

Chemotherapy



What do I need to know?

At all times patients should rely on the advice of their specialist who is the only person with full information about their diagnosis and medical history.

For further advice please contact the patient information team on 020 7405 0101.

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Front cover: (right) Ex-England footballer Geoff Thomas had chronic myeloid leukaemia (CML) and underwent chemotherapy and then a bone marrow transplant. He went into remission in early 2005 and then took on the Tour de France in summer 2005 for Leukaemia & Lymphoma Research.

Geoff is now working in partnership with Leukaemia & Lymphoma Research.

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Introduction

You or someone you know is going to have treatment with chemotherapy. We hope this booklet helps to reassure you by explaining exactly what chemotherapy is, how it works and how you and those closest to you are likely to feel during treatment.

What is chemotherapy?

Chemotherapy is the use of drugs to treat cancer. Chemotherapy is very important in treating blood cancers because often the tumour cells are dispersed all over the body and cannot be removed by surgery or reduced by radiotherapy. Some lymphomas and plasmacytomas (plasma cell tumours) are exceptions to this rule and may be treated using surgery or radiotherapy, but chemotherapy is often needed as well.

It is important to note that there is a group of patients who have very early stage chronic lymphocytic leukaemia or indolent lymphoma who do not require (and may never require) chemotherapy. These patients are monitored very closely under a 'watch and wait' scheme. Studies have shown that even though the disease may progress, treatment at this stage does not affect outcome.

Although there are many different chemotherapy drugs, most work by interfering with the ability of cancer cells to divide and reproduce themselves. The affected cells then become damaged and die. Some newer agents being developed target cancer cells only, making chemotherapy more selective.

Chemotherapy can also affect normal healthy cells and tissues, causing side effects. The cells that are affected most by chemotherapy drugs are those that grow and divide rapidly such as blood-producing cells, the cells lining the mouth and intestinal tract, and those that make hair grow. Side effects tend not to be so much of a problem with low dose or targeted chemotherapy.

In most cases chemotherapy is given with the aim of achieving remission. A complete remission means that there is no sign of the blood cancer on any tests or scans. When a person has been in remission for five years they are generally considered cured; however it should be noted a blood cancer can relapse at any time.

What chemotherapy will I receive?

Chemotherapy is sometimes given as a single agent, but more often it is given in combination with other anti-cancer drugs that work together to kill the cancer cells. The type and number of drugs that you receive, and when you receive them, is called a chemotherapy regimen. Within a regimen the same pattern of chemotherapy is often repeated in 'cycles' as part of a 'course' of chemotherapy. There will usually be breaks between the courses to allow the body to recover.

For some conditions, chemotherapy is a single type of drug that is taken orally every day, sometimes for an undetermined length of time. A good example of this is Glivec™ (imatinib), which is used to treat chronic myeloid leukaemia.

The regimens used are very individual and many factors need to be taken into consideration before chemotherapy is started. Your treatment team (a group of doctors, nurses and other healthcare professionals who are responsible for your care) will discuss your treatment and recommend a course that they think is the most effective for your disease. Your treatment team should also be able to give you an indication of the length of time your treatment is planned to last. Sometimes it is difficult to be precise because the duration of treatment can depend on how the disease responds.

Sometimes chemotherapy is given in order to relieve symptoms without necessarily prolonging life when curing the cancer is not possible. In these circumstances a palliative care team may administer the chemotherapy if the drugs are not given intravenously. At other times chemotherapy is given to considerably prolong life without achieving a cure. This is often the case with slowly-progressing blood cancers. A person's treatment will involve many medications; not all of these will be chemotherapy. There could be drugs to control nausea or to protect the kidneys from the effects of the chemotherapy.

Informed consent

In order for you to agree to treatment it is essential that you are fully aware of all the potential side effects and complications that can occur following chemotherapy. Most chemotherapy units will have details about the specific side effects associated with each chemotherapy drug. It is important to remember that while a chemotherapy regimen can have a very long list of potential side effects, the majority of patients only experience a small number of them. Many side effects can be successfully prevented, or at least controlled.

It is often a good idea for you or members of your family to write down any questions you have prior to attending the hospital.

Before you start your chemotherapy

There may be a period of waiting between being told that you need chemotherapy and actually beginning your treatment. Although this can be frustrating, it is very important that your doctor has all the necessary information to make the best decision about your chemotherapy regimen.

There are often many tests and investigations that need to be carried out prior to starting your chemotherapy. Your disease will need to be assessed and all staging or prognostic factors will need to be identified.

These tests may include:

- Blood tests
- Bone marrow biopsies
- Lumbar puncture
- Scans
- Lymph node biopsy.

These tests are explained in more detail in Appendix 1.

How will my chemotherapy be given?

Chemotherapy can be given as an outpatient but those receiving more intensive regimens usually require an in-patient stay at hospital. Either way you will be cared for by a specialist medical and nursing team, all of whom will be able to answer any questions and help to lessen your fears and anxieties.

The ways that chemotherapy can be administered are:

Orally	As a tablet/capsule
Intramuscular injection	Into a large muscle – usually the buttock
Intravenous injection	Into a large vein in the arm or through a central line
Subcutaneous injection	Under the skin surface
Intrathecal injection	Into the fluid around the spinal cord

Central lines

If a lot of drugs are to be given intravenously you may have a central line put in. This will be discussed with you if necessary and it may be possible to see a line prior to having one inserted. A central line is a plastic tube that is inserted into a large vein, usually in the chest. The tip of the tube ends near the heart and the part where the drugs are injected can be placed in the neck, chest or arm. The line is inserted under general or local anaesthetic. If a local anaesthetic is used, sedation may be offered if you are nervous or worried about the procedure. You are likely to feel some pulling and pushing as the line is being inserted but this should be over quite quickly. There will be a nurse by your side throughout and you should tell them if you are in discomfort and require more local anaesthetic/sedation. Everybody is there to help you and they do not want you to feel anxious or uncomfortable so let them know how you are feeling.

Side effects of chemotherapy

Listed below are some of the more common side effects along with things that you, your family and your treatment team can do to help you cope with them. The exact side effects that you experience will depend on what kind of drugs you are receiving along with many other individual factors.

Extravasation

If you receive your chemotherapy intravenously you must let the nursing team know if you experience any pain, discomfort or notice any swelling whilst the drugs are being infused. It is possible that the chemotherapy may have leaked out from the cannula into the surrounding skin, this is called extravasation. This can occur if the cannula has moved out of the vein, so the drug is not flowing into the blood stream, but is collecting in the tissue around the cannula. The infusion should be stopped immediately as some chemotherapy drugs can cause serious damage to the skin, which if left untreated can result in scarring or the need for a skin graft. All centres that give chemotherapy will have guidelines for the treatment of extravasation. The nurses will be appropriately trained in how to deal with such an occurrence to prevent serious damage to the skin.

Problems associated with eating and appetite

Maintaining a healthy diet is a good way that patients and their families can do something positive. Even if you cannot eat you should try to maintain an adequate intake of fluids. This is important to keep organs, such as your kidneys, functioning as normal. Your treatment team will be able to advise you about diet and fluid intake. If any aspect of your diet, such as weight loss, particularly worries you, speaking to the hospital dietitian may be helpful.

There is publicity for certain diets claiming they can cure cancer. There is no evidence that this is true and it is far more sensible, and safer, to eat a well balanced diet. The hospital dietitian will be able to provide you with lots of information regarding diet and nutrition.

There may be some foods that you need to avoid due to interactions with chemotherapy drugs. Please ask your treatment team if there are any restrictions that you need to bear in mind.

➤ Nausea and vomiting

Feeling sick is probably the most common side effect experienced but there are many things that can be done to minimise this. There are very effective anti-sickness (anti-emetic) injections and tablets that can be given during your course of treatment. You may also be given some tablets to take at home.

It is important to tell your doctors/nurses if you start feeling sick or that the anti-sickness medication you are taking is not working or has stopped being effective. The earlier you let them know, the better; they can review your chemotherapy and possibly alter the timings of your anti-sickness medication.

How you can help:

- Take your anti-sickness medication as prescribed
- Ask someone else to prepare your meals for you if you are feeling sick
- Eat small amounts regularly; snacking can often prevent nausea developing
- Try dry food such as toast or crackers
- Eating ginger (i.e. ginger biscuits) sometimes helps to reduce nausea
- Avoid cooking smells whenever possible
- Avoid fatty/fried foods
- Acupressure bands may be helpful

- Try to maintain a positive approach. You could use distraction therapy; take a relative or friend to your chemotherapy appointments, listen to music or relaxation tapes/CDs
- If you are worried about your diet or weight ask to speak to the hospital dietitian for further advice.

➤ Anorexia – loss of appetite

This is the reduction of appetite for food and can happen for a number of reasons.

How you can help:

- Try to have your meals early in the day as they are usually easier to tolerate
- Have small frequent meals every two hours if possible
- Try to tempt your taste buds by making your food look as attractive as possible
- Keep a supply of foods to snack on when you are out and about such as crisps, nuts, fruit or chocolate
- Try using nutritional drinks, soups and yoghurts (yoghurt may not be suitable if you are neutropenic – please ask your treatment team) to supplement the occasional meal. You could make your own supplements such as fruit smoothies or milk shakes
- Take your time over your meals, keep relaxed and eat in a room without distractions. Take time to digest your food
- Your appetite will fluctuate from day to day, so on your good days make the most of them and remember that after your treatment has finished you will begin to have more and more good days and eventually your appetite should return
- Alcohol can often help stimulate the appetite before a meal. Your treatment team will advise you about drinking alcohol whilst receiving chemotherapy

- Chemotherapy can also affect your sense of taste. This will return to normal after treatment. Experiment and find foods that taste good to you now. Some dietitians recommend avoiding your favourite foods during treatment as the taste changes can put you off them permanently.

➤ Altered bowel habit

Chemotherapy can affect the bowels at various times during or after your treatment. You may find that you become constipated or experience diarrhoea. These side effects can be distressing but there are things you can do to help ease them. It is very important that you let your treatment team know if your bowel habits change.

Constipation is difficulty in emptying the bowels. Your team should be able to inform you if the chemotherapy you are receiving is known to cause constipation. You should always discuss symptoms with your doctor, who will advise you if a laxative is necessary.

How you can help:

- Drink plenty of fluids
- Ensure your diet is high in fibre. This can be found in some breakfast cereals, brown bread/rice, fresh fruit and vegetables
- Gentle exercise can often help if you feel able.

If you begin to experience diarrhoea (loose bowel motions) you must let your treatment team know because although diarrhoea is usually a side effect of the chemotherapy they need to rule out infection as the cause. Once this has been established they may be able to prescribe some medication to ease the frequency of the diarrhoea.

Drinking plenty of water is particularly important if you are having diarrhoea. If your diarrhoea is severe you may need to have some fluid replaced intravenously whilst you are attending the hospital. Your doctor may also recommend that you take a medicine to replace the electrolytes (salts) that you lose when you have diarrhoea.

How you can help:

- Avoid foods with lots of fibre, for example salad, bran, brown breads/rice and eating too many vegetables
- Contact the hospital for advice if the diarrhoea lasts more than two days.

➤ Mucositis

Some chemotherapy drugs can damage the cells that line the digestive tract all the way from the mouth to the anus. This leads to inflammation and soreness that can be very painful. This is called mucositis. When this occurs in the mouth it is called stomatitis.

How you can help:

- Drink lots of fluid. Try diluting fruit juices; however the more acidic ones (citrus fruits) may sting the mouth
- Use a very soft toothbrush, such as one designed for children. This will make cleaning your teeth much easier
- Ensure you use your mouthwashes as prescribed from the hospital and avoid alcohol-containing mouthwashes. You will probably be given antibacterial and antifungal mouthwashes. If your mouth is painful you may be prescribed one with a local anaesthetic in it; ask your specialist team for advice
- Avoid very hot drinks; often the cooler the drink the more soothing you will find it
- Avoid heavily spiced foods
- Alcohol and smoking will irritate your mouth so try to limit these activities wherever possible
- If your mouth has become very sore you may need to consider a soft diet such as ice cream, rice puddings, mashed potatoes etc
- If you wear dentures leave them out as much as possible (unless your team advises you otherwise) as this will prevent them chafing your gums.

Hair loss (alopecia)

Some chemotherapy drugs cause complete hair loss. Other drugs may only cause your hair to thin whilst some rarely or never cause hair loss. Your treatment team can advise you about the chance of your particular chemotherapy causing hair loss. This can be a distressing side effect for many patients, male and female alike, so it is important for everyone to find their own way to cope. Some people find it easier if they have their hair cut short prior to starting treatment so that it is not so much of a shock when it starts to fall out. You will not wake up one morning and find yourself completely bald, your hair will take time to come out and often thins first, or you may find that small clumps come away whilst washing or brushing your hair. Most hospitals can assist you in obtaining a wig if you need one.

Please remember hair almost always grows back once treatment has finished.

Infection

The chemotherapy you receive will affect healthy cells as well as cancer cells, including those involved in the production of normal white blood cells. Neutrophils are a type of white blood cell that helps to protect the body against bacterial and fungal infection. When you have a low neutrophil count (called neutropenia) your ability to fight infection is reduced. This can lead to a serious infection developing rapidly. If you develop symptoms whilst your blood counts are low during or after chemotherapy you must report this to the hospital immediately.

These symptoms may include:

- A temperature of 38°C or above
- Chills or sweating
- Cold or flu-like symptoms (runny nose, stuffy nose or watery eyes)
- Feeling generally unwell

- Rash
- Pain, redness or swelling around your central line site or other skin sores
- Diarrhoea or vomiting
- Burning sensation during urination
- Toothache, sores or ulcers in the mouth, a dry/cracked tongue
- Unusual vaginal discharge or itching
- Shortness of breath or rapid breathing
- Cough or sore throat.

Do not think that these symptoms will just pass – infection when your neutrophil count is very low can be life-threatening so you must seek advice.

If an infection does develop you may require treatment in hospital for several days; you will be closely monitored and given strong antibiotics to combat the infection.

How you can help to prevent an infection:

Hygiene

- Wash your hands often and with extra care before eating or preparing food and after using the toilet
- Clean your bottom gently but thoroughly after each bowel movement; women should always wipe from front to back
- Take a bath/shower every day. Dry your skin gently and carefully. Use a simple moisturiser or lotion to prevent dryness and cracking of the skin
- Attend to your mouth care as advised by the hospital. Use a soft toothbrush that will not hurt your gums. Do not allow anyone to share your toothbrush and replace it every two months
- Wash any cuts immediately with soap and water. Clean with antiseptic and cover with a dressing. Remove the dressing and look at the cut daily and contact your hospital if it appears to be getting worse

- Always wear shoes or slippers to prevent cuts and bruises to the feet
- Use paper tissues only once and place directly in a bin — do not leave them lying around. Handkerchiefs are not recommended
- Use an electric shaver, not a razor, to minimise damage to the skin and avoid shaving underarm and leg hair. This can damage the skin and cause in-growing hairs.

Diet

- Make sure that all foods are handled properly, washed and thoroughly cooked. Follow your hospital guidelines concerning any high-risk foods
- Drink plenty of fluids every day to prevent urinary tract infections.

Lifestyle

- Ask your treatment team if there are any sexual practices you should avoid while you have a low white cell count and always use a barrier method of contraception
- Do not have vaccinations without first consulting your doctor
- Seek advice about contact with children who have received live vaccinations such as the MMR vaccine
- Seek advice if you have been in contact with anyone who has chicken pox/shingles or measles or have been in contact with someone else who has been exposed.

Household tasks

- Arrange for someone else to groom your pets, empty cat litter trays and clean pet cages. If this is not possible always wear protective gloves to perform these tasks and ensure you wash your hands when finished
- Do not change a baby's nappy; if absolutely necessary wear protective gloves and wash your hands well afterwards
- Always contact the hospital if you are at all concerned, don't be afraid

that you are bothering them unnecessarily — it is better to be safe and the sooner treatment is started for an infection the better the outcome.

Other cytopenias

Chemotherapy can also cause a reduction in the number of red blood cells and/or platelets. A deficiency in red cells causes anaemia which can have symptoms of breathlessness, fatigue and chest pains. You may receive blood transfusions to alleviate anaemia. A lack of platelets (thrombocytopenia) causes bruising and bleeding to occur more easily. Platelets can also be given by transfusion although usually only in the case of an emergency or if the platelet count is very low. This is because platelets do not last very long once they have been transfused and your body can mount an immune response against them more easily than transfused red cells.

Women who have not been through the menopause may be prescribed a drug called norethisterone, to stop periods, whilst platelets (a type of blood cell that is important in the clotting process that controls bleeding) are low and bleeding is less controlled.

Fatigue

Fatigue is one of the most commonly reported symptoms of cancer and its treatment. There are many possible causes of fatigue. Don't be afraid to discuss it with your treatment team in case there is something which can be easily corrected.

The definition of chronic fatigue is mental and/or physical tiredness that cannot be relieved by rest. A feeling of exhaustion can be overwhelming and it is understandable to try and deal with this by resting and sleeping. There are ways in which you can help yourself. It is important to balance sleep and rest with short periods of activity. Studies have shown that being inactive can lead to a 'vicious circle' of feeling even more fatigued; while maintaining some activity can lead to a 'virtuous circle' of feeling less fatigued and so being able to do more.

Sexuality and fertility

Fertility

Fertility may not be something you have thought much about but it is really important that you discuss this subject with your partner/family prior to starting any chemotherapy if it is relevant to do so.

Some chemotherapy agents do not have any effect on fertility. However, other chemotherapy regimens can damage your reproductive tissues which can be temporary or permanent. High dose intensive chemotherapy regimens tend to have the most damaging effect on fertility.

Men should always be given the option to store sperm. It is only in extreme cases where this would not be offered – such as where delaying treatment would be life threatening or if the white cell count is too high. There are strict regulations surrounding the storage of sperm and each hospital will have their own guidelines so it is important to ask your team to go through these with you.

This could be your only chance to have your sperm stored so think about it very carefully and try to put any embarrassment, fears or anxieties to the back of your mind whilst you come to a decision.

For women it is much more difficult to preserve fertility. To obtain and store an egg takes weeks and includes procedures such as hormone injections and visits to a fertility clinic. Embryo storage is only possible for women who have a partner and involves the same procedures as egg collection. For many women these procedures are not possible because delaying the treatment could prove life threatening. Ovarian reimplantation (removing tissue from the ovaries before treatment starts and reimplanting it after the patient is cured) is a very experimental technique that is thought to restore fertility after cancer treatment. It is also time-consuming and there may be a risk of reintroducing

One of the ways to help yourself is to pace your activity. This is a method to help you regulate daily activities and can be used for anything you do during the day. This will help by providing structure to what you do and you can gradually increase your activity in a controlled way.

Key points of pacing your activity:

- Take regular breaks
- Avoid pushing yourself too far by doing those extra five minutes
- Increase activity in a controlled way – set realistic goals
- You are an individual, so find your own level, and build on that
- Remember everyone has setbacks, sometimes these are caused by setting a target too high and expecting too much of yourself.

If you find it difficult to relax try asking at the hospital for some relaxation techniques such as breathing exercises and maintain a base level of activity. Try keeping a record of all your achievements so you can see that you are moving forward.

cancer cells into the body. You should discuss your concerns with your team and they may be able to offer you counselling to help you through this difficult time.

Your fertility can be assessed once you have finished your treatment in order to advise you about the likelihood of being able to have children. None of these tests are 100% accurate so if you are not trying to conceive a child it is still important to use contraception.

Early menopause

For some women treatment for their cancer can cause the onset of early menopause. Inform your healthcare team if you begin to develop the symptoms of menopause such as your periods becoming infrequent, hot flushes, night sweats, irritability, depression, vaginal dryness or breast tenderness. They will be able to advise you of the best treatment available or refer you on to a specialist in the treatment of the menopause.

Pregnancy

Men must ensure they use a barrier method of contraception (a condom) whilst they are receiving chemotherapy as the effects of chemotherapy on sperm are not fully understood.

If you are a woman receiving chemotherapy it is not advisable to become pregnant. Ensure you take every precaution possible to prevent a pregnancy. Once in remission it is wise to talk to your doctor about planning to have a child.

People who have had chemotherapy and radiotherapy often worry about the impact of their treatment on the health of their future children. You can be reassured that studies of children born to parents who received cancer treatment show no excess of abnormalities or of childhood cancer.

Sex

Whilst sex might not be the first thing on your mind during treatment it is important to give you some general advice on sexual activity during chemotherapy.

During your treatment (and for a week after completion) chemotherapy drugs can be present in all bodily fluids such as saliva, urine, semen and vaginal secretions. Because of this it is important to use a barrier method of contraception (a condom) for the duration of your treatment and for the week following.

It is usually recommended that certain sexual practices are avoided when your blood counts are low. It is likely that each hospital will have its own guidelines so please check with your healthcare team.

If impotence has become a problem talk to your doctor. It could just be due to the treatment you are receiving or there may be a psychological problem that needs addressing. Your team are there to help you and the only way to solve the problem is to talk about it.

If vaginal dryness has become a problem try using a lubricating jelly available either on prescription or via your local chemist. This should not be a long-term problem and should resolve without treatment, but if your symptoms persist or if you are worried, inform your doctor.

There are a number of reasons why your desire for sexual activity could be diminished. For example, you may have become anaemic (low red cell count) which could cause you to feel tired and interfere with your ability to feel aroused.

Relationships and feelings

You may find that the treatment you have received has altered your self-image. This may be due to weight gain/loss, having a central line inserted or other scarring or hair loss. Most people find their self-confidence returns with time but, if you are concerned, talk to one of your healthcare professionals. You may just be tired and find that sex is the last thing on your mind. Rest assured that with time this will resolve. Try to keep positive; all relationships have their high and low periods of sexual activity.

Although you may not feel like having sex during your treatment, it is important that you and your partner talk about how you are feeling and find alternative ways of showing your feelings for each other.

Every family deals with a cancer diagnosis in a different way but many people find that being honest with their friends and family really helps. You will find that everybody has your welfare at the top of their list even though they might find it difficult to know when to visit or what to talk about. People often have a preconception about what cancer or treatment will do to you or they may fear the unknown. Explaining your disease and what side effects you might experience can help to break this tension. If you don't feel comfortable with this you should ask someone close to you to let people know how you are coping with treatment.

Regardless of how you and your family are feeling, your healthcare team is always there to listen and may be able to refer you to a counsellor if you want someone impartial to talk to.

Joining a support group can be a good way of meeting other people in similar situations who understand what you are going through. Your hospital may have a support group attached or they may have details of national organisations.

Getting back to 'normal'

Each patient and situation is unique, but everyone will have regular check-ups during and after chemotherapy to monitor the disease or check for long-term side effects of treatment.

For some diseases chemotherapy may only last a few weeks or months but for others it may become part of your daily routine. For example, people taking Glivec™ (imatinib) will need to take their drugs everyday, probably indefinitely.

Although chemotherapy can cause a disruption to your life it is important to remember that there are still many activities and experiences that you can enjoy.

Appendix 1: Investigations you may need throughout treatment

Blood tests

➤ Full blood count

This is a blood test that measures the numbers of each type of cell in the blood. There are three types of blood cell. Red cells carry oxygen from the lungs to the rest of the body. There are several different categories of white cell that are involved in fighting infection. Platelets are part of the clotting process needed to prevent and control bleeding. You will probably have this test quite often and you should be aware of your blood counts as they can affect your every day life.

➤ Liver function tests

This is a blood test to check that your liver is functioning normally. This is very important for people who are receiving medication as many drugs are broken down in the liver.

➤ Urea and electrolytes

This is a blood test to assess how your kidneys are functioning. This will help the doctors to calculate the doses of drugs you need and it will also show any damage that may have been caused either by the cancer or its treatment. It can also show if you have become dehydrated. You will usually have your kidney function checked every time you attend the hospital.

24-hour urine collection

This test also checks kidney function. It involves collecting your urine for 24 hours in a bottle containing a preservative that will be provided for you. Your treatment team will tell you exactly how to perform the collection.

Scans

➤ CT or CAT scan

This is a form of X-ray that produces a detailed picture of internal organs throughout the body to assess staging of disease. This is a painless procedure where you will be required to lie on a couch that moves into a cylindrical tunnel while the pictures are taken. The results can take quite some time to reach your team so do not worry if you don't get them back straight away.

➤ Magnetic Resonance Imaging

This scan uses radio waves rather than X-rays and produces images that can be analysed on a computer. You will be asked to lie on a table and the table will move you through the scanner. It is a painless procedure which can take up to an hour to perform. You may need to have some fluid injected into a vein to help the computer form a better image.

➤ PET scan

This is similar to an MRI, but with this scan you are injected with a radioactive tracer. This scan can detect the difference between active disease and old scarring from inactive disease. The radioactive tracer is taken up much more quickly by active disease and shows up as 'hot spots' of tumour growth. For some diseases it can give a much clearer picture of your response to treatment and will let the doctors know of any areas still to be targeted.

➤ X-ray

This technique allows an image of the denser tissues in the body to be taken. X-rays can be used at diagnosis to aid staging, during treatment to monitor response and as a tool to check for chest infections when your white cell count is low.

Bone marrow and cerebro-spinal fluid tests

➤ Bone marrow aspirate

This is a procedure to assess any abnormalities within the bone marrow. A small amount of bone marrow is taken using a needle either from the hip bone or sternum (breastbone). This can be done as an outpatient with the use of local anaesthetic alone or with some mild sedation. The procedure is usually quite quick but is likely to be uncomfortable for the short time the needle is in place. Once the sample has been obtained the doctors will look at the bone marrow under the microscope and assess the bone marrow and any disease that may be present.

➤ Bone marrow trephine

This is the removal of a 'core' of bone marrow from the hip bone under local anaesthetic. This sample provides information about the structure of the bone marrow and the number and distribution of the different blood cell types and cancer cells if present.

➤ Lumbar puncture

This is to assess if there is any disease present in your cerebro-spinal fluid (the fluid that surrounds the brain and spinal cord). Some leukaemias can spread from the blood to the brain. It is essential to establish if this is the case prior to starting chemotherapy as the regimen you have may need to be modified. A needle is inserted in to the spinal column in the lower part of your back and a small amount of fluid is removed and then analysed. Sometimes it is necessary to administer chemotherapy this way; this is called an intrathecal injection. You may be required to undertake several lumbar punctures throughout your chemotherapy regimen.

➤ Lymph node biopsy

This is a minor surgical procedure to investigate an abnormal lymph node. If the node is easily accessible the biopsy may be performed under local anaesthetic. Sometimes the whole lymph node is removed; this is called an excision biopsy.

Glossary

➤ Alopecia

The loss of hair.

➤ Anaemia

A deficiency in the oxygen-carrying pigment haemoglobin in red blood cells. Causes pallor, tiredness and breathlessness. Red cell transfusions can be given to alleviate this problem.

➤ Anorexia

The loss of appetite.

➤ Blood cancer

Cancers of the blood cells or blood-producing cells in the bone marrow. Includes leukaemia, lymphoma and myeloma.

➤ Bone marrow

The tissue which produces the blood cells. It is found in the hollow cavities of some of the bones in the body.

➤ Cells

The individual units from which the tissues of the body are formed.

➤ Cerebrospinal fluid

The fluid which surrounds and protects the brain and spinal cord. Samples can be taken by lumbar puncture.

➤ Cytopenia

A reduction in the number of circulating blood cells. This can happen as a result of chemotherapy.

➤ Electrolytes

Salts found in the body fluids, tissues and blood. The body needs to maintain the correct balance of electrolytes to function properly.

➤ Glivec™ (imatinib)

A chemotherapy drug for chronic myeloid leukaemia. It is targeted towards a specific molecule within the cancer cells.

➤ Infusion

The continuous delivery of substances, including drugs, into the body over a period of time. Infusions are usually given through a central line.

➤ Intrathecal injection

An injection of chemotherapy drugs into the spinal fluid to kill any cancer cells 'hiding' there.

➤ Laxative

A substance used to help you empty the bowels.

➤ Menopause

When a woman ceases to have her menstrual periods.

➤ Neutropenia

A deficiency of a type of white blood cell called neutrophils that fight bacterial and fungal infections.

➤ Palliative care/treatment

Treatment aimed at alleviating symptoms and pain without aiming to cure a disease.

➤ Platelets

A type of blood cell that forms part of the clotting process needed to prevent and control bleeding.

➤ **Prognosis**

A prediction of the outcome of a disease based on factors that are individual to the patient.

➤ **Progression of disease**

When a disease becomes more advanced.

➤ **Red blood cells**

Cells which carry oxygen from the lungs to the rest of the body.

➤ **Regimen**

The number and type of chemotherapy drugs and how and when they are given.

➤ **Relapse**

When cancer comes back after a period in remission.

➤ **Remission**

When cancer can no longer be detected.

➤ **Thrombocytopenia**

A deficiency of platelets. Sometimes platelet transfusions can be given to alleviate this problem.

➤ **White blood cells**

There are several different types of white blood cell. They help to fight infection.

Questions for your healthcare team

There are some questions you may like to ask:

What are the objectives of the treatment?

What is involved with the treatment?

What other medication/examinations will I need?

How long will I have treatment?

Are there any alternatives to the treatment?

How am I going to feel?

What are the specific side effects?

When can I go back to work?

You can use the space below to write down your own questions:

Personal information

Name: _____

Address: _____

DOB: _____

Hospital telephone no: _____

You can use the space below to record your blood counts:

Date: _____

Results: _____

Typical normal values for blood test results

	WBC x 10 ⁹ /l	RBC x 10 ¹² /l	Hb g/dl	ANC x 10 ⁹ /l	Platelets x 10 ⁹ /l
Adult male	3.7 to 9.5	4.3 to 5.7	13.3 to 16.7	1.7 to 6.1	143 to 332
Adult female	3.9 to 11.1	3.9 to 5.0	11.8 to 14.8	1.7 to 6.1	143 to 332
West Indian	2.8 to 9.8			1.0 to 6.5	122 to 374
African	2.8 to 7.8			0.9 to 4.2	115 to 342
Child 2-5 yrs	5 to 13	4.2 to 5.0	11 to 14	1.5 to 8.5	143 to 332
Child 6-9 yrs	4 to 10	4.3 to 5.1	11 to 14	1.5 to 6.0	143 to 332
Child 9-12 yrs	4 to 10	4.3 to 5.1	11.5 to 15.5	1.5 to 6.0	143 to 332

Normal ranges vary slightly between laboratories so you may wish to ask your doctor to enter your normal values below:

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WBC White blood cell count

RBC Red blood cell count

Hb Haemoglobin concentration

ANC Absolute neutrophil count

Separate ranges are quoted for West Indian and African populations as these groups have different normal ranges for white cell counts, absolute neutrophil counts and platelet counts.

This information is adapted, with permission, from *A Beginner's Guide to Blood Cells* Dr Barbara Bain. Pub. Blackwell, Oxford, 1996.

The following patient information booklets are available free of charge from Leukaemia & Lymphoma Research. You can download them from our website or request copies by phone.

Leukaemia and Related Diseases

Acute Promyelocytic
Leukaemia (APL)

Adult Acute
Lymphoblastic Leukaemia (ALL)

Adult Acute
Myeloid Leukaemia (AML)

Childhood Acute
Lymphoblastic Leukaemia (ALL)

Childhood Acute
Myeloid Leukaemia (AML)

Chronic Lymphocytic
Leukaemia (CLL)

Chronic Myeloid Leukaemia (CML)

Aplastic Anaemia (AA)

The Myelodysplastic
Syndromes (MDS)

The Myeloproliferative
Neoplasms (MPN)

Multiple Myeloma (MM)

Hodgkin's Lymphoma (HL)

Non-Hodgkin's Lymphoma (NHL)

**Leaflets on a range of
associated blood disorders are
also available from Leukaemia &
Lymphoma Research**

Bone Marrow and Stem Cell
Transplantation (BMT)

– for children and adults

Donating stem cells
– what's involved?

Donor Lymphocyte Infusion (DLI) –
what's involved?

The Seven Steps – Blood & bone
marrow transplantation

Undergoing high dose therapy and
autologous stem cell transplant

Chemotherapy
– what do I need to know?

Clinical Trials

Complementary and
Alternative Medicine (CAM)

Dietary advice for patients
with neutropenia

Supportive care

Treatment decisions

Watch and wait

Young adults with a blood cancer –
what do I need to know?

Jack's Diary: an illustrated children's
book to help young patients
understand and deal with blood
cancers, treatment and life changes

Wiggly's World: a colourful A-Z
illustrated booklet, designed to take
the anxiety out of treatment for
children and their parents

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