

## Treatment decisions



The diagnosis of a blood cancer can be a devastating event for patients, families and friends. It is therefore vital for everyone to have access to reputable and understandable information to help cope with the illness. Whenever possible our booklets are written in line with national guidelines for the treatment of patients with a blood cancer. The information in our booklets is more detailed than in many others but is written in a clear style with all scientific terms explained for the general reader.

We recognise that the amount and level of information needed is a personal decision and can change over time. Particularly at the time of diagnosis, patients may prefer less detailed information. A number of alternative sources of information are available which complement our publications.

The booklets in this series are intended to provide general information about the topics they describe. In many cases the treatment of individual patients will differ from that described in the booklets.

**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 contact the clinical information team on 020 7269 9060.**

**Leukaemia Research**

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# Forks in the road

**There are often several treatment options available to a patient. Often the choice of treatment will depend on a variety of medical and non-medical issues. This booklet will help you to understand the choices you are being asked to make and help you with your decision.**

Not all sections of the book are relevant for all patients and so each section stands by itself – it is not necessary to read the book from start to finish. If you are not sure which sections apply to you, it may help to ask for advice on this from a specialist nurse, a doctor or another member of the team looking after you.

# Meeting the doctor

**You cannot make a decision about your treatment unless you have the correct information. The first opportunity to get the information you want will be in the clinic or on the ward when you meet your consultant and other healthcare professionals.**

It is now usual for patients to be assigned a specialist nurse who will have knowledge and experience of your type of blood cancer, and who will guide and monitor you throughout your hospital treatment. Often the specialist nurse will spend much more time with the patient than the medical team. Care of patients with cancer and related conditions is now usually undertaken by a team of specialists from various sections with the hospital – together they are known as a multi-disciplinary team or MDT.

You should let your healthcare team know how much information you wish to receive at this stage. You may want to know everything there is to know and meeting with your doctor will only be part of gathering this information. Alternatively you can inform your doctor that you only wish to have essential information relevant to your treatment.

If you are very anxious at your initial diagnosis, or when waiting for test results, it may be particularly difficult to make choices about treatment options. It can be helpful to write down the questions that are important to you.

You could also take notes during the meeting to help you remember what the doctor has said (most doctors are willing for you to record the conversation so you can go over the details again). Taking someone with you for support can also help in taking in the information and may give you extra confidence to speak up when you don't understand something. Alternatively, you may wish to go alone, if you feel that having a family member there will not be helpful. Your doctor can also give you written information or advise you about sources of reliable information about your condition<sup>1</sup>. If you are concerned, you should feel free to talk to your doctors and nurses about any aspect of your treatment, remember, you are entitled to a second opinion from another consultant if you are unsure about anything.

<sup>1</sup> As well as Leukaemia Research, information about leukaemia and related conditions can be accessed from CancerBackup – [www.cancerbackup.org](http://www.cancerbackup.org), MyelomaUK – [www.myeloma.org.uk](http://www.myeloma.org.uk), Lymphoma Association – [www.lymphoma.org.uk](http://www.lymphoma.org.uk)

# What do doctors base their decisions on?

**There are tests that can be carried out in order to identify the specific type of leukaemia or related disease that you have and which treatment should work best for you. These include identifying the type of blood cell which is affected by testing for different protein ‘markers’ on the outside of the cell, by looking for abnormalities in chromosomes of the affected cells and by looking for particular genetic mutations with very sensitive imaging techniques. Such tests are increasingly being used routinely to diagnose subtypes of leukaemia and related conditions and the treatments they require.**

Doctors use all or some of these tests to enable them to more accurately determine the diagnosis, treatment and follow-up of your disease. The doctors will use test results, your exact diagnosis and factors such as your age and general health to categorise your disease as low, medium or high risk. Risk, in this context, means things such as the chance of your disease progressing or the risk of the disease returning after treatment. For some blood cancers, this may determine the recommended treatment regime.

Doctors base their decisions, whenever possible, on published reports of large well-designed clinical trials. If there are no large clinical trials, they will use evidence from smaller trials or from other scientific studies. Sometimes a method called meta-analysis will be used, which combines the results of several small trials to reduce the effect of chance.

Published guidelines are based on the scientific literature and they will show the quality of information available to justify their recommendations. This approach is known as evidence-based medicine (EBM) and is now considered the gold standard for the practice of medicine. It is important to stress that EBM does not mean that doctors are simply following a recipe – they will adapt the guidelines for each individual patient.

# What kinds of decisions need to be made?

**You will need to make decisions about your treatment throughout the course of your illness. The decisions that you and your doctor make together will not be based purely on your disease and treatment options. Personal factors may also influence your choices. Your priorities and goals may change depending on how much treatment you have already received, how much your disease has progressed and how you feel both physically and mentally. You should be prepared to be flexible as situations change.**

Your doctor will decide, in consultation with you, which treatment is most appropriate for your circumstances. It is important that both you and your doctor agree that the correct decisions have been made about your treatment. For some patients, who have more aggressive forms of disease, early treatment is essential. In other cases, treatment may not be necessary at an early stage or treatment will be aimed at controlling the disease rather than cure. In this latter group there is usually more time to consider options.

Not starting treatment straight away, yet being monitored regularly for any changes in your disease is called 'watch and wait'. Understandably, this approach can cause concern as you may have expected to start treatment soon after diagnosis. However, studies have shown that people with certain forms of leukaemia or related conditions, who are managed on a watch and wait basis, do just as well as people with a similar diagnosis who start intensive chemotherapy straight away.

Whilst at first sight this seems contradictory, if there is no need for treatment until your disease progresses you can be spared the side effects of unnecessary chemotherapy. If you find yourself in this situation, you must keep your doctor updated about any changes in how you are feeling.

For some patients the response to initial treatment will not be what was hoped for or expected. If your doctors feel it is unlikely that you will benefit from more intensive treatment, or if you are unwilling to accept the side effects of such treatment, other options will be considered.

For whatever reason, if curative treatment is no longer appropriate, your care team will discuss options for palliative or supportive care with you.

**Supportive care**<sup>2</sup> covers all those elements of treatment that do not directly target your disease. For example, you may need blood transfusions for anaemia or antibiotics to prevent or treat infection.

**Palliative care** is used to alleviate the symptoms and give patients a good quality of life. Palliative care services include looking after the emotional and physical well-being of the patient, alongside the needs of their family. There are many forms of palliative care including pain relief and low-dose chemotherapy or radiotherapy to keep blood cell counts under control. Your care team will be able to advise you about what services are available locally such as hospital-based units or community-based services. Palliative treatment may be offered within the hospital setting or it can sometimes involve time spent in respite care such as hospices. The palliative care team may also offer support for patients who are being cared for at home.

Contrary to belief, hospices are not only concerned with terminally ill patients. In cases where it is thought that a patient may eventually require hospice care, the patient is now often referred at an earlier stage

of their illness so that they become familiar with the staff and facilities. It should not be assumed that, because the hospital has suggested a hospice referral, the medical team think that the patient is terminally ill. For example, it may be that a patient is referred because of the need for respite care.

# How do I decide?

**Any decision is a careful ‘weighing up’ of the potential benefits versus the potential risks. This will not only involve clinical decisions but also personal circumstances. For example, a parent with young children is likely to make long term survival their goal regardless of the short term impact of treatment. An older patient may place greatest emphasis on quality of life and may be reluctant to receive treatment which will have a severe impact on this. Patients who have been advised that long term survival is unlikely may wish to avoid treatments which either involve long hospital stays or prevent them enjoying life to the full. It cannot be stressed enough that the final decisions about treatment rest with the patient.**

**Whatever your circumstances, there are some questions that you can ask yourself and your doctor:**

- What does the treatment involve?
- How effective is it likely to be?
- What will the side effects be?
- What will be the effect on my everyday life? (How will it affect my work, my family, my need to travel for treatment etc?)

It is understandable that decisions are hard to make alone. It is very important for you to discuss all options with your doctor and/or your

specialist nurse so that the best course of action is agreed. Sometimes patients prefer to leave treatment decisions to the doctor. If this is true for you, let your doctor know. Nonetheless, you will still need information about your condition and the agreed treatment. Do not forget that to be entirely comfortable that the decision is the right one, you are entitled to ask for a second opinion.

Sometimes patients will nominate a family member to be briefed about their condition and their treatment. If this is so, you should let your doctors know. Although in some cultures it is usual for important decisions to be made by the head of the family or the family collectively; British law requires the patient's consent for treatment.

A specific situation where important decisions need to be made is in the case of a stem cell transplant<sup>3</sup>. Transplants may use either donor stem cells (allogeneic) or the patient's own stem cells (autologous). They tend to be offered to younger, fitter patients because of the toxic conditioning therapy required, although a newer technique called reduced intensity conditioning transplants (sometimes called "mini-transplants") has widened eligibility. Making decisions about stem cell transplants, particularly if you are an older person or in poorer general health, can be complex. It is unlikely that you will be offered a transplant unless the benefits clearly outweigh the risks. Even if you are relatively healthy, choosing to have a stem cell transplant is not one to be taken lightly. It is also clear that in certain circumstances transplants offer little likelihood of benefit and may even shorten your life. Hospitals that carry out stem cell transplants will have a transplant counsellor who can answer questions and help you through the process of making your decision.

<sup>3</sup> There are three separate Leukaemia Research publications about stem cell transplants.

## What happens if I already have another illness?

**General health is an important factor in how well your body can cope with treatment and certain conditions can make chemotherapy more risky, e.g. a heart condition or respiratory disease. Having another illness can narrow the treatment choices available. For example, you may find that the treatment offered is less intensive than would otherwise be the case. Some chemotherapy drugs can affect the heart and these may not be suitable for someone with a pre-existing heart condition.**

If you take medication for another condition, this may affect which treatments you are able to receive. Drugs can interact with each other in the body, so your doctors must be careful to make sure they don't treat your blood cancer with a drug known to interfere with your existing medication.

# Why am I not being offered intensive treatment?

**Not all patients will be fit enough to receive intensive treatment. This particularly applies to older patients (over the age of 65) but can also include younger patients with existing medical conditions, such as heart disease and diabetes.**

The potential benefits need to be carefully considered especially where treatment may cause unpleasant side effects. In an elderly patient, treatment decisions will take account of the person's anticipated life expectancy had they not been diagnosed with their present condition. If supportive care or low dose chemotherapy can control the disease, there may be no significant benefit in continuing with aggressive treatment.

Recent advances in treatment mean that more intensive options can now be considered for some patients where this has not been possible before. This means that patients may potentially have to choose between lifesaving but demanding treatment or supportive/palliative care to maintain quality of life.

# Should I take part in a clinical trial?

**Clinical trials<sup>4</sup> are planned studies involving patients. Trials are usually designed to test new treatment approaches. These may be new drugs that have successfully passed the required safety studies, new medical devices, new combinations of current treatments or different ways of giving the treatment.**

Clinical trials are always aimed at improving treatments and reducing the side effects. The outcome of a trial enables doctors to identify the best treatment for a disease and thus helps to improve medical care.

Phase I trials are the earliest clinical studies that a new drug or treatment has to pass. The questions addressed in these trials concern the safety, side effects, optimum dosage and frequency of the new therapy.

Phase II trials establish whether a treatment or new drug has any measurable effect on the disease. Side effects and their management, as well as the optimum dose and whether the treatment is effective for all groups of patients are assessed.

Phase III clinical trials compare new treatments with the best currently available treatment (standard treatment). Most phase III clinical trials are randomised, meaning that patients are randomly assigned to either the existing or the new treatment. It is important to remember that both treatments are effective against the disease, the trial is designed to determine which is better.

If both you and your doctor agree that you should enter an appropriate trial for your condition, you will need to consider the benefits and risks before deciding to take part.

Patients entered into a trial may have to attend hospital more often, which can cost time and money and general disruption to daily life. With any new treatment, the long-term side effects are not known and new treatments may not necessarily be better.

Patients are often asked to decide between treatment options where the expected outcome is similar or even identical. In this situation, quality of life is obviously paramount and therefore data may be collected on the effect of each treatment option on the quality of life as well as on survival.

Ultimately, the decision on whether to enter a clinical trial is one for the individual patient, but there can be no doubt that clinical trials are essential to advance treatment options. Clinical trials are only carried out when there is no certainty on which treatment is better, which means that choosing between treatment options is often a very difficult problem. Although no one can predict the outcome for an individual patient, there is no doubt that overall patients in trials do at least as well as other patients and some evidence suggests they may do better.

## How can I help myself?

**Whatever kind of treatment you are receiving, you can help yourself by trying to maintain as good a general health as possible. General health is very important when being treated for and recovering from a blood cancer. The stronger and fitter your body the more able it will be to cope with treatment. When it comes to food, the key is everything in moderation. Try to eat a healthy, balanced diet and avoid too much saturated fat and carbohydrate. During some stages of treatment, you may be asked to follow a ‘clean diet’. This diet avoids foods such as seafood, eggs, soft cheeses and takeaway food any of which may contain harmful bacteria. Although bacteria are normally removed in the cooking process, your reduced immunity means you are very sensitive to such infections, so the safest thing to do is to avoid such foods altogether. The hospital dietician can offer detailed advice on how to maintain a good standard of nutrition while complying with any limits of food choices.**

Because your immune system will be affected by your disease, and possibly by your treatment, you will be at increased risk of serious infection. Even normally trivial infections, such as the common cold, may be dangerous to somebody whose immune system is not functioning. Particular care should be taken to avoid anyone with chicken pox.

For this reason it is important that family and friends understand they should not expose you to the risk of infection. When you are particularly vulnerable, it is advisable to avoid busy places where you will have contact with many people<sup>5</sup>.

If you drink alcohol, you should try to moderate the amount you drink whilst you are receiving treatment for a blood cancer. Smoking is known to be a contributory cause of several cancers and the best thing you can do to help yourself in this situation is to stop. You can get help with quitting from your local NHS Stop Smoking Service<sup>6</sup>.

It is likely that you will feel fatigued during your treatment. Although it may be the last thing you feel like doing, moderate exercise has been shown to help recovery rates in people with blood cancers, compared to those who do not exercise at all. It is important to maintain as active a lifestyle as possible. Studies have shown that patients who have a sedentary lifestyle tend to have worse fatigue problems than those who remain active.

<sup>5</sup> There is more detail on avoiding infection in the separate Leukaemia Research publication Supportive Care

<sup>6</sup> You can find details of this at <https://data.gosmokefree.co.uk/localservicesearch.aspx>

# Can I decide not to have treatment?

**All decisions on treatment need to balance the potential benefits with the level of side effects that patients are prepared to tolerate. You may decline treatment if you decide it is of little benefit or if you decide the side effects are unacceptable.**

For example, your disease may have relapsed and you decide that you don't want to go through the same experience again. In this situation your doctors will want to be sure that you understand the full implication of your choice. You may be asked to sign a document to this effect.

Patients may decide to refuse treatment because of religious beliefs. For example they may refuse blood products. Blood products are an important supportive measure in the treatment of blood cancers and not accepting them may adversely affect survival.

Other patients may refuse all treatment. Communication is of the utmost importance in such situations. If certain treatments are unacceptable to you, for whatever reason, you must discuss this with your doctors as early as possible.

Very ill patients sometimes decide that they do not wish to be resuscitated if they have a heart attack. When this is the case, the specialists looking after the patient will clearly record this in the patient's notes — this is known as DNR (Do Not Resuscitate). A decision for DNR can be changed at any time.

# Summary

**It may be difficult to make decisions about treatment; sometimes these have to be made very quickly and this is particularly stressful. At all times the members of your healthcare team will be available to support you in making these decisions.**

Often specialists looking after a patient will clearly recommend one treatment in preference to others. Even in this situation, the final decision on treatment must be the patient's; if this applies to you, your specialists will explain what is involved in treatment and then request your consent. On other occasions, there may be two or more treatments with no clear medical grounds to prefer one to another. In this case, you will be given as much information as possible about the effects of different treatments on your quality of life.

It may help you to think of these decisions not as a stressful burden but as an opportunity to be in charge of the management of your own treatment. It may help to discuss the options with your family or with a trusted friend. At all times remember that, although the decision is yours, the health care team will always be glad to offer support and advice. Do not hesitate to ask questions of your specialist or other members of the team; the more information you have the more comfortable you are likely to be in making a choice.

Always remember that decisions can be re-considered at any time. Occasionally, treatment already received may change the options available to you. If this is the case your specialist(s) will discuss with you in detail the choices now available.

# Notes



The following patient information booklets are available free of charge from Leukaemia Research. You can download them from our website or request copies by phone or post (see form inside):

Leukaemia and Related Diseases

Acute Promyelocytic Leukaemia (APL)

Adult Acute Lymphoblastic Leukaemia (ALL)

Adult Acute Myeloid Leukaemia (AML)

Aplastic Anaemia (AA)

Bone Marrow and Stem Cell Transplantation (BMT)

Childhood Acute Lymphoblastic Leukaemia (ALL)

Childhood Acute Myeloid Leukaemia (AML)

Chronic Lymphocytic Leukaemia (CLL)

Chronic Myeloid Leukaemia (CML)

Complementary and Alternative Medicine (CAM) (from May 07)

Hodgkin's Lymphoma (HL)

Multiple Myeloma (MM)

Non-Hodgkin's Lymphoma (NHL)

The Myelodysplastic Syndromes (MDS)

The Myeloproliferative Disorders (MPD)

Clinical Trials

Chemotherapy – what do I need to know?

Donating stem cells – what's involved?

Donor Lymphocyte Infusion (DLI) – what's involved

Supportive care

The Seven Steps – Blood & Bone Marrow Transplantation

Treatment Decisions (from May 07)

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

**Leaflets on a range of associated blood disorders are also available**

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