

For young people aged 13+

Fighting the Big 'C'

A guide for young people
and their families to
understand cancer
and its treatment.

SARAH J PALMER





This booklet has been written to help you, your family and your friends understand a little more about cancer, its treatment, how it may affect you and the ways you can look after yourself whilst on treatment.

By showing it to your family and friends it will help them to understand a little bit of what you are going through. It is very important for them to understand as they will want to help you through this time.

The booklet has been written to reinforce what the doctors and nurses tell you and to help you to remember what has been said. It does not cover all the types of treatment, the drugs used or their side effects. This is because there are many different types of cancer, each requiring their own special treatments. Everyone is different and may respond differently to treatment.

You will all therefore be treated as individuals.

It is important that you and your family ask questions if there is anything that you are concerned about or if you require further explanation regarding any aspect of your treatment or illness.

We are only too happy to help you.

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With grateful thanks to many colleagues for their professional
advice, as well as patients, their parents, my family and friends
for their help and encouragement.

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Cancer may be one of the most frightening words you have ever heard.

It is often thought of with many negative feelings. In the last 30 years there have been so many very positive advances in the field of diagnosis and treatments of cancers that the outlook is now one of great hope, forward thinking and positive outcomes.

The fear of the unknown is often very frightening but this booklet has been written to take away many of those fears so you are able to understand what is going on and why.

WHAT IS CANCER?

Our bodies are made up of millions and millions of cells. There are about 200 different types of cells which all do different jobs, have different shapes, and behave in different ways: for example, a muscle cell is different from a bone cell, which is different from a skin cell etc.

New cells are made to help us grow or repair old worn-out cells. Some cells will carry on dividing throughout our lives in a special way so that new healthy cells are produced. However, if something goes wrong when they are dividing so that an abnormal cell is produced, this cell will divide again and again giving us more and more abnormal cells. These abnormal cells are the cancer cells. Cancer cells tend to divide and grow quicker than normal cells.

Cancer is the word given to an abnormal growth of cells in the body which is malignant. Malignant means the abnormal cells are able to spread to other parts of the body if they are not treated.



THERE ARE 3 MAIN TYPES OF CANCER:

SOLID CANCERS - when a lump forms, eg. the bone, muscle, brain cells, etc. divide and multiply abnormally.

LEUKAEMIAS - when the blood cells divide and multiply abnormally.

LYMPHOMAS - when the cells of the lymphatic system divide and multiply abnormally. This can produce large lumps.

There are 3 main ways cancer can be treated. By:

CHEMOTHERAPY RADIOTHERAPY SURGERY

The treatment the doctors choose for you depends on the type of cancer you have and the stage that it has reached. You may receive one treatment, a combination or all three of these different types of treatments. The doctors will decide on a special plan of treatment for you or **PROTOCOL** and will explain exactly what is going to happen.

PLEASE REMEMBER THAT:

- You cannot catch cancer from anyone else.
- You cannot give cancer to anyone if you have it.
- Nobody knows why some people develop cancer and others do not.
- It is nothing you have done or said that has caused it.

Did you know that cancers are not only found in people but in animals and plants as well?

WHAT IS CHEMOTHERAPY?



The word “CHEMOTHERAPY” comes from two words:

CHEMO **THERAPY**
'CHEMICAL' 'TREATMENT'

CHEMOTHERAPY is the use of drugs (chemicals) to destroy the cancer cells.

The drugs work by disrupting the growth of cancer cells. They can reach cancer cells wherever they are in your body.

Length of treatment

The chemotherapy is given as a course of treatment. Often, you have the drugs for between 1 and 5 days, then have a break for 3 to 4 weeks. This makes up one 'cycle'. Then the cycle begins again. You may have up to 8 treatment cycles.

Some people have surgery during the chemotherapy cycles but your doctor will let you know if you need this.

The **ANTI-CANCER DRUGS** are sometimes referred to as **CYTOTOXIC DRUGS**

Often you will need several different drugs to treat your type of cancer. When the doctors have decided on your treatment plan (or **PROTOCOL**) they will tell you about:

- Each type of drug and what it is called.
- Any side-effects (more information about side effects can be read throughout this booklet).

- How often you will need it. The chemotherapy is given as a course of treatment. Often, you have the drugs for between 1 and 5 days, then have a break for 3 to 4 weeks. This makes up one 'cycle'. Then the cycle begins again. You may have up to 8 treatment cycles.

Some people have surgery during the chemotherapy cycles but your doctor will let you know if you need this.

- The doctors will also talk to you about how your chemotherapy will be given to you. There are three main ways:

- As a tablet.
- As a drip into the vein where the drug is infused in fluid.
- As an injection. An injection could be given in two ways; the first possible way is using a PICC line (peripherally inserted central catheter). It is inserted into one of the veins of the arm and then slid into the vein until the tip sits in a large vein just above the heart. The other way the injection could be given is via a Hickman Line which is a tube placed into the vein in the chest – usually this is the vein which lies just under your collar bone. The Hickman Line can stay in place like this for weeks or months if necessary.

Please discuss your chemotherapy in more depth with your doctors and nurses.

WHAT IS RADIOTHERAPY?



The word “RADIOTHERAPY” comes from two words:

RADIO	THERAPY
‘RADIATION’	‘TREATMENT’

RADIOTHERAPY is the use of controlled doses of high-energy radiation which destroy the cancer cells, while doing as little harm as possible to normal cells. Only some people will need this type of treatment, depending on the type of cancer they have.

Your doctor will tell you if you will be having radiotherapy and will discuss it in much more detail with you, as well as any side effects it may have.

Types of RADIOTHERAPY

There are two types of radiotherapy:

- **EXTERNAL RADIOTHERAPY:** from outside the body using x-rays or electrons (in rare cases, other particles called protons are used). External radiotherapy is like having an x-ray taken and only lasts a few minutes. You will have to lie very still. The course of radiotherapy is normally divided into periods of a few days with breaks in between – these are called ‘**FRACTIONS**’. Giving the treatment in fractions ensures that less damage is done to normal cells. External radiotherapy does not make you radioactive and it is safe for you to be with other people during your treatment.

- **INTERNAL RADIOTHERAPY:** from within the body, either by drinking a liquid that is absorbed by the cancerous cells or by putting radioactive material into or close to the tumour. For this type of treatment, you will need to stay in hospital for a few days until most of the radioactivity has disappeared from your body. Occasionally, radioactive ‘seeds’ may be used and you will be made radioactive for a few days. You may then have some temporary restrictions on your social life. This will be explained to you by the doctors.

Radiotherapy is sometimes given combination with other treatments, such as chemotherapy. Also, if surgery to remove a tumour is required, radiotherapy may be given alongside it. Your doctors will talk with you about:

- If you need radiotherapy on its own or in combination with other treatment.
- If you will be given external or internal radiotherapy.
- How often you will receive it.
- Any side-effects (information about side effects is given throughout this booklet).

WHAT IS SURGERY?



SURGERY means to have an operation.

Operations are done in an operating theatre in hospital. You will have a general anaesthetic which will send you to sleep so that when you wake up the operation will be finished and you will not remember or know anything about having it. After your operation you will be given some pain-killers, but please tell the nurses if you are still uncomfortable and they will try to help you further.

If you have a lump or a tumour you may need to have a **BIOPSY** taken. A biopsy is when a small piece of the lump or tumour is removed. The doctors can then examine it under a microscope and do some special tests on it to find out more about it and therefore reach a diagnosis. This is done as a small operation.

The nurses and doctors will tell you a lot more about operations if you need to have one.

WHAT ARE STEROIDS?

Some patients are given steroids to help treat their cancer. There are a number of reasons why you may need to take steroids for cancer. You might have them

- To treat the cancer itself, often alongside chemotherapy treatment.
- To reduce inflammation.
- To reduce your immune response, for example, after a transplant.
- To help relieve sickness when having chemotherapy.
- To help increase your appetite.

Most people who have steroids as part of cancer treatment only need to take them for a few days or weeks. But you may need treatment for longer after a bone marrow transplant.

How steroids can be taken

- As a tablet that you swallow – you need to take your tablets after a meal, or with milk, as they can irritate your stomach
- As a syrup or tablet that dissolves – this is easier if you find swallowing tablets difficult.
- As an injection into a vein or muscle (normally your leg or buttock muscle).

Courses of steroids

The frequency and length of time you take steroids for depends on why you are taking them. You may need to take them every other day, once a day or several times a day. If you miss a dose of steroids, it is important that you don't take a double dose. Talk to your nurse or doctor about what you should do.

If you are on steroids for more than a week, you should have a steroid card or medical alert bracelet to carry with you all the time. This is because if you needed treatment in an

emergency, medical staff would need to know that you are taking steroids. If you visit a dentist during a course of steroids you should also mention this to them.

AT THE END of your course of steroids

Your doctor will gradually reduce your dose of steroids, rather than stopping them suddenly. This is because your body produces steroids naturally and a course of steroids can stop this process. Your body needs time to readjust so it can produce steroids naturally again.

SIDE EFFECTS OF YOUR TREATMENT

The different treatments for cancer can cause different side effects. Some people may have very few side effects while others will have more. Almost all side effects are only short-term and will gradually disappear once the treatment has stopped.

The main treatments for cancer, such as chemotherapy and radiotherapy, have some common side effects which are described over the next few pages. It is important to remember that everyone is different and will react to cancer treatment in a different way.

The possible side effects of steroids are dealt with separately towards the end of this section as they have some affects which are unique to them.

Don't forget to ask your nurse or doctor if you have any questions or concerns about the side effects of your treatment.

YOUR BLOOD AND BONE MARROW

Your blood is made up from three main types of blood cells which are affected by certain cancer treatments:

RED BLOOD CELLS - carry oxygen around the body.

WHITE BLOOD CELLS - fight infections.

PLATELETS - help to clot the blood to prevent bleeding and bruising.

Blood is made in your **BONE MARROW**, which is a spongy material in the middle of your bones. Normally blood cells are produced constantly throughout your life.

All bones help to make new blood cells, although some make a lot more than others.

Our bone marrow is like a factory that is producing new cells all the time. The cells in your bone marrow divide rapidly to produce new blood cells.

The cells that divide rapidly in our body are affected by **CHEMOTHERAPY** and **RADIOTHERAPY** in the following way:

Types of cells affected:

cancer cells

blood cells

hair cell

cells in the mouth and gut

Effect of chemotherapy/radiotherapy:

kills the cancer cells

reduces the number of blood cells

causes hair loss

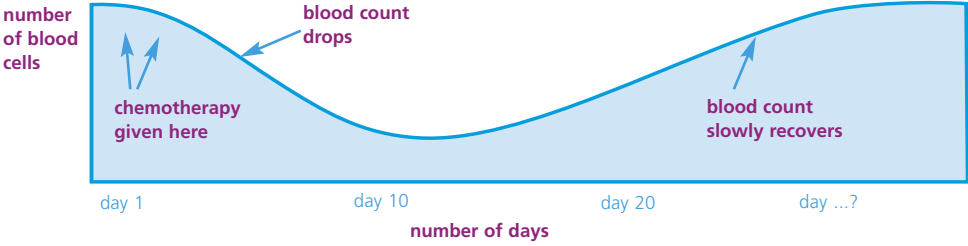
causes a sore mouth and possible upset stomach

RADIOTHERAPY is usually given to a particular area of the body. For example, if you had a lump on your leg, only that area of your body would be treated and you would lose the hair on that part of your leg.

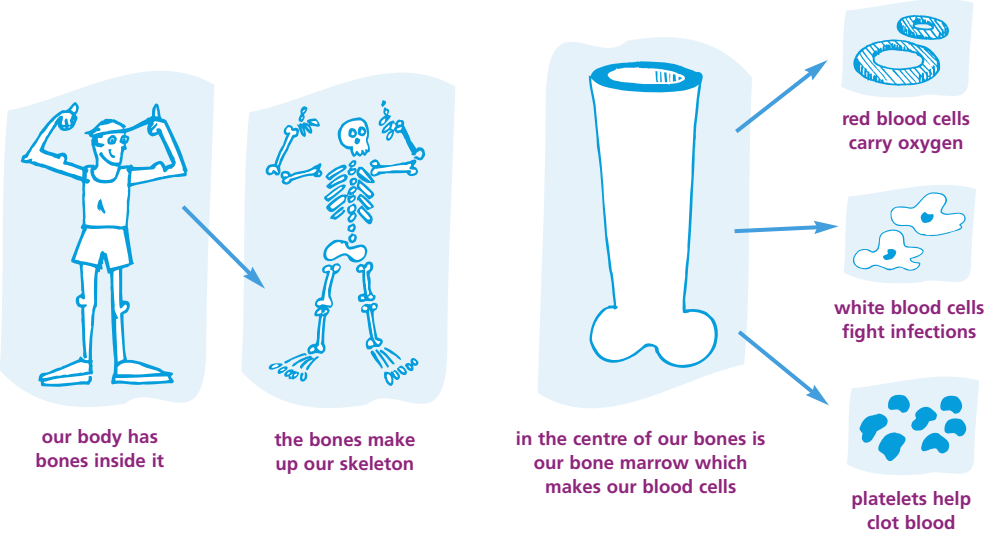
CHEMOTHERAPY affects the bone marrow of all the bones of the body and therefore the number of blood cells that are made.

If you receive **CHEMOTHERAPY** the number of blood cells produced will get less or drop. We say your '**blood count**' has dropped, which is usually at its lowest point 10 days after the start of your treatment.

EFFECT OF CHEMOTHERAPY ON YOUR 'BLOOD COUNT'



WHERE ARE THE BLOOD CELLS MADE?



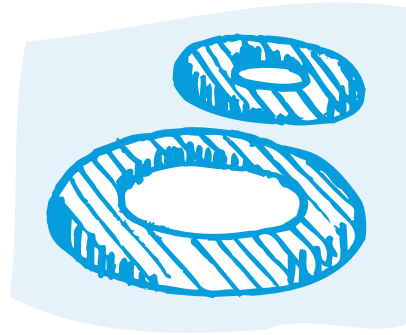
RED BLOOD CELLS

Red blood cells are responsible for carrying oxygen around the body. They contain an iron compound called haemoglobin (Hb) which helps to carry the oxygen.

A low number of red blood cells (a low Hb) is called '**ANAEMIA**'. Someone with this condition is described as being '**ANAEMIC**'. If you become **ANAEMIC** because of your treatment you may:

- Feel tired and lack energy.
- Look pale.
- Become breathless when doing only a little exercise.
- Feel the cold more than normal.
- Feel dizzy and have headaches.

Your normal **RED BLOOD CELL COUNT** or **Hb** is between **12** and **14**, (some hospitals measure this as **120** to **140**, both are correct, just different units used). Your body can usually manage to make enough red blood cells again but if your **Hb** falls to as low as **8 (or 80)** then you may be given a **blood transfusion**. This is a bag (or unit) of blood given through a drip into your veins. This will be given in hospital over several hours, about 3 to 4 hours per unit of blood.



RED BLOOD CELLS

WHITE BLOOD CELLS

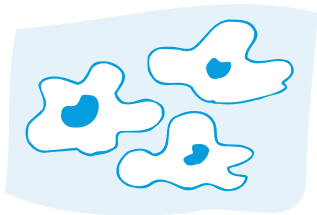
White blood cells are the main FIGHTING CELLS in our blood. They help fight off infections that come from bacteria, viruses or fungal agents.

When there is a low number of white blood cells in our blood we can develop **INFECTIONS** much more easily than normal.

There are three main types of white blood cells:

- Neutrophils, [also called granulocytes or polymorphs, (polys)].
- Lymphocytes.
- Monocytes.

Together they make up the total white blood count - normally 4 to 10. (Which is actually 4,000 to 10,000 white blood cells per cubic millimetre of blood!!!)



WHITE BLOOD CELLS

The cells we are particularly concerned with are the **NEUTROPHILS**. Neutrophils are important because they contribute to the body's natural defence or immune system. They do this by finding and killing bacteria and other infectious organisms. The normal **NEUTROPHIL** count is between **2** and **6**.

When a sample of your blood is taken and checked and the **neutrophil** count is **less than 1** we say you are **NEUTROPENIC**.

A low number of neutrophils is called **NEUTROPENIA**.

You will have to wait for the body to make its own white cells again in the bone marrow "factory" as we do not give white blood cells as a transfusion.

PLATELETS

Platelets are tiny cells which help to clot the blood to prevent bleeding and bruising.

A low number of platelets is called **'THROMBOCYTOPENIA'**.

If your platelets are low it is said you are **'THROMBOCYTOPENIC'**.

You may:

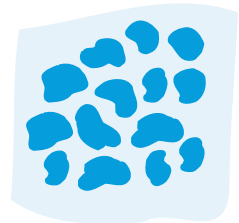
- Bruise more easily.
- Bleed for longer than normal if you cut yourself.
- Have nosebleeds.
- Have bleeding gums.
- Develop pin-prick bruises called 'petechiae'.
- Find that your urine or stools change colour, due to traces of blood.
- Have headaches.

Your normal **PLATELET COUNT** is between **150** and **400**

(Which is actually 150,000 to 400,000 per cubic millimetre of blood!!!)

If your **platelet** count falls to **about 20** you may require a platelet transfusion. This will be given in hospital and usually takes about half an hour depending on how many units of platelets need to be transfused.

NEVER TAKE ASPIRIN OR TABLETS CONTAINING ASPIRIN AS THEY AFFECT THE BLOOD CLOTTING - it thins the blood making the time for the blood to clot even longer and you will bruise more easily. **'BONJELA'** and **'TEEJEL'** used to relieve the discomfort of a sore mouth and/or ulcers also contain **'ASPIRIN'**, so please do not use these either. You may use **'CALGEL'**, this is a paracetamol/calpol based gel which can help relieve localised pain from mouth sores.



PLATELETS

SUMMARY OF BLOOD CELLS

	RED CELLS (Haemoglobin)	WHITE CELLS (Neutrophils)	PLATELETS
used to:	carry oxygen	fight infection	clot blood
low number:	anaemic	neutropenic	thrombocytopenic
normal count:	12 - 14 (120-140)	2 - 6	150 - 400
low count:	about 8 (about 80)	less than 1	less than 20
symptoms if low count:	tired lack energy pale breathless feel cold dizzy headaches	may develop infections	bruise easily bleed longer nosebleeds bleeding gums blood in urine and stools headaches
action taken:	red blood transfusion	prevent infections antibiotics	platelet transfusion

NEUTROPENIA AND INFECTION

Low number of white cells - neutrophils - to help fight infections.

Everyone has naturally occurring bacteria on their skin and in their bodies, for example in the ears, nose and gut (bowels). These bacteria are usually harmless and cause no problems.

If your body has a low number of fighting (white) cells you can develop infections from the normal bacteria of your body. Unfortunately, sometimes no matter how careful you are, some infections cannot be prevented when receiving treatment for cancer.

Infections usually come from within ourselves and not from contact with friends and visitors. It is advisable though not to have close contact with people who have coughs, colds, flu or sore

throats. It is also advisable to avoid crowded places when you are neutropenic, such as supermarkets, shops, cinemas, buses...

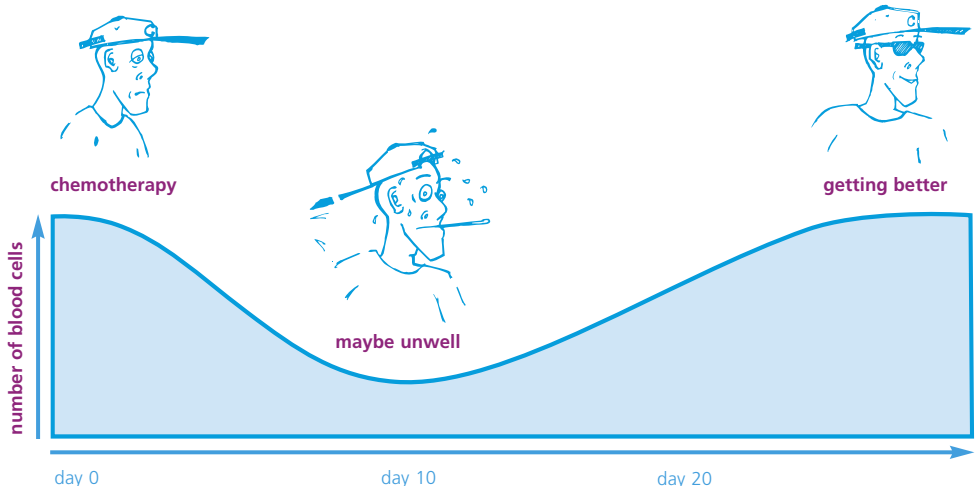
If you develop an infection it can be treated with **ANTIBIOTICS** and other drugs.

If you receive **CHEMOTHERAPY** it will affect the **BONE MARROW "factory"** which produces blood and your blood count will fall.

Your blood count will be at its lowest point about 10 days after the start of your treatment.

Your body will then start to make new blood cells but you may also require some red blood cell and platelet transfusions at this time.

You will pick up infections more easily than normal during this time when your blood count is low.



CHICKENPOX, SHINGLES OR MEASLES

If you discover you have been in contact with someone who has CHICKENPOX, SHINGLES or MEASLES then it is very important to let your hospital know as soon as possible.

A special viral blood test will be able to identify if your body has its own immunity or not to chickenpox and measles. If you have already had these infections or have had the measles vaccination when you were

younger then there is little risk of you catching them again.

VACCINATIONS

You should not receive any vaccinations whilst you are on treatment, as your body's immune system is lowered during this time. If your brothers/sisters need to receive their routine **polio** vaccination then please ask their doctor to give them the non-live (killed) version. This is **an injection not the oral drops.**

INFECTIONS – WHAT TO LOOK FOR

If you develop an infection your body temperature will go up. Normal body temperature is below 37° Celsius.

- If you feel hot and look flushed take your temperature.
- If it is 38°C and you feel well, take it again in half an hour's time.
- If it is still 38°C (or above) you will need to telephone the ward and come into hospital, **even if you feel well.**
- If it is **38.5°C** or above you should telephone the ward and you will be advised to come **straight to hospital**

where you will be given **ANTIBIOTICS** into a vein (intravenous/IV).

- If you do not have a temperature but 'feel unwell' you should also contact your doctor for their advice.

DO NOT TAKE PARACETAMOL (CALPOL) until you have been advised by the doctor.

- Your temperature will be taken every 4 hours in hospital.
- You do not have to do this at home; only take your temperature if you feel hot or unwell.

TAKING YOUR TEMPERATURE

Whilst you are in hospital the nursing staff will teach you how to take your temperature.

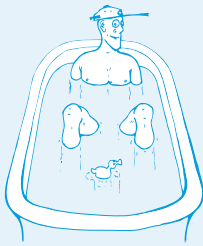
Digital thermometers are very accurate and quick to use. (Be sure you buy one that records in DEGREES CENTIGRADE (CELSIUS), not in degrees Fahrenheit, as these are the units used to measure temperatures in hospital).

BODY TEMPERATURE

normal:	37°C or below [in mouth]	36.5°C or below [under arm]
sign of infection:	38.5°C or above [in mouth]	38°C or above [under arm]

The above figures are to be used as a guide-line when taking your temperature, please check with your doctor for any additional advice.

WAYS TO HELP PREVENT INFECTIONS



Good body hygiene



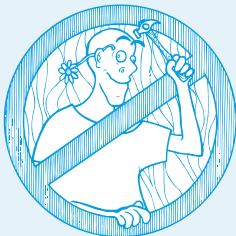
Good healthy diet



Good mouth care



Keeping a positive attitude and healthy mind



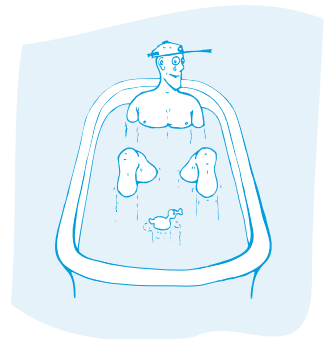
Preventing injury/accidents



**Keeping active/
moderate exercise**

GOOD BODY HYGIENE

- Always wash your hands thoroughly before eating any food and after going to the toilet.
- You should wipe from front to back after opening your bowels.
- If you are **neutropenic** it is advisable that:
GIRLS: you avoid using tampons.
BOYS: you avoid using a razor/shaver.
- If your bottom becomes sore it is very important that you let the nurses/doctors know, especially if you are neutropenic. If it is not treated quickly it could lead to a serious infection. If you have diarrhoea please take extra care to wash your bottom gently after going to the toilet. The doctors can give you a cream to prevent you getting sore... please let them know before it gets too sore.
- Have a bath/shower every day - be extra careful to wash and dry in areas that get hot and sweaty, eg. under your arms, between your legs.
- It is best not to use heavily scented soaps, talcs, perfumes etc.
- Use a moisturising lotion on dry skin - the doctor can prescribe some 'E 45' cream for you.
- Take extra care to look out for early signs of any minor sores or infections from cuts, grazes, spots, fingernail beds, etc. The area may appear red, sore and inflamed. If you are neutropenic (low number of white cells) you will not actually produce any white pus from a cut or sore as you would normally because pus is actually dead white cells!
- Take extra care when cutting your fingernails and toe-nails not to cut too short and damage your skin under the nail beds.
- You should not have your ears, or other body parts pierced, or new tattoos, whilst on treatment as they may be a source of infection. On any areas already pierced, keep the holes clean and tell your doctor if they become sore or inflamed.
- Avoid close contact with people who have coughs, colds or flu.
- Avoid cat (animal) litter trays.



GOOD MOUTH CARE

THIS IS VERY, VERY IMPORTANT!!!

The cells in your mouth are rapidly dividing cells - just like your blood cells and your hair cells. Therefore when you are given chemotherapy to kill off the 'bad' cells that are rapidly dividing, the cells in your mouth will also be affected.

About seven days after the start of your chemotherapy your mouth is at great risk of developing mouth ulcers and sores.

From day seven until your white blood cells (fighting cells) recover and you are no longer neutropenic, you must take **GREAT CARE** to look after your mouth.

A tiny sore in your mouth that you may normally think nothing of, can lead to a very serious infection when you are neutropenic.

So **please** look after your mouth and tell your doctor **as soon as possible** if you develop a sore mouth so it can be treated quickly before it gets too bad.

When you are in hospital the nurses or doctors should check in your mouth at least once a day to look for any signs of infection or ulcers and teach you how to inspect it yourself.



THIS IS WHAT YOU CAN DO TO HELP YOURSELF

- Have frequent **DENTAL CHECK-UPS**. Please tell your dentist about your diagnosis and the treatment you are now on. It is important they should know as they may wish to delay any planned dental treatment and offer advice about preventing tooth decay.
- **CLEAN** your teeth and mouth **GENTLY** after each meal and before you go to bed.
- Use a small, soft, nylon bristle toothbrush such as an 'Oral B' (B20 or B25 or "Sensodyne") **TOOTHBRUSH** and **FLUORIDE TOOTHPASTE**.
- Your toothbrush should be stored in a dry place and changed every three months. If your mouth is sore then you should still try to gently clean your teeth and mouth.
- If you are having **active orthodontic treatment**, you should discuss this with your consultant, it is probably advisable to discontinue this whilst having chemotherapy. It may be advised that fixed orthodontic appliances should be removed completely prior to commencement of chemotherapy, retainers can be worn as long as there is no trauma, but if any soreness or ulceration occurs these should also be discarded. If you are due to have fixed appliance orthodontic treatment then the orthodontist should be informed and treatment put on hold until after any active therapy.
- **CHECK YOUR MOUTH EVERY DAY** for sores or ulcers and cold sores. Let your doctor know as soon as you can if they do occur. You will be given some special mouthwashes and you may need some extra drugs to prevent or clear up any infection.
- If you have had radiotherapy to your head or neck your mouth may become dry and dental decay may occur more rapidly. Your doctor/dentist will be able to prescribe some **fluoride tablets or fluoride mouthwash** for you to have.
- If your mouth is **sore** ask the nurses if you can use a sponge mouth care stick to gently clean it and also to help apply your mouthwashes, gel or liquids.
- Stop your **LIPS** from cracking by using 'Vaseline' or a lip salve - there are lots of tasty flavours available from the chemist.



- If your mouth does become sore you can be given a spray or mouthwash to make it **NUMB** and take away the pain, as well as other **PAIN-KILLERS** if you need them.
- If your mouth is sore it is a good idea to **DRINK PLENTY** to keep your mouth moist. Avoid dry foods and add lots of sauces and gravy to your meals; this will make it easier to swallow.
- Strong flavoured or hot spicy **FOODS** and salt or vinegar may be irritating to your sensitive mouth; you may have to avoid these for a while.
- Chemotherapy can sometimes change the way things **TASTE** or **SMELL** so that your food and drink may taste slightly different (metallic or bitter tasting). It is usually worse towards the end of the day so make sure you try to eat a good healthy breakfast. This change is only temporary and will return to normal about 2 to 3 months after you have finished treatment. You may find that you only have a strange taste in your mouth when the drug is being given to you and then returns to normal straight away. If so, try sucking a sweet (preferably sugar-less) or using sugar-free dental gum to take away the taste when you are being given that particular drug.



**IT CANNOT BE STRESSED ENOUGH THAT:
GOOD MOUTH CARE CAN PREVENT SERIOUS INFECTIONS
PLEASE LOOK AFTER YOURSELF!!**

The nurses will explain exactly when, how often and how to carry out your mouthcare with the different types of medicines and mouthwashes.

If you are worried at all about the condition of your mouth or mouthcare please speak to one of the nursing or medical staff who will be able to examine, teach and advise you further. They will also advise you about how long to continue using your mouthcare solutions.

GOOD HEALTHY DIET

It is very important that you try and eat properly when you are on treatment so that you can make new, strong and healthy cells. Eating well will also help you cope with treatment.

The types of food you eat are important. It is not good just to have snacks like crisps, sweets and biscuits all the time. So try to have a well-balanced and varied diet.

This means eating:

Foods that contain **PROTEIN** which help our bodies to make new and healthy cells.

Foods that contain **CALORIES** which give us energy and help prevent weight loss.

Foods that contain **VITAMINS** and **MINERALS** (eg. fruit, fruit juices and vegetables).

Several high protein foods are also useful sources of calories eg. full fat dairy products.

We would therefore encourage you to have foods that are:

HIGH-PROTEIN and HIGH-CALORIE

This is a list to make you aware of some of the foods that will help you to build up your strength and make new cells, but there are lots of exciting ways to prepare and eat these foods or add them to your diet. Ask to see your dietician for more ideas.

HIGH-PROTEINS

milk/milkshakes
yoghurt/fromage frais
cheese/eggs
meat/poultry
fish
nuts
lentils/pulses
beans
quorn/tofu (vegetarian protein sources)

HIGH-CALORIES

butter/oil
potatoes/bread
rice/pasta
cakes/biscuits
crisps/peanuts
sugar/honey
cream
ice-cream and puddings
peanut butter/chocolate spread

If your appetite is poor and/or you have lost weight the doctor can prescribe high protein, high energy nutritional supplement drinks. These come in a wide range of flavours, including a neutral flavour, and should be taken daily in between your meals. Ask your dietitian how many drinks you need each day. Examples of these are:

MILKSHAKE TYPES: Ensure Plus Milkshake Style, Fortisip Bottle, Fresubin Energy Drink, Scandishake

FRUIT JUICE TYPES: Ensure Plus Juice, Fortijuice, Clinutren Fruit

YOGHURT TYPES: Ensure Plus Yoghurt Style, Fortisip Yoghurt Style

Energy supplements such as **POLYCAL** or **MAXIJUL** are also available as powders or liquids to add to your food or drinks.

Please ask the nursing staff for more information about them/ask to see the dietitian to discuss diet, eating properly and which supplements may be appropriate.

It may be advisable to take extra care when you are neutropenic with the food you eat and how your food is prepared to prevent gut infections from such things as 'listeria' or 'salmonella'.

For example:

- Wash (and peel if possible) your fruit and vegetables thoroughly.
- Avoid pre-washed and prepared salads, salads from salad bars and deli's.
- Avoid all unpasteurised soft cheeses, such as Brie and Camembert.
- Make sure your eggs are cooked until the yolk is solid.
- Avoid home made mayonnaise (as this contains uncooked eggs).
- Avoid pâté, prawns, shellfish and cold meat from delicatessens, make sure all meat is thoroughly cooked.
- Do not reheat savoury dishes and avoid products such as hot pies and take-away meals which may be kept 'warm' for long periods.
- Ready meals can be useful if you suddenly feel hungry and need to eat quickly.
- Good mouth care is important if eating frequent sugary snacks as they can lead to mouth problems.

Your dietitian will be able to give you more information.

RECOMMENDED LEAFLET

A booklet called '**DIET AND CANCER**' can be obtained from Cancerbackup (contact details at back of this booklet).



UPSETS TO YOUR DIGESTIVE SYSTEM (GUT)

NAUSEA AND VOMITING

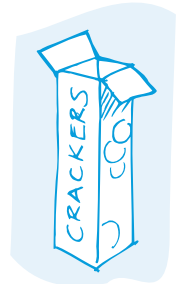
Nausea is a feeling of sickness and to vomit is to be sick.

Sometimes **CHEMOTHERAPY** and **RADIOTHERAPY** can make certain people feel sick, but this **does not happen to everyone**.

The doctors will always prescribe some anti-sickness drugs (or anti-emetics) to help prevent you feeling nauseous and being sick. These drugs can be given into your veins through a drip or as tablets or medicine.

WHAT YOU CAN DO?

- Even though you may feel sick (or nauseous) it is important to still try and **DRINK** during the day. In fact if you do not drink this can make you feel even more nauseous!!
- Fizzy drinks like soda water, sparkling mineral water or ginger ale (not sweet fizzy drinks) are usually the best to have, ie. **CARBONATED DRINKS**.
- Sucking **ice-cubes**, 'ice-pops', or frozen juice chips is often refreshing (but please be aware of the possible adverse effects of ice-pops etc. on teeth enamel).
- Try to eat **small, light meals regularly**, if you are able to, and eat slowly. If you are sick you may not feel like eating for several hours, but please remember to try and drink.
- Dry toast, crackers and plain biscuits are especially good if you feel nauseous.
- Cold foods with plain/mild flavours are usually the best.
- Avoid spicy foods and fatty fried foods, also foods that have strong flavours and smells, although some patients find that anything with ginger in it reduces nausea - such as ginger biscuits or ginger tea.
- Try to avoid things that may make you feel worse, such as the smell, sight or sound of foods or seeing other people eat.



- One of the best things to do is to **DISTRACT** yourself by keeping your mind busy with other things. How about chatting to your family and friends, watching television, listening to music, reading books or magazines, playing a game, writing a poem or a diary, or making a scrap book about your time in hospital
- Try to rest quietly after you have eaten.
- Try to **RELAX**. There are some special relaxation tapes that you can listen to; they help by teaching you different relaxation exercises. Please ask the nursing staff if you wish to listen to them.
- Some people have found using '**SEABANDS**' helpful in reducing nausea. These are wristbands that press on an acupuncture point on the wrist which are meant to reduce the feeling of sickness (although they may not take the nauseous feeling away completely). You should put them on your wrists just before your treatment begins and leave them on until you have finished your treatment in hospital. Please ask nursing staff for a pair of **SEABANDS** if you want to try wearing them (or they can be bought from the chemist, also known as travel sickness bands).
- **A SLOW BACK MASSAGE** from your parents, a friend or the nurses, can often be very helpful. This can help you to relax and slow down the muscles in your gut (bowels). If your platelet count is low however it should be done very gently to avoid bruising and trauma. Please ask the nursing staff who will teach you and your parents how to do this.

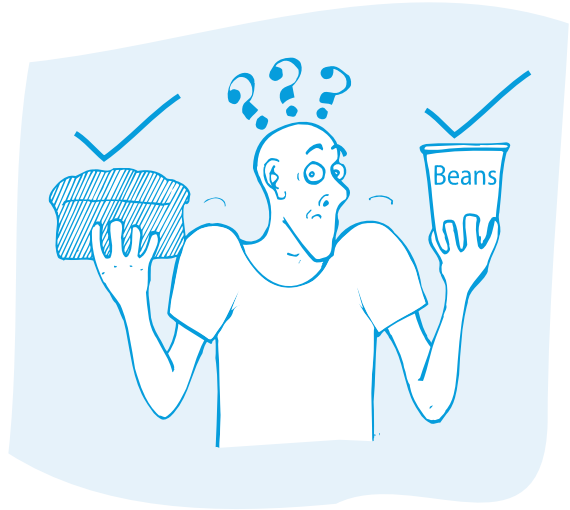


CONSTIPATION

At some time you may have difficulty in going to the toilet (that is opening your bowels).

This is called constipation. This may be due to a number of reasons, for example:

- Some of the **CHEMOTHERAPY** drugs, eg. Vincristine.
- Some pain-killers, eg. Codeine Phosphate, Morphine.
- You are not drinking enough.
- You are eating much less than normal.
- You are not as active as normal.



WHAT CAN YOU DO?

- Try to drink at least 2 litres a day (ie. 10 glasses of drink).

Try to eat more high-fibre foods, for example:

- Wholemeal bread.
- Brown rice.
- Wholemeal pasta.
- Potatoes with their skins on.
- Cereals (eg. 'Weetabix', 'Bran Flakes', 'Shredded Wheat').
- Washed fresh and tinned fruits (especially bananas, oranges).
- Dried fruits (eg. dates, apricots, prunes).
- Fresh, washed vegetables.
- Baked beans, peas, sweetcorn.

Please ask to see the dietitian or ask the nurses for more advice on what to eat.

When you are in bed or not able to move around very much, this will slow down the muscles in your gut and you may become constipated. To help prevent this, try to spend some time out of bed and move around as much as you are able to. The doctor can prescribe some medicines or tablets for you which will help you to open your bowels.

Pure fruit juices (if your mouth is not sore) and hot or warm drinks are very good for constipation.

DIARRHOEA

You may have diarrhoea (very loose stools) when you go to the toilet.

You should let the nurses know in case a sample has to be sent to the laboratory to be tested.

WHAT CAN YOU DO?

- Make sure that you have plenty to drink, at least 2 litres a day (ie. 10 glasses of drink), but avoid chilled drinks straight from the fridge.
- Sip your drinks slowly throughout the day and try not to drink only water.
- It is best to avoid fizzy drinks and natural fruit juices.
- Eat less fibre in your diet (eg. fruit and vegetables, wholemeal bread, high fibre cereals).
- Avoid any specific foods known to aggravate the diarrhoea.
- Try to eat foods that are high in protein and calories (eg. white bread, white rice, hard cheese, eggs, meat and fish).
- You may find it easier to eat small frequent meals, instead of three large meals a day.
- If your bottom becomes sore the nurses can give you a water-repellent cream which will help to relieve the soreness. A warm bath can often reduce discomfort as well.
- Make sure you wash your hands properly after going to the toilet.



LOSING YOUR HAIR

(HAIR LOSS = ALOPECIA)

Losing your hair may be one of the hardest side effects of your treatment for you to cope with.

WHY DOES IT FALL OUT?

Chemotherapy and radiotherapy are both used to destroy bad cancer cells. These cancer cells divide very quickly just like our hair cells. So when you receive chemotherapy and/or radiotherapy, it not only destroys the quickly dividing cancer cells but our hair cells as well.

With CHEMOTHERAPY

- Some people lose all their hair others go very thin on top.
- Others have patchy clumps.
- Any remaining hair may be thin and brittle.

BUT...

It does not all fall out at once. It will start to come out about 2 to 3 weeks after your first course of chemotherapy.

It will not hurt.

IT ALWAYS GROWS BACK

- Often thicker and better than before treatment started.
- Sometimes a different shade of colour and often wavy!!
- It grows at the same rate as before and usually 3 to 6 months after your treatment has stopped, you will have a full head of hair again.....**HOORAY!!!**

If your treatment means you have surgery or radiotherapy to your head, your hair will not grow along a scar line from an operation and can sometimes be a little thinner in places but this is not always the case.

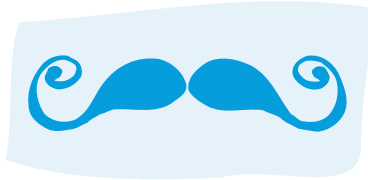


The rest of your body hair may not be affected such as:

EYEBROWS



EYELASHES



MOUSTACHES



BEARDS

It will all depend on the type of chemotherapy drugs you have and how much and how often you have them.

EVERYONE IS DIFFERENT!!!

If your treatment plan includes **RADIOTHERAPY**, the area of your body that receives the radiation will lose its hair. Sometimes the hair may grow back in patches and occasionally not at all in this area.

HANDY TIPS

HOW ABOUT...

A SHORT HAIRSTYLE before it starts to fall out - it's easier to look after and you will have got used to having less hair.

It may be possible to arrange for you to have your hair cut in hospital if you would like that.

Some people like to **CUT OFF** or **CUT SHORT** any remaining hair if it is thin and patchy - it is less of a nuisance and may actually look better. It is best not to shave your head as you may cut yourself and cause more harm than good, especially if your platelets and white cells are low.

Some people wear a **HAIRNET** when they go to sleep at night - to stop their hair going all over their pillows and sheets.

Use a **GENTLE SHAMPOO** and take care when washing and brushing your hair.

Use a **SOFT HAIR BRUSH**.

It is best not to use hairdryers, heated brushes etc. or strong chemicals such as highlights or perms.

It is best not to have a tight pony-tail or plait your hair as this puts extra stress on your hair roots.

WIGS

Some people choose to wear a **WIG**. CLIC Sargent's special hairdresser can come and visit you on the ward, preferably before your hair has started to come out and they can match your colour and style.

The wigs are:

- All washable.
- Easy to care for.
- Can be cut and trimmed to your exact style by your own hairdresser.

Wearing a wig will not interfere with your new hair growing.

GIRLS:

How about wearing some elegant and chunky jewellery, like large earrings that are brightly coloured or unusually shaped (but be careful to keep them clean!!)

How about wearing some **MAKE-UP**, paint your fingernails and wear lipstick if you are going out.

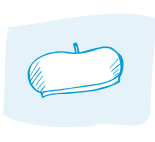
YOU MAY BE BALD BUT YOU CAN STILL BE BEAUTIFUL.

HEAD GEAR

What about some **HEAD GEAR!!!**



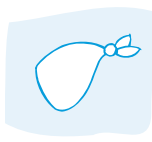
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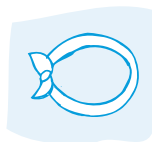
BERET



TOP-HAT!!!



SCARF



HEADBAND



HAT

WATCH OUT!!!

Wear a **HIGH FACTOR SUN SCREEN** in the sun and a **HAT**.

Did you know you lose one third of your body heat through the top of your head!!! So **wrap up** warm in the winter.

If your scalp is itchy or has flaking skin, rub a **MINERAL OIL** into it such as baby oil or lanolin cream.

When your hair **GROWS BACK** it is best not to use any strong chemicals or lotions on it, or have it permed for the first year until it is strong and healthy again.

Try to remember that if people stare at you because you are bald, be **BRAVE** and **BOLD! IT WILL GROW BACK.**

SIDE EFFECTS OF STEROIDS

Any SIDE EFFECTS you may have from taking STEROIDS will depend on the dose you take and how long you have them for.

Some common side effects include:

- **Increased appetite and weight gain** - feeling hungrier can make it difficult to keep your weight down your appetite will go back to normal when you stop steroids, but some people need to diet to lose the extra weight.
- **Swollen hands, feet or ankles from water retention** - if you have swollen ankles, avoid standing for long periods of time and put your feet up when you are sitting down.
- **Increased risk of infection** - you must tell your nurse or doctor straight away if you think you might have an infection, as you may need to take antibiotics.
- **Changes in blood sugar levels with high dose or long term treatment** - tell your doctor if you feel thirstier or if you are passing urine more often, as these can be symptoms of high blood sugar.
- **Changes in mood and behaviour** - you may feel more anxious and emotional than usual when you take steroids and can be a bit tired and low for a while after you stop taking them.
- **Difficulty sleeping** - taking your tablets first thing in the morning may help.
- **Difficulties with pregnancy** - steroids may be harmful to a baby that is developing in your womb. It is not advisable to become pregnant or father a child if you are on steroids. Talk about contraception with your doctor before having the treatment if you are concerned that you or your partner could become pregnant.

PREVENTING INJURY AND ACCIDENT

You must be a little more careful than usual when you are having treatment.

This is because:

- If your **WHITE CELLS** are low you will be at risk of developing infections more easily than normal.
- If your **PLATELETS** are low you will be at risk of bleeding and bruising more easily than normal.

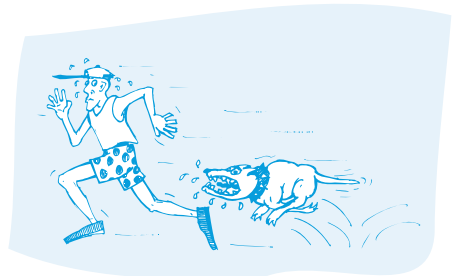
So be a little more careful when you are out and about, especially when your blood count is low. This does not mean you have to stop seeing your friends. Try to lead as normal a life as possible.



KEEPING ACTIVE/ MODERATE EXERCISE

There will be times when you feel very tired. Do not worry about this, it is quite normal. So have a rest or an extra sleep in the day and do not try to do too much at school or when you are out playing with your friends. This is not an excuse to spend all day in bed!!!

When you are well and not in hospital having treatment, it is good for you to keep active and on the move. Carry on with your sports and normal activities as much as possible as this will help to keep your muscles strong and healthy. Unfortunately though, contact sports are not advisable.



KEEPING A POSITIVE ATTITUDE AND A HEALTHY MIND

**There may be times when you feel down and low.
You may feel angry, confused, frightened and afraid.
You may feel alone or isolated.**

It is normal for you to have these feelings, and most people at some time through their treatment have times when they feel miserable.

Lots of questions may go through your mind. You may ask “why me”? Nobody knows why it is that some people get cancer and others do not. However one thing is certain, we are all here to help you through your treatment. There will be difficult and hard times but there are good times as well.

Many people find it a great help if they talk about their thoughts and feelings to a close friend, or possibly their brothers, sisters, parents, or the nurses and doctors. You may find it a great help talking to others who are also going through treatment for cancer or those who have finished treatment and have returned for follow-up appointments. As they are going through or have been through treatment, they will have a good idea of how you feel and what you are going through.

Talk to the nurses and doctors about your worries. They will be able to explain things more clearly and help you to understand things better and hopefully take away many of the fears you have.

Do not be afraid to ask. It does not matter how simple your questions may sound to you, we are all here to help you.

Even though you are having treatment it is important that you do not lose contact with your friends. Your friends may find it difficult to understand what you are going through, scared to ask questions about your illness and treatment, and do not know what to say to you.

Sometimes it will be up to you to speak to them first and let them realise that you are the same friend and have not changed. Talking to people nearly always helps. Ask them to carry on visiting, telephoning, texting, emailing and writing to you and you must do the same back to them. Although you may spend some time away from school/college/work try to keep up your friendships.



THINKING ABOUT YOUR FUTURE

Even when your treatment has finished it will still be important for you to take care to look after your health generally. A good well balanced healthy diet and exercise are recommended. It is strongly advised that you **NEVER SMOKE** as it is extremely bad for your health and can be a contributory factor in developing some types of cancers later on in life.

At some stage you may like to talk to your doctor about the possibility that some of the drugs or treatment you have had may affect your chances of having children in the future. This is certainly not the case for everyone and there are many people who have had treatment for cancers and have healthy children today. Please talk to your doctor about this if you have any worries at all.

Your care professional will also talk to you about attending the clinic after your treatment has finished. This is really important to check that you haven't got any side effects from the treatment. Also, although the chances of you getting cancer again are very, very small, it makes sense to have things checked. Follow-up clinic is also an opportunity for you to ask any questions you may have.



LOOKING AHEAD

MICHAEL was diagnosed as having a rhabdomyosarcoma (a muscle tumour) in his throat when he was 15 years old. He was having treatment for his cancer whilst he was taking his exams but still managed to get a place to go to university. After studying for three years Michael graduated from university with a degree in Aeronautical Engineering.

DONNA was diagnosed with leukaemia when she was a teenager. After having chemotherapy and radiotherapy treatment she was able to take up many sports again, including dinghy sailing, rock climbing and canoeing and has even sailed across the Atlantic to the Azores. Donna then went to university to study for a degree in Business Studies and Environmental Policy.

PEDRO was diagnosed as having cancer in Lisbon, Portugal. He was flown to Britain and treated here where he responded well. Two years later he became the champion butterfly swimmer of Portugal. Pedro went to university and studied Economics and several years later married.

CHRISTOPHER was diagnosed as having leukaemia when he was 7 years old. At school he became a very successful footballer and played in goal for many teams. After leaving school Christopher applied to join the army and was accepted into the 3rd Royal Tank Regiment.

DAWN was diagnosed with leukaemia at the age of 14. After her treatment had finished she left school and got a job working in a solicitor's office. When she was 21 Dawn got married and now has two beautiful daughters.

JOSH was diagnosed with Acute Lymphoblastic Leukaemia when he was 19. He responded well to chemotherapy and, still during treatment, Josh began studying a degree course in Philosophy at Glasgow University.

JAMES was treated for a rhabdomyosarcoma when he was 16 years old. After school he joined the Royal Air Force and later graduated as an officer. Five years later James married his long term fiancée Amanda.



WHAT'S AVAILABLE FOR YOU?

CLIC Sargent

CLIC Sargent runs a variety of youth programmes across the UK.

CLIC Sargent offers residential holidays for young people (15 - 24 years) affected by cancer. It offers programmes specifically designed to help you build your confidence and learn new skills.

For confidential information and support, please speak with your CLIC Sargent Social Worker or Youth Development Worker. A range of publications for young people can also be accessed via the CLIC Sargent website at www.clicsargent.org.uk.

Teenage Cancer Trust (TCT)

Teenage Cancer Trust (Tel: 020 7387 1000) is a charitable organisation which builds and equips specialist units for young people with cancer. For further information about the Trust and its work please write to: Teenage Cancer Trust, 38 Warren Street, London, W1T 6AE.

www.teenagecancertrust.org

Holidays

Camp Quality UK (Tel: 07983 563747), a registered charity, provides holidays for children and adolescents who have cancer. Each holiday is very different and may include activities such as sailing, rock climbing, abseiling, trips out and craft work..... Every holiday is funded by Camp Quality UK, and is provided free of charge. For further information about these holidays please call or email enquiries@campqualityuk.org.uk. Alternatively, write to: Camp Quality UK, PO Box 217, Sidcup, Kent, DA15 0BL

www.campqualityuk.org.uk

"Teenagers in Hospital" Booklet

Action for Sick Children (Tel: 0800 0744519) has published a booklet called "Teenagers in Hospital". It is to help young people, wherever they are being nursed, giving examples of questions they may wish to ask, helps them to think about consent to treatment and gives ideas on how to ask staff about things that might be worrying them. It is available from: Action for Sick Children, 36 Jacksons Edge Road, Disley, Stockport, SK12 2JL

www.actionforsickchildren.org

Youth Cancer Trust (YCT)

The Youth Cancer Trust (Tel: 01202 763591), a registered charity, provides holidays for young people (14 – 25 years), who have, or have had, cancer. Holidays can include horse riding, bowling, go-karting and just relaxing. You can take a brother, sister or friend. For further information please write to: 5 Studland Road, Alum Chine, Bournemouth, BH4 8HZ.

www.yct.org.uk

Teens Unite Fighting Cancer

Teens Unite Fighting Cancer (Tel: 01992 440091), a registered charity, is dedicated to improving the lives of young people aged between 13-24 with life limiting illnesses.

teensunitefightingcancer.org

USEFUL ORGANISATIONS

CLIC Sargent

The UK's leading children's cancer charity, supporting children and young people with cancer and their families.

Tel: 0300 330 0803

Email: info@clicsargent.org.uk

Web: www.clicsargent.org.uk



There is a useful booklet for parents published by the Children's Cancer Leukaemia Group and Macmillan Cancer Support:

'A PARENT'S GUIDE TO CHILDREN'S CANCERS'

This can be obtained through the Macmillan Cancer Support website at www.macmillan.org.uk. Copies should also be available in your treatment centre.

The booklet contains a list of other organisations that are available to anyone who has cancer or is involved in the care of a child with cancer: parents, families, friends and professionals. It has the addresses for further correspondence with specific organisations for you or your child such as:

LEUKAEMIA AND LYMPHOMA RESEARCH

LYMPHOMA ASSOCIATION

CHILDHOOD EYE CANCER TRUST

THE JIMMY TEENS WEBSITE:

WWW.JIMMYTEENS.TV

THE LEUKAEMIA CARE SOCIETY

NEUROBLASTOMA SOCIETY

TENOVUS CANCER INFORMATION CENTRE

There are many more organisations listed in the booklet which you might find helpful.

Please note that CLIC Sargent is unable to vouch for the standards set by other organisations, so it is vital that you make a judgement on whether or not you wish to access the service being offered.



RECOMMENDED READING LIST

Why, Charlie Brown, Why?	Charles M. Schulz
You and leukaemia. A day at a time	Lynn S. Baker
Am I still a sister	Alicia M. Sims
I'm Still Me (young people)	Macmillan Cancer Support
Young Adults with Blood Cancer – What do I need to know?	Leukaemia and Lymphoma Research
Young Person's Guide to Lymphoma	Lymphoma Association
End of Treatment: what happens next?	CCLG
Chemotherapy, cakes and cancer	A – Z guide to coping with treatment by Megan Blunt, age 14

Please ask the nursing staff, your social worker or your community nurse if you would like to know more about these books.



MEDICAL TERMS/DEFINITIONS

ALOPECIA: hair loss.

ANAEMIC: low number of red blood cells.

BENIGN: non-cancerous.

BIOPSY: a small sample of the body tissue is removed and examined under a microscope.

BONE MARROW: spongy material found in the centre of bones, produces blood cells.

CANCER: abnormal growth of cells.

CHEMOTHERAPY: the use of drugs to destroy cancer cells.

CYTOTOXIC DRUGS: anti-cancer drugs.

DIAGNOSIS: identify actual type of disease from symptoms, tests and investigations of patient.

HAEMOGLOBIN: (Hb) part of the red blood cell; contains iron and helps to carry oxygen around the body.

INTRAVENOUS: to give drugs or fluids directly into a vein.

LEUKAEMIA: a cancer of the blood cells.

LYMPHOMA: a cancer of the lymphatic system (which contains the lymph nodes/glands).

MALIGNANT: cancerous. The abnormal/cancer cells are able to spread to other parts of the body if not treated.

METASTASES: the spread of cancer cells from the original site (primary) to other parts of the body (secondaries).

NEUTROPHIL: a type of white blood cell.

NEUTROPENIC: a low number of neutrophils/white blood cells.

ONCOLOGY: the study of cancer.

PETECHIAE: small pin-prick bruises, from tiny blood vessels just beneath the skin.

PLATELETS: tiny cells which help to clot the blood to prevent bleeding and bruising.

PROGNOSIS: the prediction of the outcome of the disease.

PROTOCOL: plan of treatment.

RADIOTHERAPY: the use of radiation treatment or high energy rays which destroy the cancer cells, while doing as little harm as possible to normal cells.

RED BLOOD CELLS: they carry oxygen around the body and also contain iron.

RELAPSE: when the disease comes back after a period of time when symptoms had disappeared or decreased.

REMISSION: a healthy state when all the abnormal cancer cells can no longer be detected.

SURGERY: to have an operation.

TRANSFUSION: fluids or blood products given as an infusion into the vein using a drip.

THROMBOCYTOPENIC: a low number of platelets in the blood.

TUMOUR: a growth of abnormal tissue which grows at a faster rate than normal tissue and serves no function there.

WHITE BLOOD CELLS: main fighting cells of the blood which help to fight off infections.

QUESTIONS

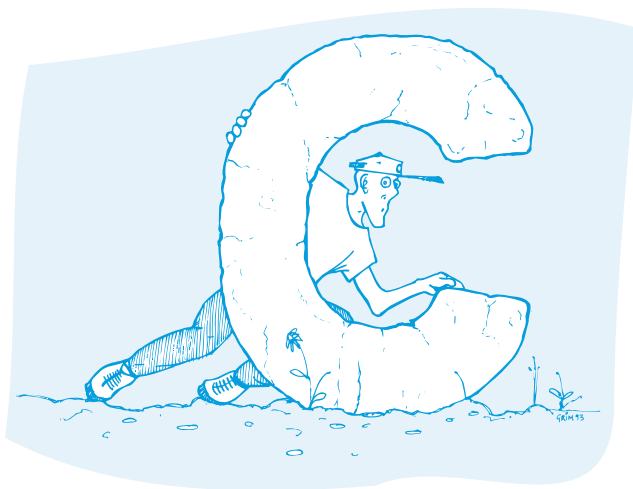
IF YOU HAVE ANY QUESTIONS TO ASK THE DOCTORS OR NURSES
PLEASE WRITE THEM DOWN HERE TO HELP YOU REMEMBER THEM,
OR IF YOU WOULD LIKE THINGS EXPLAINED AGAIN**PLEASE ASK.**
YOUR DOCTOR AND NURSES ARE ONLY TOO HAPPY TO HELP YOU.



QUESTIONS

NOTES

NOTES



Special thanks to Graeme Davis for the cartoon drawings of 'Mr C'.



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To obtain further copies of this booklet,
please visit the CLIC Sargent website:
www.clicsargent.org.uk

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