to tell your doctor or nurse right away so they can respond quickly.

"The impact of my treatment on my confidence has been a really big challenge for me. My hair started falling out during chemotherapy and that really got to me, and I got into a bit of a rut just staying in bed and secluding myself from friends and family. It was hard to motivate myself to do anything because I just felt so tired and ill. I didn't have the confidence to go out and I felt really embarrassed about my situation."

Michael, diagnosed with non-Hodgkin lymphoma and lung cancer

Little things mean a lot

We asked young people what helped them get through treatment, and here is what a couple of them said:

- "People bought me lemon Lucozade - that got me through treatment." *Katie, 20*
- "Fish and chips made my Friday so good!" *Leonorah, 17*

Fatigue or feeling tired

Treatment can be intense and many people having cancer treatment get really tired. This can make it hard to concentrate and get on with your everyday life. It should ease up when your treatment is finished but some people continue having problems with fatigue for a long time afterwards.

You may find it helpful to keep a tiredness diary. This will help you keep track of when you feel particularly tired. Also, it's useful to show your doctor or nurse who can suggest ways to get the rest you need, while still keeping up with what's important to you.

Pace yourself and try to plan a rest period into your day. You might want to think about things you can do with friends that are not too demanding, like watching a DVD together.

Sleep problems are really common in people with cancer and the usual advice applies. Try to keep regular times for going to bed and waking up. If possible, make your bedroom a peaceful haven, not a place where you work, study or use the computer. If your sleep problems continue, talk to your nurse or doctor as they might be able to help.

Some people say that relaxation techniques, a nice massage or aromatherapy really help them feel better in themselves. It's always best to check with your doctor or nurse first to make sure it's safe while you are having treatment. Sometimes you can even get these for free, so ask a member of your care team what's available in your area.

It might sound surprising but exercise has also been shown to help with cancer-related fatigue. Ask your nurse if you can talk to a physiotherapist about a programme that's right for you.

Concentration and thinking

Lots of people having cancer treatment say they have a hard time concentrating, or doing things like studying or solving problems. You're also getting a lot of new information that's hard to take in when you're feeling ill. So here are a few tips to help you:

- To make things simpler, try to plan each day as it comes
- Use things to help your memory such as planners, calendars, post-it notes, to-do lists and reminders on your phone
- Keep notes of anything important, such as conversations with your doctor
- Tell your family and friends about any difficulties you're having with concentration and memory so they can support you.

If you do begin to have concentration or memory problems, it's a good idea to talk to your doctor or another member of your care team so they are aware of the problem.

Hair loss

This can be one of the most difficult side effects to cope with. You don't know how people are going to react, even your friends. If you get a chance, ask about hair loss before your treatment starts so you know what to expect. Not all treatments cause this, or your hair might just get thinner. Sometimes you can lose your eyelashes and eyebrows, or other body hair.

Hair does usually grow back, although it might look different to before. It might be curlier, or finer, or a different colour. After radiotherapy, at points where the beam was strongest, the hair may be much thinner and patchy when it returns. If you're having radiotherapy on your head there may be a patch of hair that doesn't grow back, but this can usually be covered up by the rest of your hair.

"I was told about the side effects of my treatment, including losing my hair. I used to have really nice, long hair but it all started falling out. That made me feel really sad." Anais, 16

You may find it helpful to get prepared before your hair starts to fall out, instead of waiting until it happens. You might want to take a sample of your hair before it falls out so you can match a wig to it. Or you could try out a completely different colour. Ask your nurse about support available for hair loss as there are services that can help you get wigs or choose hats and scarves.

You can also get a prescription to help with the cost of a wig. Wigs can be made from donated human hair so they are easy to care for and style, and can be made for males or females. Some salons also offer special programmes for people having cancer treatment to help you look and feel your best.

"When I lost my hair my friends all came round and we cut it short. Then we shaved it. We made it fun and had a good time." Kathryn, 21

It's not right for everyone but sometimes you can have scalp cooling alongside your chemotherapy. This involves wearing a cap that's filled with a refrigerated gel, or which is connected to a refrigeration machine. It's not guaranteed to work but it might slow down the process of hair loss. You can ask your care team if this is an option for you.

Sometimes, it can be difficult to know what to say when someone asks you why you've got no hair or asks a question about your appearance. You'll find information to help you handle questions you might get about your appearance at **www.clicsargent.org.uk**

HELPING WITH RESEARCH

When your treatment plan is being put together, your doctor may ask if you would like to take part in a clinical trial, which is a medical study involving patients. The aim of these studies is to improve care in the future. Many treatments that are available today have been developed and improved through such research.

Some studies examine existing treatments, looking for better ways to combine them or administer them.

The emotional and practical effects of cancer are another growing area of study. This is to know more about the experiences of young people with cancer, and what kind of support would help others in the future.

There are different phases of clinical trials. Phase I and II trials are used to investigate a new treatment and determine the effective dosage. These usually involve a small number of patients. Phase III trials aim to confirm the benefits of this new treatment over the standard treatment. These trials involve a larger number of patients.

All medical research studies have to be approved before they can go ahead, which means the safety and ethical aspects have been considered by a panel of experts.

Informed consent

If you want to take part in a clinical trial, you and your parents (depending on your age) will need to give informed consent. This means that the trial has been explained to you, someone has told you what will be involved, and you have agreed to take part. You should be given at least 24 hours to think about your decision, if you need to.

If you like, ask if you can talk to a member of the research team so you can learn more about the study. It will be a matter of understanding the potential risks and benefits. You don't have to say yes, and your medical team will still give you the best possible care if you decide not to go ahead. You can also choose to withdraw from a clinical trial at any time.

To find out more about clinical trials, visit www.cclg.org.uk and download CCLG's factsheet, *A guide to clinical trials*.

AFTER TREATMENT

After your treatment is complete you will still need regular visits to an outpatient clinic. At this clinic, your doctor will be looking for any signs that your cancer has returned (a relapse). They will also check that your major organs, such as your heart and lungs, are still functioning well and haven't been affected by your cancer treatment.

Long-term follow up

In the longer term, your care team will be looking to see how you have recovered from your treatment, if you have been left with any problems, and whether you feel like life is getting back to normal. You should receive a follow-up schedule which will tell you what future check-ups and tests you need, and when. You can also ask your doctor what warning signs to look out for, and when you should get medical advice.

Your GP will be kept up-to-date whenever you attend a clinic and throughout your treatment. Afterwards, your GP will be your main doctor again. They can always help when you are ill or unsure whether to worry about something. Part of the process is learning to manage your own health and your GP can be really good at supporting you with this.

Getting back to normal

Many people have mixed emotions when they finish treatment. They're happy but also worried. How will they manage without all that support from the care team? And what if the cancer comes back?

If what you've been through does begin to catch up with you, don't worry. It's understandable to feel this way. And it's okay for you to seek support to help you come to terms with these feelings.

Also, after the end of treatment, it's not unusual for people to have to deal with a lot of the same issues they faced after being diagnosed and during their treatment. You may be worried about your health, troubled by side effects, have relationship issues or find it hard to cope with day-to-day problems.

There are people and organisations who can help you. If you have one in your area, speak to your CLIC Sargent Young People's Social Worker or Community Worker to find out how you can access support. You can also visit our website at **www.clicsargent.org.uk**, or contact one of the specialist organisations listed at the back of this booklet.





HOW CLIC SARGENT CAN HELP

Today, 10 children and young people in the UK will hear the shocking news that they have cancer. CLIC Sargent provides clinical, practical and emotional support to help them cope with cancer and get the most out of life.

Here's an idea of all the different ways we can help you:

- ◉ A wide range of **information** for young people with cancer, to help you navigate your way through diagnosis, treatment and life after treatment
- ◉ **Financial support**, including grants and referral to a specialist CLIC Sargent welfare rights advice service, to help you deal with the financial difficulties a cancer diagnosis can bring
- ◉ **Face-to-face practical and emotional support** to help you, and your family, cope with the impact of a cancer diagnosis and its treatment
- ◉ **Free accommodation** at our nine Homes from Home – close to specialist hospitals where families can stay during treatment, and patients too when treatment allows
- ◉ **Free holidays** and **specialist short breaks** away from the everyday challenges of cancer, with the support of our care professionals and with medical support close by, giving you the opportunity to spend time with others who are going through a similar experience.

We also campaign and influence others to raise awareness of the needs of children and young people with cancer and to improve the support they and their families receive.

For more information, talk to your CLIC Sargent Young People's Social Worker or Community Worker if you have one, visit **www.clicsargent.org.uk** or contact us on **0300 330 0803** or **info@clicsargent.org.uk**

USEFUL ORGANISATIONS

There are many organisations that can provide support and information. Here is a list of some that you may find useful.

Important: freephone numbers are free from landlines but not always from mobile phones. Also, check an organisation's website in case their helpline number has changed, and to find out helpline hours.

The Brain Tumour Charity

www.thebraintumourcharity.org

0808 800 0004 (freephone)

Provides information and support for those affected by brain tumours.

Breast Cancer Care

www.breastcancercare.org.uk

0808 800 6000 (freephone)

Provides information and support for everyone affected by breast cancer.

Cancer Research UK

www.cancerhelp.org.uk

0808 800 4040 (freephone)

Reliable, easy-to-understand patient information.

Cancer Support Scotland

www.cancersupportscotland.org

0800 652 4531 (freephone)

Provides support including counselling and complementary therapies to those affected by cancer, including young people.

Leukaemia Care

www.leukaemiacare.org.uk

08088 010 444 (freephone)

Provides care and support to those whose lives have been affected by blood or lymphatic cancer.

Leukaemia and Lymphoma Research

www.leukaemialymphomaresearch.org.uk

020 7504 2200

Detailed information on all blood cancers and related disorders.

Lymphoma Association

www.lymphomas.org.uk

0808 808 55 55 (freephone)

Information and emotional support for anyone affected by lymphatic cancer.

Macmillan Cancer Support**www.macmillan.org.uk****0808 808 00 00 (freephone)**

Provides high quality cancer information and medical, practical, financial and emotional support. You'll also find information about treatment and side effects, tips on eating and hair loss, and coping with limb surgery.

NHS Choices**www.nhs.uk**

The NHS website has information about cancer, diagnosis, treatments and services. There's also information for young people with cancer up to the age of 24.

Rarer Cancers Foundation**www.rarercancers.org****0800 334 5551 (freephone)**

General information and advice about rare and less common cancers.

Teenage Cancer Trust**www.teenagecancertrust.org**

Information and support for teenagers and young adults with cancer.

Youthhealthtalk.org**www.healthtalk.org/peoples-experiences/cancer**

Videos and personal stories from young people with cancer.

The quotes in this publication are from young people. These are personal views and should not necessarily be taken as the view of CLIC Sargent. Please note that everyone's experience is different and may not follow the order outlined in this publication, and that services will differ across the UK. CLIC Sargent does not accept any responsibility for information and services provided by third parties, including those referred to or signposted to in this publication.

We endeavour to ensure that the information provided is accurate and up-to-date at time of printing. CLIC Sargent cannot accept liability for any loss or damage resulting from any inaccuracy or omission in this publication. Information in this publication should not be relied on in place of appropriate professional or other advice specific to your circumstances.

CLIC Sargent would like to thank everyone who helped develop this booklet.

Supporting young people with cancer

REF: SER023_14244
Version 2, December 2014
Next planned review in 2017

For information about the sources used to put this publication together, or if you have any comments or questions about it, please contact CLIC Sargent on **0300 330 0803** and ask to speak to the Information Manager.



www.clicsargent.org.uk

Registered charity number 1107328 and registered in Scotland (SC039857)

