PATIENT INFORMATION

NEWLY DIAGNOSED WITH A BLOOD CANCER
If you, or someone close to you, has been diagnosed with a blood cancer or related condition, we understand that this can be a time of great uncertainty and confusion.

Having access to reliable and clear information at this time is an important step towards understanding your condition and we hope that this booklet will answer many of the questions you may have.

This booklet is one in a series of booklets Leukaemia & Lymphoma Research produce, which are written in line with national guidelines where possible.

Our booklets provide general information about the topics they describe. In many cases the treatment of individual patients will differ from that described in the booklets. Patients should always rely on the advice of their specialist who is the only person with full information about their diagnosis and medical history.

For further information, please ring 020 7504 2200 and ask to speak to the Patient Information team.

You can find more information about the topics covered in this booklet on the Leukaemia & Lymphoma Research website: beatingbloodcancers.org.uk/newlydiagnosedlinks

The information contained in this booklet is correct at the time of going to press (October 2012).
INTRODUCTION

We hope that you find this booklet helpful. It is one in a series that we have written for people affected by a blood cancer, or related condition. The full range of our booklets is listed on the back cover.

Hearing that you or someone close to you has just been diagnosed with a blood cancer or related condition can be a great shock and very distressing. You may feel overwhelmed and confused and there may be many questions that you want to ask: Why me? What types of treatment are there? What is right for me? What are the side effects? What will I be able to do? What does the future hold? How and where can I get the help I may need? Where can I go for more information? In our booklets we try to provide you with some of the answers and also let you know about other organisations you may like to contact.

Around 30,000 people of all ages are diagnosed in the UK with a blood cancer every year. Leukaemia & Lymphoma Research was founded in 1960 and we are the only UK charity dedicated to improving the lives of all blood cancer patients. Our life-saving research is focused on finding causes, improving diagnosis and treatments for blood cancers including leukaemia, lymphoma and myeloma. Through our Trials Acceleration Programme (TAP) we also run groundbreaking clinical trials so that patients can have access to new treatments more quickly.

Please do get in touch if you would like more information about Leukaemia & Lymphoma Research or if you would like to speak to someone in our Patient Information team.

We welcome all feedback on our information booklets as we want to ensure that they are as helpful as possible. Please complete our survey online at beatingbloodcancers.org.uk/bookletsurvey.

CONTENTS

| My details     | 3 |
| Introduction   | 4 |
| Blood cancers and related conditions | 6 |
| Coping with your illness | 7 |
| Normal blood cells | 14 |
| The immune system | 17 |
| Signs and symptoms | 19 |
| Tests and scans | 21 |
| Treatment | 26 |
| Help and support | 39 |
| Questions you may like to ask | 45 |
| Feedback form | 49 |
BLOOD CANCERS AND RELATED CONDITIONS

All the cells in the body are produced from rare cells called stem cells. Different stem cells produce different types of cell. Blood cancers all arise from the stem cells which are responsible for producing blood cells.

About one person in 25 will be diagnosed with a blood cancer at some time in their life. Blood cancers include:

- leukaemia
- lymphoma
- myeloma
- myelodysplastic syndromes
- myeloproliferative neoplasms.

Leukaemia & Lymphoma Research produces booklets on all these conditions. You can find a full list of these on the back cover of this booklet, along with details of how to order them.

These conditions can all be treated, but some patients may not need treatment immediately after diagnosis. Some forms of blood cancer can be cured with standard treatments. Others do not yet have a cure but may respond well to treatment. Even if there is currently no cure for your condition, you may still have a normal lifespan depending on how old you are when you are diagnosed and how well your condition responds to treatment.

Because blood cancers, and related conditions, are so variable, you should always rely on information from your specialist healthcare team.

COPING WITH YOUR ILLNESS

Being told that you have cancer can be very upsetting and may bring with it many different emotions. There are some important things to think about, and we hope that this section of the booklet will help you to cope and to understand the information you are being given.

Being clear about your diagnosis

It is important that you are clear about your diagnosis. It is usually a good idea to ask your consultant to write it down so that you can refer to it at any time or show it to the people you may contact for help and information, so that there is no confusion. Knowing your diagnosis may help others to offer you the best possible support.

Your healthcare team

Your hospital should give you contact names and details for your consultant, clinical nurse specialist and other members of your healthcare team. This is particularly important if you are not staying in hospital, as you may want to ask questions at any time, so it may be useful to have these details.

Any patient with a diagnosis of a form of cancer is usually given a key worker, normally a clinical nurse specialist. That person will act as your point of contact with the rest of the healthcare team.

Most patients with a blood cancer or related disease are treated by a haematologist, who is a doctor who specialises in treating patients with blood diseases. Occasionally, especially if you have lymphoma, you might be treated by an oncologist, who is a specialist in the treatment of cancer. In either case, you can expect that your consultant at the hospital will be an expert in treating your specific disease.

It is usual, when you are diagnosed with a serious illness, for your condition to be discussed at a multidisciplinary team (MDT) meeting. An MDT brings together doctors, nurses, pharmacists, physiotherapists, dietitians and any other specialist staff who will
be directly involved in your care. MDTs meet regularly and review all patients being cared for by that team. The meeting is usually led by a senior consultant and it will allow the team looking after you to be aware of any development in your condition and how you can be treated in the best way.

Later you may want to ask your consultant or key worker if it is possible for you to talk with someone who has had the same diagnosis and treatment. If you choose to do this, it is important to remember that each patient is different and you may have a very different experience to the patient you are speaking with. An example is side effects from treatment. Some patients have very unpleasant side effects from a drug which another patient can tolerate very easily.

It is important to tell other healthcare professionals you may see (for example, your dentist or optician) about your diagnosis and any medication you are taking.

Finding out about your condition

People feel differently about how much information they want and when they want it. You may not want a lot of information at the beginning; you may want it bit by bit or you may want to have as much information as possible. It is important to let your consultant and clinical nurse specialist know how much information you want. You can always ask for more information at any time. Even if you decide at the beginning that you do not want detailed information, you will be able to ask more questions later on.

If you have questions about your condition, it is a good idea to write them down to have them handy when you see your consultant or key worker. If they are not the best person to ask, they can tell you who you should speak to. You can find some suggestions of questions you might want to ask at the end of this booklet.

If your hospital has a clinical nurse specialist, it may be possible to arrange time with them to discuss your condition. Some patients prefer this to asking the consultant. You should decide what is right for you.

It is usually possible to take someone into the room with you on visits to the consultant. This person need not be a family member - you can choose who you want to be there. If you are staying in hospital, it may be more difficult to arrange for someone to be there with you when you speak to your consultant, but you should always ask, if this is what you would like.

Often it is difficult to decide how much to tell people about your diagnosis and treatment and then for them to know if they are expected to keep this confidential. If you work, or are in further education, you may find support from colleagues or through a human resources department. It is likely that you will need to tell at least a few people at work or college as it can be difficult to ask for time off at short notice if no one knows about your illness. It can be very stressful to have to discuss your condition lots of times. You may find it easier to ask someone you trust to pass on details on your behalf.
Your GP will always be kept informed about your condition and about what, if any, treatment you are being given. It is very common now for patients to be given copies of letters from their hospital to their GP. If you receive a copy and you are worried or puzzled about anything in the letter, you should let the hospital or your GP know. Often an explanation can help to reassure you.

Emotional impact

For most patients the initial news that they have a serious blood condition is a great shock. Usually, friends and family will rally round and offer support, but it may be hard for them to understand the long-term emotional impact on you of dealing with your illness. Also, it is becoming increasingly common for people to be diagnosed by chance, at a time when they have few or no symptoms and require no treatment. A diagnosis can then be an even greater shock for you and those around you.

Your healthcare team should assess your emotional, as well as physical, needs – this is called a holistic needs assessment. This is repeated during the course of your illness, as treatment can take a long time and your emotional needs may change at different stages.

Making contact with one of the organisations listed towards the back of this booklet and speaking to others in a similar situation can be very helpful. These organisations can offer support both for you and for family members.

The future

You may find it particularly difficult to ask about or to discuss your future. (You may know this is called a prognosis.) Sometimes your family members may want to know the prognosis even if you do not, however your hospital is not allowed to give detailed information to anyone, not even family members, unless you give your permission. You need to decide who you want to know about your condition and treatment and to make sure that your healthcare team and the hospital know your wishes. (You can change your mind at any time.) You should remember that the outlook may change, for example based on how well your condition responds to treatment. If there is a change in your condition, or if you have completed all or part of your treatment, it may be a good idea to ask whether this affects your prognosis.

What you may need to do

Work, education and domestic arrangements

If you work or are studying you may need to contact your employer or college or have someone do this for you. Most employers or places of study will do all they can to help.

You may make a short-term arrangement with an employer or college at the time of diagnosis for time off to attend hospital. If you have to stay in hospital for your treatment, or you are not able to go to work or college, you will probably need to make a more formal agreement. It may be necessary to have a letter from the hospital to explain your diagnosis and the effects of this on your ability to work or study.

If you are a parent or a carer, you may need to look for support during your treatment, including making alternative care arrangements for the people you look after. You may have unplanned stays in hospital because of infection or other acute problems and it is helpful to have plans in place just in case this happens.

People with cancer, or any other serious disease, are covered by a law called the Equality Act – for the purposes of the act, cancer is considered a disability. This means that employers and places of study are required by law to make reasonable arrangements for ‘people with disabilities’ and cannot discriminate against you. An example would be if you need time to attend hospital for treatment. Your employer has to make this possible and is not allowed to ‘dock’ your pay or to make you take the time as unpaid leave. If you have cancer, you are covered by the act from the time of your diagnosis, whether or not you are suffering any specific disability.
The Act also protects anyone who needs time off to help a family member who has cancer.

**Getting to hospital**

If you are being treated as an outpatient, you may need to make many visits to the hospital, over a long period. If this is difficult because of transport or for other reasons, you should ask your consultant whether any part of your treatment can be given near to where you live. This can often be arranged, but is not always possible; this will depend on the facilities that are available closer to your home and the type of treatment you are receiving. If it isn’t possible and transport is a problem, you should ask about hospital transport.

**Financial support**

It is very difficult to think about financial arrangements when you have just had a diagnosis of a serious health condition, but there are many sources of help and advice.

Your hospital will normally have medical social workers or welfare rights (benefits) advisors who can give expert advice on which benefits you may be able to receive. You should ask to speak with one as soon as possible after your diagnosis. Alternatively, the hospital may be able to arrange a visit by an advisor from a local office or cancer information centre.

If you are on a low income, or unemployed, there may be additional benefits which will help you to cope with extra costs, such as the costs of getting to hospital for treatment or check-ups.

If you normally pay for your prescriptions but are being treated for cancer (including the effects of cancer or the effects of cancer treatment), you can apply for a medical exemption certificate which means you do not have to pay charges on any prescriptions. Application forms are available from your GP surgery or hospital clinic.

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**Change in your condition**

If you are not starting treatment straight away, you should ask your consultant if there are any changes in your condition which you need to report immediately. If you do notice any change in your general health, or if there are any symptoms which are worrying you, contact your key worker who can arrange, if necessary, for you to have an earlier check-up visit.

There is information on some symptoms that you need to be aware of later on in this booklet; page 19.
NORMAL BLOOD CELLS

In order to understand your condition it may be helpful to understand a little about the normal functions of the blood and bone marrow.

The blood

Your blood functions as a transport system to carry food and oxygen to your tissues and to carry waste chemicals away to the kidneys and lungs to be passed out of the body. It also carries proteins and other ‘building blocks’ around the body to where they are needed to form new tissues. It provides:

- a defence system, as white cells carried in the blood are part of the immune system and will travel to wherever they are needed to fight infection
- a communication system, as organs in the body release hormones into the blood which act as chemical messengers between organs
- a repair system, like a self-sealing tyre, it contains cells and chemicals which can automatically seal off damaged blood vessels and control blood loss.

Your blood is made up of liquid called plasma, which contains three main types of cells: red cells, white cells and platelets.

- **Red blood cells (erythrocytes)**
  These contain a pigment called haemoglobin, which can pick up oxygen and carry it from your lungs to the tissues. Muscles and other tissues need oxygen to produce energy from your food.

- **White blood cells (leukocytes)** – neutrophils and monocytes, eosinophils and basophils and lymphocytes
  Different types of white cells either ‘swallow up’ bacteria or fungi, destroy parasites, or produce antibodies to fight infection.

- **Platelets (thrombocytes)**
  These stick together at the site of any tissue damage and stop the bleeding. They also release substances that trigger the forming of a firm clot, a scar and healing.

The numbers of each type of blood cell vary from person to person but are quite stable for people who are healthy.

Blood cell production

All types of blood cell are produced by stem cells in your bone marrow, which is a spongy tissue in the middle of bones.
About one in every 10,000 bone marrow cells is a stem cell – stem cells are blood cells at the earliest stage of development. When a stem cell divides it produces either replacement stem cells or cells which form blood – these are known as progenitor cells.

Progenitor cells divide a number of times and each time they divide they mature, which means they become more like a fully formed blood cell. Mature blood cells do not divide. Blood cancers and related conditions all arise in the progenitor cells or stem cells.

Your bone marrow produces a very large number of cells every second – about three million red cells and about 120,000 white cells. All blood cells grow old and die when they are no longer needed. The growth and production of blood cells in your bone marrow is carefully balanced to make sure that you have the exact numbers you need of each type of cell to keep your body healthy. Too many or too few of any type of blood cell can make you become unwell. If you have leukaemia, most of your symptoms will be caused not by the large number of abnormal cells present, but because your bone marrow is unable to produce normal cells fast enough.

**THE IMMUNE SYSTEM**

Your immune system is a network of cells, tissues and organs which defend your body against infection by bacteria, parasites, fungi or viruses. It can also detect and destroy cancer cells but this does not always work effectively. Some types of cancer are more likely to affect you if your immune system is not working properly.

The most important organs of the immune system are the spleen and the thymus. The spleen may become swollen in some types of blood cancer. Its main functions are to filter the blood for bacteria or other infections, and to remove worn out blood cells. The thymus is an organ in the upper chest which plays a very important role in the development of the immune system. The thymus is quite large in young children but shrinks to a very small size by adulthood. Occasionally, when blood cancer affects the thymus, this may get larger and press on the windpipe or blood vessels.
The organs of the immune system are known as lymphoid organs because they contain large numbers of lymphocytes, which are a type of white blood cell. The different types of lymphocyte, and other white cells, all work together to defend your body against infection. There are many different types of lymphocyte but the most important types are called B and T cells. If you have a lymphoma or a lymphatic leukaemia, this is most likely to be B cell in type.

As well as blood vessels, your body has a network of lymph vessels, which collect lymph, a fluid that has squeezed out of the smallest blood vessels. The lymphatic circulation drains this fluid back into the blood. Along the lymphatic vessels there are small lumps of lymphoid tissue, called lymph nodes or lymph glands. There are about 600 lymph nodes in your body, many of them deep inside your chest, abdomen and pelvis. If you develop an infection it is quite common for the nodes to become enlarged and tender. This may be described as ‘swollen glands’. There are also collections of lymphocytes in the gut and other tissues in the body which can be affected by some blood cancers.

SIGNS AND SYMPTOMS

Before being diagnosed, you may have noticed signs and symptoms such as tiredness, itching, a swollen lymph node or bruising, which led to you being given a hospital appointment.

Now that you have been diagnosed, you need to be aware of what to do if you develop new symptoms.

If you develop symptoms

If you feel unwell, or develop new symptoms, however mild, you should contact the hospital immediately. You should do this even if you are not sure if this is related to your blood condition. The hospital team can tell you whether you should go to your GP or go to hospital.

In some hospitals there are special arrangements for patients who have been diagnosed with a blood cancer or related condition and who need to attend the accident and emergency department (A&E) for any reason. You should find out if this is the case at your hospital because, if it is, you will then not have to wait in A&E to be seen. That reduces the risk of you being exposed to infection. Even if your hospital does not have such an arrangement, it is a good idea to ring the hospital and let them know you are coming.

Although they are not common, there are some conditions which need to be dealt with urgently. If you have any of the following symptoms, you must contact the hospital team without delay.

Possible signs of infection:

• cough or sore throat
• confusion or agitated behaviour, especially if this comes on suddenly
• rapidly becoming more ill
• fast heart beat and breathing
• difficulty in passing urine or not producing urine
• abruptly increasing pain.
Because of your diagnosis, it is likely that your immune system is not working properly and a minor infection could become more serious. Symptoms of infection may be less obvious because of your illness, so if you are in any doubt you should seek medical advice immediately.

Possible signs of pressure on the spinal cord – especially with myeloma or lymphoma:

- central back pain, made worse by movement, coughing, or straining
- a sudden change in the nature of a long-standing pain
- ‘crescendo’ pain: pain that becomes worse and then eases off
- pain made worse by lying down or by leg raising
- leg pain, either one leg or both, especially if this starts in the back and spreads to the legs
- a tingling, ‘electrical’ feeling in the arms or trunk when you bend your head forwards
- not being able to control your bowels or bladder
- weakness or loss of feeling, usually in your legs, starting in the feet and moving upwards.

Possible signs of raised calcium level – a potential problem for myeloma patients:

- feeling of sickness
- loss of appetite
- constipation
- needing to pass urine more often
- feeling thirsty or being dehydrated
- not having as much energy as usual
- being confused or dazed.

You should make sure that carers or colleagues know that they should get medical help urgently if you become confused or unconscious.

TESTS AND SCANS

You will probably need to have a number of tests to confirm your diagnosis, see how well your condition is responding to treatment and to check your general health.

Some investigations, such as blood tests, may need to be done quite frequently, but others are done less often, possibly only at the time of diagnosis or if you are changing treatments. For some tests you may need to fast (have nothing to eat or drink except water) beforehand, or prepare in other ways. You should be given information about what each test will involve and what you need to do.

If you should feel anxious about any of the tests, it is important that you talk to your healthcare team about your concerns, so that they can support and help you.

This section briefly describes some of the investigations which you are most likely to experience. You can find more detailed information on our website. Our booklets on specific conditions describe more specialised tests.

Laboratory tests

Full blood count

This is a blood test that measures the numbers of each type of cell in the blood. It will also look for any abnormalities of the cells and check that the proportions of different white cell types are normal.

You may like to keep track of your blood count results as this usually gives some idea of how your condition is progressing and the effects of treatment.

Other lab tests

You may have tests to check that your liver, heart and kidneys are working properly. You may also have a blood test to check your urea and electrolytes. This test makes sure that your kidneys are passing
urea (a waste product) out of the body and that it is keeping the right balance of certain minerals in your blood and other body fluids.

The tests may be used to check your general health or to monitor your response to treatment. You can ask any member of your healthcare team to explain what they are for and what the test results mean.

More detailed information on laboratory tests can be found on the website labtestsonline.org.uk; which is supported in part by the Department of Health.

Cytogenetics

All cancer cells have changes in their genetic information. Most of these changes are not inherited and are only present in the cancer cells, not in the normal cells in your body.

Information about the exact changes present in the cells can help doctors to diagnose your illness, to decide how likely it is that your condition may worsen, and help to monitor how your condition responds to treatment. The study of these changes is called cytogenetics.

Biopsy

Biopsy means taking a sample of a tissue or organ eg the liver or spleen, to be examined in the laboratory.

Bone marrow sample

Bone marrow samples may be taken to confirm a diagnosis, to monitor response to treatment, or in some blood cancers to check whether the marrow is affected. Most people with blood cancer will have at least one bone marrow sample taken, usually from the hip bone. If you are not due to start treatment immediately, your doctor may still want to get a bone marrow sample so that this can be compared with later samples.

X-rays and scans (imaging)

Most hospitals now have the ability to do far more than just x-rays. They also use CT scans and MRI scans, which show up soft tissues (non-bony parts) much more clearly than x-rays. Ultrasound gives a less detailed picture than CT or MRI scans but it can be very useful, for example in measuring the size of the spleen, which is often enlarged in lymphoma or leukaemia.

X-ray

X-rays provide very good images of the more dense tissues in the body, such as bone. They can be used at your diagnosis to help with staging (determining how advanced the illness is), during treatment to find out how your condition is responding, and to check for chest infections when your white cell count is low.
CT or CAT scan
This is a form of x-ray that produces a detailed picture of internal organs to assess the stage of the disease. It is a painless procedure where you will lie on a table that moves into a cylindrical tunnel while the pictures are taken.

Magnetic resonance imaging (MRI)
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 which will move you through the scanner. It is not painful but can take time to complete and is quite noisy. You will usually be given headphones so you can listen to music during the procedure. You may need to have some fluid injected into a vein to help the computer form a better image.

Whole body scans
Depending on your exact diagnosis you may need to have scans of your whole body to check if there is disease in internal organs. If this is the case, your healthcare team will explain what this means.

Special tests
There are some tests which are very specific for abnormalities seen in certain conditions. If you need any special tests, your healthcare team will make sure that you have all the information you need about them and you will have a chance to ask questions.
TREATMENT

If you are due to start treatment soon after diagnosis, there are some questions you may want to ask. You might like to take someone with you when you see the doctor to help you to remember and understand discussions about your treatment.

Treatment decisions

You will be involved in any decision and choice to be made. It is important to stress that this does not mean that you will be expected to make detailed choices about which drugs or doses you should be given. It means that you should be allowed to choose between, for example, more intensive treatment which may be more effective against your disease but will have more side effects, and a gentler, but possibly less effective treatment. However, if for example you have a condition for which the recommendation is ‘watch and wait’, it would not be possible to insist with your consultant that you start treatment immediately if they do not think that is in your best interest.

Although most patients choose to have treatment, it is your right to refuse it. If you are doubtful about having treatment, you should be very clear about what this means for you. You do not have to give reasons for any choice you make about treatment, but it is very important to discuss any worries with your consultant or key worker before making a decision. As an example, you may be worried about side effects, such as nausea and vomiting, but there are very good drugs to control this now and it is not usually a serious problem.

If you are asked to make treatment decisions, you should make sure that you have as much information as possible and that you understand the implications of your choices. Sometimes it may be necessary for you to make a very quick decision on treatment. If this is the case, you will have a chance to talk over future treatment plans, once you have received any urgently needed treatment.

Decisions about longer-term treatment can usually wait, but not always. You may need to make decisions early on which will affect your treatment options at a later stage. If this applies to you, it will be explained before a treatment decision is made.

Taking your time

When you are first diagnosed, it may be difficult to think straight but there are often important decisions, especially about tests and treatments, which cannot be delayed. You should still make sure that you take some time to consider all the options open to you. If it is necessary to make decisions immediately, make sure that you understand the different options. It may be helpful to have a friend or relative with you when this is being discussed and you may also find it useful to have the options written down for you.
Second opinions
You may worry that your consultant will think you lack confidence in your medical team if you ask about a second opinion. However it is very common for patients with serious conditions to ask about a second opinion, and doctors are used to this.

If you would like to arrange for one, you can do this by asking your GP or your consultant to refer you. Alternatively you can arrange for a private consultation, though you will still need to arrange this through your consultant. (This is a rule of medical ethics, meant to protect you.)

The timing of a second opinion is important. If you ask for a referral when you have very early stage disease, there may be very little another consultant can add to what you have already been told. The times when you are most likely to benefit from a second opinion are if you are being asked to make a choice about treatment options, or if you have been told by your consultant that your present treatment is not working and you need to explore all the different options. You should be aware that it is very unusual for a second opinion to raise any new treatment options but it may help in deciding which ones to choose. Having the treatment options confirmed independently can also help you to feel more confident about your future.

If you are a very young patient with a disease which mainly affects old people, or if you have other medical problems complicating your treatment, these could be situations when you may benefit by asking to be referred to a leading expert.

Active monitoring
You may not need to start treatment straight away; you may never need treatment; or you may start treatment after months, or even years, of ‘active monitoring’. If this is the case for you, then discuss with your consultant or key worker how the decision will be made when to start treatment, and whether there are any special precautions you should take while you are being monitored (sometimes called ‘watch and wait’).

If you are on ‘watch and wait’, it is unlikely that your consultant can predict if or when you will need to have treatment. There is currently research being done on tests which might help doctors to make these predictions in the future. If these tests make it possible to predict when disease will progress early, this may allow early treatment to be offered to just those patients. It is likely to be several years before such tests become routine. If the tests applied to you, then you would be able to have them as soon as they enter clinical use.

If you do not need treatment straight away it is a good idea to ask if there is anything you need to be aware of in the meantime. You may need to take special precautions against infection, or there may be signs or symptoms which you should report immediately.

Where ‘watch and wait’ is recommended there are well-established guidelines on when to start treatment. For some conditions the decision is based on whether or not you have symptoms, or if your signs or symptoms have changed. In other cases it depends on the result of laboratory tests.

Starting treatment
After diagnosis, some people require urgent admission to hospital. There is usually a delay of a few days before starting treatment but, less commonly, some people need to go into hospital immediately. Others can wait for a long period before having treatment without this having a negative effect on their condition, in which case delaying admission is appropriate.

Delayed admission
It may be possible for you to go home and return at a later date for a ‘planned’ admission. This is easier to arrange but you should make sure that you know when to come back, what you will need to bring with you, and how long you are likely to be in hospital.

If you are going to be treated without staying in hospital, you will need to make sure that you know when to go to the hospital and
where to go when you arrive. As you may not feel well enough to drive or take public transport after your treatment, it is sensible to consider beforehand how you are going to get home. It might be helpful to have a bag with overnight things, just in case you need to be admitted. (Avoid taking anything of sentimental or financial value.)

Unfortunately, even in the best run clinics, long waits are common so it can be useful to take something to occupy your time while you wait. If you are allowed to have a drink, these can usually be bought from the hospital shop; small change may also be useful to buy a drink from vending machines.

Urgent admission

There may be a short delay, usually only a few days, before you start treatment. This is to allow doctors to carry out any necessary tests to make sure you receive the right kind of treatment for your condition and to check for any other health problems which might affect your risk of complications from treatment. This will not affect the likelihood of the treatment being successful.

Some types of blood cancer quickly become worse if they are not treated soon after diagnosis. If you have this type of blood cancer, you are likely to have been admitted to hospital straight after diagnosis. When urgent treatment is needed it is often, but not always, high-dose (intensive) and may make you feel very ill at the time.

Being admitted to hospital as soon as you are diagnosed can be worrying and is likely to cause more disruption to your day-to-day life than a planned admission. You may need help from your key worker or a hospital social worker, with work, study or domestic arrangements. It is also here where a family member or trusted friend may be able to offer practical help. If you are going to be in hospital for some time and you live alone, you may want to ask a friend or neighbour to keep an eye on your home.

Where you will have your treatment

It is important to understand whether your treatment will mean that you have to stay in hospital all or part of the time (inpatient) or if you can be treated while living at home (outpatient). This will depend on the treatment you need and also perhaps on what support you have available from family, friends or others. If you are to be treated as an outpatient, you may need help to get to hospital for your appointments. If you have had inpatient treatment, you may be a little nervous about going home afterwards, so it may also be a good idea to make sure that someone can be there to help you.

Phases of treatment

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<th>Phase</th>
<th>Goal</th>
<th>Types of treatment</th>
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<tbody>
<tr>
<td>Remission induction</td>
<td>To reduce the number of cancer cells to as low as possible</td>
<td>Usually combinations of drugs</td>
</tr>
<tr>
<td>Consolidation</td>
<td>To kill any remaining cancer cells</td>
<td>Further blocks of treatment, usually with drugs</td>
</tr>
<tr>
<td>Maintenance</td>
<td>To prevent return of the condition</td>
<td>Drug treatment</td>
</tr>
</tbody>
</table>

Your treatment will usually be divided into different phases. There are three phases of treatment. Depending on your diagnosis, you may receive some or all of these phases.

Most patients will receive induction and consolidation, but whether you receive maintenance therapy will depend on your illness and your treatment plan. The plan for what treatment is given and the timing and dose of the treatment you receive is called a protocol (or sometimes a regimen).
The different types of treatment

There are several different types of treatment which you may be offered. You may need chemotherapy (treatment with drugs), radiotherapy (which uses radiation to kill abnormal cells), a stem cell transplant, or a combination of two or more of these.

We have separate booklets available on treatment decisions, chemotherapy and stem cell transplants, with more information. There is also more specific information about treatments in our booklets on the different blood cancers.

Undergoing treatment is a difficult time and you need to make sure you are taking proper care of yourself before and during your treatment. Try to lead a healthy lifestyle with a balanced diet. Get as much exercise as you can comfortably manage, but ask for advice if you have a condition such as myeloma which may weaken your bones. If you smoke, you should ask for advice and support to help you quit.

Being aware of your general health and wellbeing may help you to feel more in control and more positive.

Chemotherapy (drugs)
Chemotherapy means using drugs to treat any disease, though many people only use this word to talk about anti-cancer drugs. In cancer treatment, there are many different kinds of chemotherapy, which nearly always use a combination of drugs. There are also differences in the ways in which drugs are used. Chemotherapy may be given by mouth, by an injection under the skin or into a vein.

In some conditions there may be abnormal cells in the cerebro-spinal fluid (CSF), the fluid that surrounds the brain and spinal cord. If this is a risk, you may also receive medication given by an injection into the CSF. This is called intrathecal therapy.

Sometimes you will need to stay in hospital during a course of chemotherapy, but this is not always the case.

Radiotherapy
Radiotherapy means using high-energy radiation, such as x-rays, to kill cancer cells. It is most likely to be part of your treatment if you have lymphoma or myeloma. It is not part of routine treatment for most patients with leukaemia.

If you are to receive radiotherapy, you will have a chance to discuss your treatment plan with the specialists from the radiotherapy team.

Biological therapy
A very effective way to treat blood cancer is to use your body’s own defence mechanisms against your illness. This is known as biological therapy and it may take different approaches. For example, it may involve using very specific antibodies called monoclonal antibodies, which will only attach to the surface of specific cells; or it may mean using vaccines to stimulate your immune system to kill cancer cells. The only biological therapy which is currently in routine use is monoclonal antibody therapy.
**Stem cell transplants**

You may have been told that a treatment option for your condition is a stem cell transplant. This used to be called a bone marrow transplant, but other sources of stem cells are now more commonly used than bone marrow.

There are several types of stem cell transplant differing, among other things, in whether they use donor cells or your own cells, how the stem cells are collected and the type of treatment given before the transplant.

Donor stem cell transplants may be planned as part of consolidation treatment if your doctors think standard treatment is unlikely to succeed. (See Phases of treatment; page 31.) This type of transplant may also be considered at a later stage if your initial treatment has not been completely successful. Transplants using your own cells, called autologous transplants, are often considered for patients with myeloma or lymphoma.

Leukaemia & Lymphoma Research publishes booklets on several different types of transplant and your consultant or key worker can tell you which ones are relevant to you.

**Supportive care**

As well as active treatment of your illness, you may also require supportive care. Supportive care includes aspects such as prevention and treatment of infection, blood transfusions, mouthcare, diet, pain management and dealing with complications of your illness or of your treatment.

A booklet on supportive care is available from Leukaemia & Lymphoma Research.

**Palliative care**

Palliative care is treatment which is mainly aimed at controlling signs and symptoms of the illness, and is often given alongside other treatment.

When palliative care is started after you have been under treatment for some time, it can be confusing to have new people taking over part of your care. It is now thought better that, if you may need palliative care at some time, you should meet the team and discuss this well in advance. This means that, if you reach a point where palliative care is planned, you will not find yourself dealing with strangers.

If your consultant or key worker suggests you meet the palliative care team, do ask questions and tell them if you have any anxieties.

**Complementary and alternative therapies**

There is an important difference between complementary and alternative therapies.

Complementary therapies are non-standard treatments which are used alongside standard treatment for your illness. There is some evidence that some of these therapies may help, particularly with side effects of standard treatment.

If you are considering using any form of complementary therapy, it is very important to tell your consultant or key worker. This is because there is a risk that some treatments may interfere with the standard treatments you are receiving. There is also a risk that some treatments, for example deep massage or acupuncture, may be unsafe if you have a weakened immune system.

Alternative therapies are used instead of standard medical treatment in an attempt to cure or control the cancer. Very extensive research has shown no evidence that any non-standard treatment has any benefit in treatment of any form of cancer. Leukaemia & Lymphoma Research recommends that you should not use any alternative therapy in place of proven medical care.

A booklet on complementary and alternative medicine is available from Leukaemia & Lymphoma Research.
Common side effects

You may be worried about the possible side effects of your treatment. Not all treatments have any serious side effects and, even when side effects are expected, there are usually ways to control them.

Your healthcare team will tell you about any likely side effects before you start treatment. If you are still worried about side effects, talk to your healthcare team, as they can only help you if they know about any concerns you have.

Some side effects may be seen with several different types of treatment.

- **Hair loss (alopecia)**
  This is temporary in virtually all cases. It may include all body hair and there is unlikely to be anything you can do to prevent it and so you might want to use a wig or scarf. Not all forms of treatment cause hair loss, so if this is something which worries you, be sure to ask as you may find your fears are groundless. If it is likely that your hair will fall out and you would like a wig, you should ask about it as soon as possible so that it can be matched with your normal hair.

- **Nausea and vomiting**
  There are drugs called anti-emetics which can help in almost all cases. Not all drugs cause nausea or vomiting, so again you should ask about this.

- **Inability to fight infection**
  You may be less able to fight infection as most treatments for blood cancer affect normal blood cell production. Because of this, you may need to have at least part of your treatment in a special sterile unit (clean and free of germs). You should ask for advice on how you can reduce the risk of infections.

Length of your treatment

The length of treatment varies a great deal between different conditions. Your consultant will usually have a good idea of how long your treatment will last. Many forms of treatment are given as separate courses lasting for varying lengths of time, usually with breaks in between. If you are working or studying, or if you have family to look after, it may be important for you to be able to let other people know what to expect during this time.

Follow-up arrangements

Some types of blood cancer can be cured with chemotherapy or sometimes with stem cell transplants or other treatments. If you have this type of disease, you will usually have regular follow-up appointments with the specialist team for at least five years afterwards.

Taking part in a clinical study (trial)

One of the decisions you may be asked to make is whether to take part in a clinical study or trial of treatment. This may be a difficult decision to make, especially when you have little time to think about the options. It may be reassuring to know a few things about trials.

- All clinical trials have to be approved by an ethical committee whose only concern is with protecting your safety and wellbeing.
- All studies are overseen by a committee which has the power to stop the trial at any time if there is evidence that one treatment is clearly better than another.
- People will sometimes get better even when they are given a ‘medicine’ with no active ingredients. This is called the placebo effect and the inactive medicine is called a placebo (‘sugar pill’). No patient with cancer or serious illness will be given a placebo instead of effective treatment for their illness.
If the study is about a new drug which is not directly treating your illness, a trial may involve some patients being given a placebo instead of the new drug. An example would be treatment to stop side effects like feeling sick. This is only done when the use of a placebo will not reduce your chance of getting better. If a study means that some patients may not be given active treatment, you will be told this before being asked if you give your consent.

A booklet on clinical trials is available from Leukaemia & Lymphoma Research.

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HELP AND SUPPORT

We have listed a number of organisations with a brief description of just some of the services they offer. Please contact them directly for further information.

There is also a page on the Leukaemia & Lymphoma Research website which contains up-to-date details of organisations which can offer help and support: beatingbloodcancers.org.uk/helpandsupport

- **African Caribbean Leukaemia Trust (ACLT)**
  The ACLT aims to increase the number of black, mixed race and ethnic minority people on the UK Bone Marrow Register by raising awareness and running donor recruitment drives.

  020 8240 4480 | info@aclt.org | aclt.org

- **Anthony Nolan**
  Runs the UK’s largest stem cell register, matching donors to patients with leukaemia and other blood-related disorders, who need a stem cell transplant.

  0303 303 0303 | anthonynolan.org

- **CancerHelp UK (a Cancer Research UK website)**
  Provides patient information and a telephone helpline/email advice service run by specialist cancer information nurses. Also offers an online discussion forum for people affected by cancer.

  0808 800 4040 (Nurse Helpline) | cancerhelp.org.uk
• **Children's Cancer & Leukaemia Group (CCLG)**
  Provides treatment and care of children and younger teenagers with cancer. Coordinates clinical trials and also produces a wide range of booklets for patients and families.
  0116 249 4460 | info@cclg.org.uk | cclg.org.uk

• **Children with Cancer UK**
  Provides funding for welfare projects to help children with cancer and their families.
  020 7404 0808 | childrenwithcancer.org.uk

• **CLIC Sargent**
  Offers a range of services for children affected by cancer, including a telephone helpline for emotional support and practical advice for both patients and their families.
  0300 330 0803 | info@clicsargent.org.uk | clicsargent.org.uk

• **CLL Support Association**
  Provides web-based information and support for patients with chronic lymphocytic leukaemia (CLL) and related conditions.
  020 7644 3052 / 0800 977 4396 (Membership enquiries)
  info@cllsupport.org.uk | cllsupport.org.uk

• **CML Support Group**
  Offers web-based information and an online discussion forum for patients with chronic myeloid leukaemia (CML).
  cmlsupportgroup@gmail.com | cmlsupport.org.uk

• **Leukaemia Care**
  Offers patient information, a 24 hour care line and support groups for people affected by leukaemia, lymphoma, myeloma, myelodysplastic syndromes, myeloproliferative neoplasms and aplastic anaemia.
  01905 755 977 (General enquiries) | 08088 010 444 (Care Line)
  care@leukaemiacare.org.uk | leukaemiacare.org.uk

• **Leukaemia & Lymphoma Research**
  Offers patient information booklets, and the Patient Information team can provide information over the telephone or by email.
  020 7504 2200 (Patient Information team)
  patientinfo@beatingbloodcancers.org.uk | beatingbloodcancers.org.uk

• **Lymphoma Association**
  Provides emotional support and information to anyone with lymphatic cancer and their families, carers and friends.
  0808 808 5555 | information@lymphomas.org.uk | lymphomas.org.uk

• **Macmillan Cancer Support**
  Offers practical, medical, financial and emotional support.
  0808 808 0000 | cancerline@macmillan.org.uk | macmillan.org.uk

• **Maggie’s Cancer Caring Centres**
  Have centres throughout the UK, run by specialist staff who provide information, benefits advice and psychological support.
  0300 123 1801 | enquiries@maggiescentres.org | maggiescentres.org
• Marie Curie Cancer Care
  Runs nine hospices throughout the UK and offers end of life support to patients in their own homes, free of charge.
  0800 716 146 | supporter.services@mariecurie.org.uk | mariecurie.org.uk

• MDS Support Group
  Provides patient information and an online discussion forum for people affected by myelodysplastic syndrome (MDS).
  020 7733 7558 | mds-uk@mds-foundation.org | mdspatientsupport.org.uk

• MedicAlert Foundation
  Provides an identification system for individuals with hidden medical conditions and allergies, in the form of body-worn emblems and necklets.
  0800 581420 | info@medicalert.org.uk | medicalert.org.uk

• MPD Voice
  Provides patient information and emotional support for people affected by myeloproliferative disorders (MPD), now known as myeloproliferative neoplasms.
  0800 581420 | info@mpdvoice.org.uk | mpdvoice.org.uk

• Myeloma UK
  Offers patient information, a telephone advice and information line, an online discussion forum and support groups.
  0800 980 3332 | myelomauk@myeloma.org.uk | myeloma.org.uk

• Teenage Cancer Trust
  Provides specialist units, support, education and information for teenagers with cancer and their families.
  020 7612 0370 | teenagecancertrust.org

• Tenovus
  Provides an information service, and practical and emotional support for cancer patients and their families living in Wales.
  0808 808 1010 | tenovus.com

Financial advice

• Citizens Advice Bureau (CAB)
  Offers advice on benefits and provides help with filling out benefits forms. Details of local CAB offices can be found in the Yellow Pages or a local telephone directory.
  08444 111 444 (England) | 0844 477 2020 (Wales) | adviceguide.org.uk

• Department for Work & Pensions (DWP)
  Runs a Benefits Enquiry Line (BEL), offering information and help with filling out claim forms over the phone.
  0800 882 200 / 0800 243 355
  bel-customer-services@dwp.gsi.gov.uk | dwp.gov.uk

• General financial advice is available from CancerHelp UK, Macmillan Cancer Support and Leukaemia Care. (See above for contact details.)
Equality Act

- **Direct Gov**
  There is a section of this website which provides detailed information on the Equality Act and the protection this gives to patients with cancer.


Travel insurance

When contacting organisations about insurance you will need to disclose full details of your medical condition. You will be asked questions about your condition that you may find intrusive and possibly upsetting, but these are necessary to make sure that you are adequately covered.

- **Association of British Insurers (ABI)**
  Provides information about obtaining travel insurance and contact details for specialist travel companies.

  020 7600 3333 | abi.org.uk

- **British Insurance Broker’s Association (BIBA)**
  Offers advice on finding an appropriate BIBA-registered insurance broker.

  0870 950 1790 | enquiries@biba.org.uk | biba.org.uk

- **Macmillan Cancer Support**
  Provides information about what to consider when looking for travel insurance. It also has a list of insurance companies which have been recommended by people affected by cancer.

  0808 808 0000 | cancerline@macmillan.org.uk | macmillan.org.uk

QUESTIONS YOU MAY LIKE TO ASK

**The aim of my treatment**

- Is it to cure my illness?
- Is it to control my illness?
- Is it to provide palliative care (to control the symptoms)?

**Tests**

- What tests will I be having?
- What will they show?
- Where will I have them done?
- Are there any risks associated with the tests?
- Are any of the tests likely to be painful?
- Do I need to know anything about preparing for the tests, for example not eating beforehand?
- How long will it take to get the test results?

**Treatment general**

- Will I need to have treatment?
- What does the treatment do?
- Is there a choice of treatments?
- Is there a clinical trial that I could join?
- What is likely to happen if I decide not to have treatment which has been recommended?
- If I am not starting treatment straight away, how will I know when I need to start it?
- Who should I contact if I take a turn for the worse or have any questions?
The type of treatment

Chemotherapy

- What type of chemotherapy will I have?
- How long will I have to stay in hospital or how often will I need to attend as an outpatient?
- Will I be given a single drug (unusual) or a combination (several drugs used together)?
- Will I be given it by mouth, injection or drip (into a vein)?
- Will my treatment be continuous or in blocks of treatment (with a break in between)?
- How long will my treatment last?
- What side effects should I expect from my treatment?
  - How bad are they likely to be?
  - Can they be treated or prevented?
  - Will they affect me all the time or only while I am taking certain drugs?
- What effect is the treatment likely to have on my daily life?
- Will I be able to carry on working/studying?
- Will I need to take special precautions, for example against infection?
- Will I need to change my meal times? (Some drugs need to be taken with meals or on an empty stomach.)

Stem cell transplant

- Is a transplant an option for me?
- How long will I be in hospital?
- Do I have to be in isolation?
- How long before I get back to normal?

Choosing the right treatment for you

If you are asked to choose between treatments, for each treatment you may like to ask your consultant:

- What is the best outcome I can hope for?
- How might the treatment affect my quality of life?
OUR BOOKLETS

You can download or order our booklets from our website beatingbloodcancers.org.uk or call us on 020 7504 2200 for more information.

Leukaemia
- Acute Lymphoblastic Leukaemia (ALL): Children, Teenagers and Young Adults (to 25 Years): UKALL 2011 trial
- Acute Promyelocytic Leukaemia (APL)
- Adult Acute Lymphoblastic Leukaemia (ALL)
- Adult Acute Myeloid Leukaemia (AML)
- Childhood Acute Myeloid Leukaemia (AML)
- Chronic Lymphocytic Leukaemia (CLL)
- Chronic Myeloid Leukaemia (CML)

Lymphoma
- Hodgkin Lymphoma (HL)
- Non-Hodgkin Lymphoma (NHL)

Multiple myeloma
- Multiple Myeloma (MM)

Related conditions
- Myelodysplastic Syndromes (MDS)
- Myeloproliferative Neoplasms (MPN)

Treatment
- Bone Marrow and Stem Cell Transplantation – for Children and Adults
- Chemotherapy – What Do I Need to Know?
- Clinical Trials
- Donating Stem Cells – What’s Involved?
- Donor Lymphocyte Infusion – What’s Involved?
- The Seven Steps – Blood & Bone Marrow Transplantation
- Treatment Decisions
- Undergoing High Dose Therapy and Autologous Stem Cell Transplant

General
- Complementary and Alternative Medicine
- Dietary Advice for Patients with Neutropenia
- Newly Diagnosed with a Blood Cancer
- Supportive Care
- Watch and Wait

Booklets for children and young adults
- Jack’s Diary
- Wiggly’s World
- Young Adults with a Blood Cancer – What Do I Need to Know?