Young Adults with a Blood Cancer

A guide for young adult patients, their families and friends

July 2011
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The Leukaemia Foundation also acknowledges the following groups who have provided invaluable updates on the content of this booklet for young Australians - people who have experienced a blood cancer as a young adult or as a carer, Leukaemia Foundation support services staff, nursing staff, clinical haematologists and oncologists (specialist doctors) representing the various states and territories of Australia.

July 2011
INTRODUCTION

This booklet has been written to help you and your family to understand more about the experience of blood cancer by young people in Australia.

Some of you may be feeling anxious or a little overwhelmed if you or someone you care for has been diagnosed with one of the blood cancers. This is normal. Perhaps you have already started treatment or you are discussing different treatment options with your doctor and your family. Whatever point you are at, we hope that the information contained in this booklet is useful in answering some of your questions. It may raise other questions, which you should discuss with your doctor or specialist nurse.

You may not feel like reading this booklet from cover to cover. It might be more useful to look at the list of contents and read the parts that you think will be of most use at a particular point in time.

We have used some medical words and terms which you may not be familiar with. Their meaning is explained in the booklet or you can refer to the glossary of terms available from the disease information section of our website.

In some parts of the booklet, we have provided additional information you may wish to read on selected topics. This information is presented in the boxes. Some of you may require more information than is contained in this booklet. We have included some internet addresses that you might find useful. In addition, many of you will receive written information from the doctors and nurses at your treating hospital.

It is not the intention of this booklet to recommend any particular form of treatment to you. You need to discuss your particular circumstances at all times with your treating doctor and team.

Finally, we hope that you find this booklet useful and we would appreciate any feedback from you so that we can continue to serve you and your families better in the future.
THE LEUKAEMIA FOUNDATION

The Leukaemia Foundation is the only national not-for-profit organisation dedicated to the care and cure of patients and families living with leukaemias, lymphomas, myeloma and related blood disorders. Since 1975, the Foundation has been committed to improving survival for patients and providing much needed support. The Foundation does not receive direct ongoing government funding, relying instead on the continued and generous support of individuals and corporate supporters to develop and expand its services.

The Foundation provides a range of free support services to patients and their carers, family and friends. This support may be offered over the telephone, face to face at home, hospital or at the Foundation’s office or accommodation centres, depending on the location and individual needs. The Foundation provides practical and emotional assistance to patients and carers, including access to information, education and peer support through a variety of programs.

The Leukaemia Foundation funds leading research into better treatments and cures for leukaemias, lymphomas, myeloma and related blood disorders. Through its National Research Program, the Foundation has established the Leukaemia and Lymphoma Tissue Bank at the Princess Alexandra Hospital and the Leukaemia Foundation Research Laboratory at the Queensland Institute for Medical Research. The Foundation also funds research grants, scholarships and fellowships for talented researchers and health professionals.
The Leukaemia Foundation has a team of highly trained and caring Support Services staff with qualifications and experience in nursing or allied health that work across the country. They can offer individual support and care to you and your family when it is needed.

Support Services may include:

**Information**

The Leukaemia Foundation has a range of booklets, fact sheets and resources such as this one that are available free of charge. These can be ordered via the form at the back of this booklet or downloaded from the website. Translated versions (in languages other than English) of some booklets and fact sheets are also available from our website.

**Education & Support programs**

The Leukaemia Foundation offers you and your family disease-specific and general education and support programs throughout Australia. These programs are designed to empower you with information about various aspects of diagnosis and treatment and how to support your general health and well being.
**Emotional support**

A diagnosis of a blood cancer/disorder can have a dramatic impact on a person’s life. At times it can be difficult to cope with the emotional stress involved. The Leukaemia Foundation’s Support Services staff can provide you and your family with much needed support during this time. They may refer you or a loved one to a specialist health professional eg psychologist if required.

**Online discussion forum**

The Foundation has established an on-line information and support group for people living with *leukaemia, lymphoma, myeloma,* or a related blood disorder. Registration is free and participants can remain anonymous, see www.talkbloodcancer.com

**Accommodation**

Some patients and carers need to relocate for treatment and may need help with accommodation. The Leukaemia Foundation staff can help you to find suitable accommodation close to your hospital or treatment centre. In many areas, the Foundation’s fully furnished self-contained units and houses can provide a ‘home away from home’ for you and your family.
**Transport**

The Foundation also assists with transporting patients and carers to and from hospital for treatment. Courtesy cars and other services are available in many areas throughout the country.

**Practical Assistance**

The urgency and lengthy duration of medical treatment can affect you and your family’s normal way of life and there may be practical things the Foundation can do to help. In special circumstances, the Leukaemia Foundation provides financial support for patients who are experiencing financial difficulties or hardships as a result of their illness or its treatment. This assistance is assessed on an individual basis.

**Contacting Us**

The Leukaemia Foundation provides services and support in every Australian state and territory. Every person’s experience of living with these blood cancers and disorders is different. Living with leukaemias, lymphomas or myeloma is not easy, but you don’t have to do it alone. Please call **1800 620 420** (Freecall) to speak to a local support service staff member or to find out more about the services offered by the Foundation. Alternatively, contact us via email by sending a message to info@leukaemia.org.au or visit [www.leukaemia.org.au](http://www.leukaemia.org.au)
MY DIAGNOSIS

Let’s face it, being told you have cancer at any time isn’t exactly great but at your age it can come as a hefty shock, to say the least.

To get rid of your cancer you’ll have some pretty nasty treatment and it will disrupt your life but it’s not all bad news. The outlook for a young person with a blood cancer is very promising:

• Most people your age recover fully from their blood cancer
• Your age means your body can cope better with the high doses of drugs needed to kill the cancer
• There are many Australians who have been cured of their blood cancers; working, having families and living normal lives.

So, your future is bright but you have some tough times ahead. Staying positive is the best thing you can do. There is no doubt that this will help you cope with the physical and emotional stress of your treatment.

Throughout this booklet there are comments from young people who have recovered from blood cancers, reflecting the important issues they had when they were ill.

“One thing that can be said for suffering from leukaemia is it makes you appreciate everything - even a bad-hair day!”

My diagnosis is:

My consultant is:

Telephone number:

My nurse is:

Telephone number:
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<th>Treatment summary</th>
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<td>Please use this space to record your treatments – it may be important for follow up.</td>
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HOW IS BLOOD MADE?

All the cells in blood start their journey in the bone marrow, which is the blood-producing factory where stem cells live. A stem cell is a ‘mother’ cell in that it divides to form the three main types of blood cell. These are the red blood cells, the white blood cells and the platelets. White blood cells can be either lymphoid cells (T cells and B cells) or myeloid cells (neutrophils are particularly important).

WHAT IS A BLOOD CANCER?

The production of blood cells is normally tightly controlled by the regulation of genes and their protein products. This control can go haywire, often with no identifiable reason. Sometimes when this happens, a blood cancer can develop. The type of blood cancer you have depends on the stage the cell had reached when the controls in the development process go wrong. Your doctor/care team will be able to explain this to you.

The blood cancers\(^1\) that most commonly affect young people are:

- Hodgkin lymphoma (HL)
- Non-Hodgkin lymphoma (NHL)
- Acute lymphoblastic leukaemia (ALL)
- Acute myeloid leukaemia (AML)
- Chronic myeloid leukaemia (CML)

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1. Publications about each of these blood cancers are available from the Leukaemia Foundation.
The abnormal cells in leukaemia are usually only found in the bone marrow and blood. In lymphoma the abnormal cells are found in the lymphatic tissues but in some people the bone marrow can also become involved.

There are a number of related conditions that affect the blood but these are not leukaemias or lymphomas. Most of them are extremely unusual in young people. Some of these conditions share symptoms with the blood cancers and some can transform into leukaemias.

Related conditions include:
- Aplastic anaemia
- Multiple myeloma
- Myelodysplastic syndromes
- Myeloproliferative disorders

**WHY DID I GET A BLOOD CANCER?**

We don’t usually know what has caused an individual person’s blood cancer but one thing is for certain; it is not your fault, you didn’t do anything wrong. Some important things to remember are:
- You cannot ‘catch’ blood cancers
- There is no evidence that it can be caused by anything you eat or drink
- Most blood cancers are not hereditary
WHAT DO I TELL MY FRIENDS AND FAMILY?

When you receive your diagnosis you may find it difficult to tell friends and family. It is important to remember that, like you, they will be confused and upset and may not know what to do to help. There is no right way to deal with your friends and family, after all you know them better than anyone. The important thing in any family is to talk about how you feel. Tell them how they can help, even if it is doing something ‘normal’ with your friends to take your mind off your disease or treatment.

“I felt really confused to start with as I had no symptoms except for being anaemic, then panic as I thought I was going to die. I had no idea what this cancer called ALL was, except that it was bad.”

“I felt resentful towards my best friend as she couldn’t cope with what my treatment did to me. I just wanted to talk about it, but she found it hard to listen…”
“Once I had been in hospital for a few days and I understood what was happening to me, I wrote a letter to my school to be read out in assembly to explain what was going on. It was really important to me that everyone heard from me as soon as possible as the news of my illness caused mini-hysteria throughout the school. I wanted to reassure everyone that I was OK.”

WHO WILL LOOK AFTER ME IN HOSPITAL?

You will be referred to a specialist doctor (consultant) and multidisciplinary team at your hospital who will work together to provide the best care possible for you.

The people who you will come into contact with are:

- Your consultant who coordinates your care – a specialist doctor
- Other doctors who assist your consultant
- A therapeutic radiographer if you have radiotherapy
- A specialty nurse who heads up a team of nurses
- Other specialised nurses possibly including a clinical nurse specialist who deals with one specific aspect of your care
Specialist Doctors or Consultants include:

**Haematologist** - a doctor who specialises in the care of people with diseases of the blood, bone marrow and immune system including those with blood cancers.

**Medical Oncologist** - specialises in chemotherapy to treat cancer

**Radiation Oncologist** - specialises in radiation to treat cancer

Sometimes different aspects of your treatment can take place in different hospitals. This is called ‘shared care’ and it means most of the time you can just go to your usual treatment hospital.

If you are a teenager, one important aspect of your care that may well vary between treatment centres is whether you are considered to be an ‘old child’ or a ‘young adult’. Specialist wards for young people are not normal in Australia but are being considered or planned for in some Australian treatment centres. You should certainly ask your consultant about this and what you can do to make your surroundings cheerful and encouraging.

**WHAT HAPPENS AFTER MY INITIAL DIAGNOSIS?**

Waiting for your treatment to begin can be a very frustrating time. Sometimes more tests have to be done to help your doctors decide what will be the best treatment for you. These tests will include a bone marrow biopsy, possibly for chromosome analysis. Other tests may include body imaging scans for staging lymphoma and a lumbar puncture.
Chromosome analysis – a test looking at the genetic make-up of your cancer cells. Particular genetic changes in the chromosomes may help your doctor decide on the best treatment for you. This test is usually done on the bone marrow cells or lymph nodes cells.

Staging – a description of how far a lymphoma has spread. Stage I disease is very localised whereas stage IV disease has spread beyond the lymphatic system.

Lumbar puncture – taking a sample of the fluid that surrounds your brain and spinal cord to look for leukaemia cells, using a needle to draw liquid from your lower back/spine. A local anaesthetic is given to reduce any discomfort.

HOW IS MY BLOOD CANCER TREATED?

You might have chemotherapy, radiotherapy or a combination of both. Some people also have a stem cell transplant. None of these are what you would call a pleasant experience but they are the best treatments available.

Every blood cancer patient is different; the exact treatment you receive, the length of your treatment and how it is administered is unique to you.
WHAT DOES TREATMENT DO TO MY BODY?

How does chemotherapy work?

Chemotherapy is the use of anti-cancer drugs to kill cancer cells. There are many different drugs but most work by killing cells that are growing and dividing. The faster cells are growing and dividing, the more effect the chemotherapy will have. The drugs you receive will depend on your type of cancer along with many other factors, including:

- Stage of your disease
- Age at diagnosis
- Genetic changes
- Gender - males may have longer treatments for some leukaemias
- Any other existing medical conditions

Quite often the drugs are given in combination to improve their effectiveness and reduce the chance that your cancer cells will become resistant to them.

Some drugs can be taken orally while some must be given intravenously (into a vein). Many people have a central line or PICC put in to avoid having numerous intravenous injections. You can talk to your doctor about where your line will go to make it as discreet as possible.

Central line or PICC – Even though doctors and nurses are very experienced in giving medication and taking blood having lots of intravenous injections can get painful. A tube (central line or PICC) can be put into a large vein, often in your chest or arm, so that drugs can be delivered and blood taken without lots of needles. The tip of the tube ends-up near the heart but the part where the drugs are injected can be placed in the chest, neck or arm.

It is important to consider where your central line is placed. You can request for it to be placed in a position comfortable for you eg. to avoid being under your seat belt; away from clothing which may rub eg. bra straps; and if you like to swim, a fully implanted device may be preferable. Ask your treatment team for your options.
It is very important that you follow ‘doctor’s orders’ and take the cocktail of drugs for as long as you have been told to. For some patients this can be a long time but it gives you the best chance of fighting your cancer.

What is central nervous system directed therapy?

A particular problem in acute lymphoblastic leukaemia is that cancerous cells can ‘hide’ in the fluid in the central nervous system (CNS - your brain and spinal cord). Many chemotherapy drugs cannot reach these cells so they can remain there leading to a risk of the disease relapsing.

Quite often, therapy is given as a preventative measure to prevent relapse. Unfortunately, not much of the chemotherapy given intravenously or orally can penetrate the CNS to target these ‘hiding’ cells so treatment also involves administration of drugs directly into the fluid surrounding the spine. This fluid also surrounds your brain.

Some patients also receive cranial irradiation (radiotherapy to the head) although this is becoming less common. In this procedure, radiation is used to kill the hiding leukaemia cells. If you have radiotherapy you may well get a condition called somnolence syndrome. This is characterised by nausea, depression, lethargy and drowsiness. It occurs during and after treatment and may get worse about four to six weeks after completion of treatment, but don’t worry as this side effect resolves itself within a few weeks.

“I got very severe headaches from my radiotherapy and a horrible taste in my mouth. My short-term memory was terrible too because of the treatment but luckily it is much better now. It was also pretty embarrassing, walking around with permanent pen marks on my face, like someone had done a dot-to-dot on my face while I was asleep and I didn’t know!”
What happens if I need a stem cell transplant?

If your blood cancer proves difficult to cure using chemotherapy you will need to consider having a stem cell transplant. You will be able to ask your care team as many questions as you like - they know how difficult it can be to make this decision.

But here’s the good news; as a young person you are in the group of adults best prepared to cope with a stem cell transplant. Stem cells are the primitive (immature) blood forming cells in the bone marrow. Sometimes these cells are collected from bone marrow; this is called a bone marrow transplant. Now it is more usual to stimulate stem cell release into the blood and harvest them from there; this is a peripheral blood stem cell transplant.

There are two types of stem cell transplant:

**Allogeneic** – Stem cells from a relative (preferably your brother or sister) or an unrelated donor from a volunteer database with the same tissue type are injected into your vein after intensive chemotherapy and/or total body irradiation.

**Autologous** – your own stem cells are harvested and stored before intensive chemotherapy and/or total body irradiation is given. The stem cells are then injected back into your vein.

Allogeneic transplants are better at eliminating leukaemia but carry an additional risk of a condition called Graft versus Host Disease (GvHD). These risks may be higher in those who receive transplants from an unrelated donor. GvHD isn’t all bad news; a little can be a good thing. This is because it comes hand in hand with the Graft versus Leukaemia (GvL) effect. This is where the donor cells attack any leukaemia cells that have survived the intensive treatment with chemotherapy and radiotherapy. This gives you an even better chance of beating blood cancer.

How does radiotherapy work?

Radiotherapy uses very high energy X-rays which are focused on tumours to kill the cancerous cells. This type of treatment is used quite commonly for Hodgkin lymphoma. Focusing of the beams on the tumour reduces the amount of radiation that passes through normal healthy cells. It is not used very often in leukaemia treatment.
because the cancer cells are spread throughout the body. This means that in order to kill them, high levels of radiation would be given to all healthy tissues as well.

The only time when the whole body may need to be treated with radiotherapy is prior to a stem cell transplant. This is called total body irradiation and you may hear doctors calling it TBI.

**What are new therapies?**

There has been a lot of progress in the treatment of blood cancers that make cure more likely and side effects milder. New drugs are being developed all the time although many do not turn out to be better than existing treatments. Your consultant or one of their colleagues will be aware of what new treatments are available and you should feel free to ask about your options.

Biological agents are relatively new treatments. The main ones are antibodies that recognise certain molecules (markers) on the surface of your cells. Different types of cells have different markers so the therapeutic antibodies are designed to specifically recognise and kill your cancer cells, although some cells with a similar make-up will also be targeted. Some of these antibodies have radioactive agents or toxins (special drugs) attached to make them more effective at killing the cells.

Other new novel therapies are also used in treating blood cancers. These work on targeting cell processes to effect the cell environment that causes the blood cancer.

You may receive a new therapy as part of a clinical trial.

**CLINICAL TRIALS**

Clinical trials (also called research studies) test new treatments or ‘existing’ treatments given in new ways to see if they work better. Clinical trials are important because they provide vital information about how to improve treatment by achieving better results with fewer side effects. In addition, clinical trials often give people access to new therapies not yet funded by governments.

If you are considering taking part in a clinical trial make sure that you understand the reasons for the trial and what it involves for you. You also need to understand the benefits and risks of the trial before you can give informed consent. Talk to your doctor as they can guide you in making the best decision for you.
What happens during a clinical trial?

Each study has a plan (protocol) that maps out the procedures of the study – what will be done, by whom, when and why. The protocol also explains who is eligible to participate in a trial and what is expected of each person. If you are eligible to join the trial, a team of doctors and nurses will manage your care. Trials are held at hospitals and research centres around the country and are categorised in four phases.

- Phase 1 trials determine the proper amount of a drug to be given to a patient (dosing) and major side effects.
- Phase 2 trials gather data on a treatment’s safety and benefits.
- Phase 3 trials test the treatment’s effectiveness, monitor side effects and compare the new product to an existing treatment to determine which is better.
- Phase 4 trials are conducted after a treatment has been approved by the Therapeutic Goods Administration in Australia. During this phase, researchers study the long-term risks, benefits and optimal use of the therapy.

Why are clinical trials needed?

Trials provide the scientific evidence that a treatment works. Without clinical trials, new treatments for diseases and conditions would not be discovered. Some clinical trials help to determine if a new treatment is safe and can improve the health of patients. Other trials compare a new therapy to an existing one to find out which is better at treating or preventing a disease.

Who sponsors clinical trials?

Clinical trials may be sponsored by drug manufacturers, government agencies, and patient support organisations. In addition, independent organisations or individuals, such as doctors, medical institutions, foundations and advocacy groups sponsor research studies.

Should I consider taking part in a clinical trial?

Before signing up, you should learn as much as possible about the trial that interests you. Then discuss your options with your doctor. Clinical trials are not right for everyone, nor is every patient able to participate in a trial. Before starting any trial, you should understand what will happen during the study, what is expected of you, the
type of care you will receive and the costs that you may have to cover. You will be asked to read and sign an informed consent form that details exactly what will happen during the study and what the risks may be.

**I was just diagnosed. Should I go into a trial now, or try other treatment first?**

You should discuss your options with your doctor, as there may already be approved therapies to treat your condition. It’s important to evaluate all of your options before starting any treatment. You might also like to consider getting a second opinion from another doctor.

**What are the benefits of participating in a clinical trial?**

Participation in a clinical trial gives you access to cutting-edge, potentially life-saving and life-enhancing treatments, as well as medical care from a team of researchers, doctors, and nurses. Your participation contributes to the advancement of medicine and helps others who share your condition.

**What are the risks?**

The risks depend on the type of treatment being studied and the health of the patient. For some people, there could be unpleasant, even serious, side effects. Often these side effects are temporary and end when the treatment stops. There are both known and unknown risks with any clinical trial. Be sure you understand the known risks before you join any study. Talk to your trial team about the risks.

**Isn’t it dangerous to take an experimental drug?**

Whilst most clinical trials involve some risk, researchers must follow strict scientific guidelines and ethical and legal codes to ensure that you are protected. Studies need to be approved by an Independent Ethics Committee (IEC) or Institutional Review Board (IRB), or an equivalent, depending upon the regulations of the country where the trial is being carried out. This committee – made up of scientists, doctors, and other people from the local community (e.g., consumer representative, ethics expert) – reviews each study to see that it is designed to protect the patient and to ensure that the benefits of the study outweigh the risks. In addition, each trial must meet the Good Clinical Practice (GCP) standard.
GCP is an ethical and scientific quality standard that ensures that the rights, safety and well being of study participants are protected.

**What will the cost be?**

Patients do not pay any money to participate in a clinical trial, over and above that required for standard treatment. Trial participants will receive free of charge the drug being tested. They may receive medical tests and their medical care related to the trial at no cost. They may also receive payment to cover other expenses such as parking and travel. Private insurers often do not cover the costs related to a clinical trial. You will need to check with your private health care provider to find out what, if any, costs will be covered.

**Will I still get regular medical care?**

As a participant of a clinical trial, you would receive excellent medical care from a team of doctors, nurses, researchers, social workers and other health professionals who are on hand to manage your condition. The trial’s protocol may require you to visit the study site more often to check in with your study doctor. Plus you may receive more tests and treatments than usual.

**How will I know if a trial is right for me?**

This is a decision best made by you and your doctor. Together you will need to evaluate the study options available to you, weigh the benefits and risks of each and then choose the one that’s right for you. Seek a second opinion if you are not sure.

**What if I get a placebo?**

If you want to join a clinical trial to receive a certain medication, you may want to reconsider participating. As a rule, trials of drugs for cancer do not use a placebo but rather participants receive an approved drug or the approved drug plus the drug being studied. In “randomised” trials (usually phase 3 trials), researchers use a computer to randomly decide who will get the real drug and who will receive the standard treatment. In a “blinded” trial, neither the researchers nor you will know if you’re receiving the experimental or standard drug. The randomised system ensures the process meets the scientific requirements of the trial.
If I start a trial, do I have to stay in it?

No, you can leave the trial at any time for any reason. Even if you signed paperwork at the start of the trial, you may still leave the study if you choose. You have the right to change your mind at any time.

Does my doctor have to participate (be one of the doctors involved in the trial) for me to be in a trial?

No, your doctor does not have to participate in the trial in order for you to join. Depending on the trial, trial researchers may provide you with care or they will want your regular doctor to care for you. Whether or not your doctor participates in the trial, you will need to see him or her for general medical care. Sometimes you may have to attend a different treatment centre and have a new doctor to participate in a trial.

How do I find out if I’m eligible?

Each study’s protocol has guidelines stating who can and cannot join the clinical trial. These guidelines (eligibility criteria), apply to anyone who wants to sign up for the study. The criteria vary by study and could include your age, gender, medical history, current health status and the particular type or stage of disease you may have. Before you join the trial, you will be asked to sign an informed consent form. Then a doctor or nurse will assess your medical history, perform a physical exam and perform laboratory tests to determine whether you meet the eligibility criteria.

Is everyone with my disease eligible?

No, only people meeting the study’s guidelines, or eligibility criteria, may join the study.

What if I’m not eligible?

If you are found to be ineligible, you should talk to your doctor to see if there is another clinical trial that may be right for you.

What would be required of me if I participate?

The doctor will first talk to you about “informed consent.” Informed consent is a process by which you will learn the details of the trial – what is involved, the purpose of the study, the tests and procedures that will be used, and the risks and benefits. You will
then be given a written consent form, which explains the study. If you agree to take part, you will be asked to sign the form. If there is something on the form you do not understand, ask questions. Study doctors and nurses are available to answer your questions and help you understand the risks and benefits of the trial. Even if you sign the consent form, you are free to leave the trial at any time for any reason.

**How long will the study last?**

The length of each study is different. If you are considering joining a trial, you will need to discuss the trial’s protocol with your doctor. That document will provide you with information on how long the trial lasts and what is expected of you.

**What happens at the end of the trial – will I still be able to receive the drug?**

After you complete the study, you may or may not be able to continue receiving the drug. In some cases the treatment will not be made available to you again until it is government-approved. Once the trial ends, researchers analyse the data to understand the safety and effectiveness of the treatment. If the study is considered a pivotal one and the results are positive they will be submitted to the national health authority for approval. During the approval process some pharmaceutical companies choose to continue to make the drug available through a pre-approval access program.

**How do I find a clinical trial?**

There are several ways to locate clinical trials in your area. First, talk to your doctor. He or she will be able to access an up-to-date listing of clinical trials. You may also want to call patient advocacy groups and local university medical centres to find clinical trials. A useful website to search for clinical trials in Australia is: www.australiancancertrials.gov.au.

The dramatic improvements in treatment of blood cancers in the past 20 years are a great example of steady progress resulting from clinical trials.
WHAT SIDE EFFECTS WILL I GET?

Cancer treatment 50 years ago was very different from today. Blood cancers were seen as virtually untreatable diseases but now survival rates are high and rising. This means the quality of life during and after successful completion of treatment has become increasingly important. So the challenge is to cure your cancer with the least possible side effects. Side effects include all the common stuff like being sick but also things like pain management, fatigue, depression and lifestyle issues.

Common short-term side effects include

- nausea and/or vomiting
- diarrhoea
- hair loss
- depression

Most side effects can be counteracted. You should discuss any side effects you experience with your care team; remember they are there to help. It can be useful to keep a diary of side effects to help your care team decide what is causing them.

“I always joked to my doctor that I was sure she had mixed up the blood test results and in fact they were someone else’s, as I never once got sick or was in pain.”

“I got so fed up of taking pills to counteract the side effects of other pills that counteracted the effect of yet more pills.”
Will I lose my hair?

Honestly, you will almost certainly lose your hair because of the high doses of drugs needed to fight most blood cancers that affect young adults, but it will grow back. Physical appearance is often seen as a minor consideration for cancer sufferers but for young people it can be very important.

There are options available such as:

- Wigs - some are available for hire or talk to Leukaemia Foundation support services co-ordinator
- Hats
- Headscarves
- Going au naturel

"Losing my hair was the worst side-effect for me, emotionally. I was so used to having long, dead straight hair that everyone was jealous of. When it started falling out I felt like I had lost control and I thought there must be something I could do to stop it. Of course, I couldn’t…"

"I wrapped my hair in a headscarf and my mum dealt with it. I covered the mirror in my room when she would wash it in the sink in case I got a glimpse of it. I wore a headscarf until I had 2mm of new hair. It was really exciting when my hair grew back, even though it was black and fine not thick and blond like it had been."

What can I do about pain?

Effective pain management can make the treatment of blood cancers much more bearable. For most people pain will not be a big problem but for those it affects there is no need to suffer in silence, in the belief that pain management will compromise
your treatment. On the contrary, evidence suggests good pain management can improve quality of life enormously. It is important to find out which pain medications you are allowed to take. For example, ibuprofen is often not allowed. Talk to your specialist, he/she will discuss with you the best options for managing your pain.

**Will treatment affect my eating habits?**

*I’m as sick as a dog!*

Treatment for cancer makes some people feel nauseous and vomit. This can be a very unpleasant side-effect but thankfully there are drugs called anti-emetics that work really well in controlling feelings of sickness or being sick. If you are prescribed these drugs you should take them as often as your doctor tells you too, even if you don’t feel sick, because this stops the nausea from returning. If the nausea is new or gets worse while taking the anti-sickness drugs you should let your doctor know straight away.

“At first chemotherapy made me really sick but my anti-emetics (anti-sickness drugs) worked wonders.”

**Good nutrition***

Chemotherapy and radiotherapy can cause you to lose your appetite or change the things you like to eat. This can lead to poor nutrition which in turn can lead to fatigue and susceptibility to infection. There are ways to combat poor nutrition if you have lost your appetite such as:

- Using high-energy drinks to gain a large number of calories without eating a bulky meal
- Having someone else prepare your food
- Eating small snacks regularly

It is still important to try to eat a healthy diet so that your body gets the right balance of food to help it stay strong and cope with your treatment. Your hospital dietician will be able to give you more ideas about how to make eating more appealing.

*The Leukaemia Foundation has also produced a booklet called Eating Well.*
Some of the treatments for blood cancers can make food taste different, for example some people describe a metallic taste after radiotherapy treatment. This can mean that what used to be your favourite food now tastes completely different.

“I lost a lot of weight despite eating about eight bags of salt and vinegar chips every day!”

“I didn’t lose my appetite - in fact I developed massive cravings for anything bacon flavoured!”

**Mucositis**

Chemotherapy can also cause a condition called mucositis that gives you a sore mouth. Cleaning your teeth at least three times a day with a soft toothbrush and avoiding mouthwashes that contain alcohol can reduce the symptoms of mucositis. Your doctor may prescribe a special mouthwash for you. You should also avoid alcoholic drinks and smoking as these activities will make the mucositis worse.
The worst point of my treatment was getting mucositis. I couldn’t eat or drink for days…. but having got through that, I could get through anything.”

Why am I feeling so sleepy?
During your treatment you may experience fatigue. This means exhaustion that doesn’t get any better, no matter how much sleep you have. This can be especially tough for a young person, as you see your friends in the prime of life while you seem to have been put on hold. There are lots of reasons for fatigue and it really can interfere with everyday activities. Biological causes behind fatigue can include anaemia, lack of sleep, poor nutrition or infection.

**Anaemia** – a lack of functioning red blood cells due to the cancer or its treatment. Symptoms of anaemia can be reduced by blood transfusions and the number of these required varies from patient to patient.

“I found it really weird watching someone else’s blood going into my vein. I almost didn’t want it but I felt so much better afterwards.”

“Some days people had to fight with me to get me out of bed. It was so frustrating not having the energy to do anything. The blood transfusions really helped though.”

Alongside these biological causes are psychological causes of fatigue such as depression. The important message here is that there are ways of combating fatigue, whether it be transfusions that reduce anaemia, counselling to ease depression or advice from the hospital dietitian. Studies have shown that gentle aerobic exercise
can alleviate symptoms and encourage better moods in people who have fatigue that persists both during and after the completion of treatment.

**Why do I get more infections now?**

As if your body hasn’t taken enough of a battering from your treatment, you are also more likely to get infections. This is because chemotherapy will cause neutropenia which is a lack of infection-fighting white blood cells. This condition leads to a reduced immune protection, especially against bacteria and fungi. For this reason, diet and food preparation are very important. You may need to have special menus or a ‘clean diet’ to help minimise the risk of infection. Speak to the hospital dietician or your specialist for more advice.

If you are neutropenic, you must let your doctor or nurses know immediately if you:

- Have a temperature of 38°C or higher and/or an episode of uncontrolled shivering
- Feel generally unwell
- Have a sore throat or a cough
- Have diarrhoea/or severe constipation
- Have unusual vaginal discharge or itching
- Are uncertain about anything, or if anything is worrying you

Some drug therapies can be given to reduce the severity of infection but it is very important that you are sensible about monitoring your temperature, as these drugs cannot prevent infections.

“Once when I was neutropenic and had a high temperature I didn’t tell my parents because I didn’t want to go back to hospital.”
“At a hospital check-up I mentioned that I wasn’t feeling too well so they admitted me on the spot!”

You might think these precautions seem rather extreme but an infection that would make someone with a healthy blood count feel a little off-colour can be life threatening for a neutropenic patient. Your care team will advise you about how to avoid infections. You should take precautions such as regular hand washing and avoiding friends or relatives who have an infection.

**Chemo and my kidneys**

Chemotherapy is pretty toxic stuff. When the cancerous cells die they release high levels of uric acid. Our body makes this waste product normally but the quantities produced during the first course of chemotherapy are poisonous and can damage the kidneys. If this is a problem for you, you will be given a drug to protect the kidneys. It is also very important that you drink plenty of fluid to prevent damage to your kidneys. Some chemotherapy drugs and other medicines (eg certain antibiotics) can also affect your kidney function, so your doctors will monitor this closely.
LIFESTYLE

How do I get along with my family?

For most people with cancer, the family becomes an important support network. They’ll want to help you out when you are feeling tired or ill. This can mean a life-changing time for you and your family that can lead to feelings of guilt, anger and frustration. Every family has their own way of coping with these feelings but whatever that is make sure you don’t bottle all your feelings up. Talking to your friends or a counsellor can really help.

And, just because you have cancer doesn’t mean you won’t still have arguments about the normal stuff with your families too!

Some drugs, called steroids, can make you feel grumpy. This can affect your relationships with family and friends. It will be easier to deal with this if you explain that the drugs are to blame for your bad mood and not them.

“I used to feel so bad when I would cry and complain because there was nothing I could do to make me well again. My mum couldn’t say or do anything….I just wanted to express my feelings.”

“My mum took a year off work to look after me, initially living in hospital with me. We got so fed up with each other because we were together all the time but I have a different respect for my mum now. I know what she sacrificed for me.”
A relationship can be another important support when you are diagnosed and are having treatment. A boyfriend or girlfriend or spouse can be a good person to talk about hopes and concerns.

“I was in a relationship all the way through my diagnosis and treatment. It only affected us when I had to go away to have a stem cell transplant. Other than that our relationship became stronger.”

Who gets to make the decisions?

Some parents find it hard to let their children make decisions about their treatment, even when they are young adults. In other families, the person with cancer wants their family to be part of the decision-making process. It is really important to discuss issues like this with your family and let them know to what level you would like them to be involved. Do not be afraid to say what you really think when important decisions are being discussed.

“My mum always made sure that the doctors were talking to me, not her. It really annoyed me when the doctors treated me like a child.”

Will it affect my siblings?

Brothers and sisters, especially those who are younger than you, can find it very difficult to cope with your cancer diagnosis. The attention that you need from the rest of your family can make siblings confused and resentful.
“For six weeks my sister didn’t really see my mum and she began to really resent me. She didn’t act like there was anything wrong until her teacher called my parents into school because she had written an essay about how much she hated me and how she wished that she could be ill too so that people would talk to her. When I found that out I felt so bad. If I had known I would have made so much more of a fuss of her and so would my parents. We were all so caught up with what was going on with me that we didn’t stop to make sure she was coping too.”

Many families say that the experience of cancer in the family really brings them closer and makes them realise how lucky they are to have each other.

“Things are great between my sister and I now—we are the best of friends but I wish we had all understood her more when she was eleven.”

What about my education?

Secondary school

The treatment for blood cancers, as with many types of cancer treatment, will inevitably change your everyday routine. This can limit the time and effort you can put into school or college work. Someone will need to liaise with your school about any special requirements you have such as diet. This person can be:

- You
- A parent or other relative or partner
- A specialised support nurse, social worker or other member of the treating team.
The contact at your school may be:

- A school nurse, counsellor or pastoral care teacher
- A class, house or designated teacher with whom you feel comfortable
- Your personal tutor

You can decide who knows about your illness. However, you should bear in mind who needs to know. For example, if there is a rule about not wearing hats at school, it would be useful to let the teachers know why you would like to wear one in advance to avoid any uncomfortable misunderstandings.

One of the most important things your school/college needs to know is how to deal with infections, especially chickenpox. It is vital that you do not come into contact with someone with chickenpox so the school should set up an ‘alert system’ and always get other students’ parents to inform the school if their child has chickenpox and keep you informed.

You can discuss with your teachers/tutors a plan for your education while you are being treated for blood cancer. It may include flexible timetabling so you only have to go to school for core subjects or if you are preparing for exams then you can devise a schedule to attend the most important lessons, or when you feel that you are able.

“I kept in touch with my school regularly with letters and video when I was in hospital and my nurse explained what precautions they should take.”

“My personal tutor at college was amazing; organising exam concessions and helping me to stay up to date as I was only well enough to attend about 50% of the time. I also had a note-taker in all my lessons which made college much less strenuous.”
Throughout the entire treatment process, you are still part of your school/college, even if you are not there all the time. Your teachers should provide you with schoolwork if you feel up to doing it. Friends from school/college can provide a great support network, helping to keep you on the ball with your studies.

If you miss a lot of lessons you may be asked to retake that year at school, although this is avoided whenever possible.

“I had to take a year off school the first time round and five months off during grade 12 when I relapsed. I had to work really hard.”

Going off to college or university can be quite daunting for anyone but it can be really scary if you’ve just been treated for cancer. Some people find they feel more attached to their families after their treatment and opt to study closer to home while others see going away from home as a chance to regain independence. Either way, it doesn’t just have to be a scary time; it can be exciting too.

**Tertiary Education (University, TAFE etc)**

Treatment for blood cancers will cause a disturbance to your everyday routine but that doesn’t mean you will have to give everything up. Universities have a reasonably flexible timetable and much of the study can be carried out with minimal guidance. It is essential to keep your personal tutor informed so that they can offer you the greatest amount of support possible. The student union can be a good place to look for advice and support too.

As a university student you will find it relatively easy to defer for a year if necessary. Many students do study-years abroad or a year in industry and re-enter their course with a different group of peers. While this may appear daunting, there will be many other people in a similar position.
“I deferred for one year while I was having my treatment. Although my friends were still at University, when I went back, I made a real effort to get to know the people in my year as I was aware that the next year my old friends would have moved on.”

What about work?

You will almost certainly need time off work while you are being treated for a blood cancer. As a cancer patient you are protected under the Disability Discrimination Act 1992 and the Human Rights Commission and Equal Opportunity Commission can assist you. These laws also protect you against discrimination by prospective employers in the future. Improved knowledge and education about blood cancers mean that discrimination is much less common but it is still something to be aware of.

It might be possible to claim a disability living allowance so it is worth speaking to a social worker, Centrelink or support services staff at the Leukaemia Foundation.

Your employer is obliged to make reasonable allowances for you while you are receiving your treatment so that you can either take some time off or have a more flexible working pattern. It can be very helpful to talk about your disease and treatment with your colleagues and boss; explaining how long you think it will last and what tasks you think you’ll be able to do. If you have important projects or deadlines you could choose a ‘work-partner’ for each of them so that still gets done if you have to take time off. A system like this also takes a lot of pressure off you. A Leukaemia Foundation Support Services Coordinator can assist you with these discussions.

Try keeping in touch with friends and colleagues from work to let them know how you are. A quick e-mail or phone call can help reassure everyone that you are coping and have every intention of coming back to work.
Can I have sex?

At some times during your treatment you may be advised by your doctor that it is not safe for you to have sexual intercourse. This is because you are more prone to bleeding. If you are having sex it is sensible to use a water-based lubricant to minimise the risk of excessive bleeding.

Your treatment team may want you to reach a certain blood count before they think it is safe to resume sexual activity. Again, advice will vary from person to person.

No one should try to get pregnant during treatment for blood cancers because the anti-cancer drugs used in your treatment are toxic and damage the DNA which makes up your genes. Therefore there is a real risk of causing harm to the baby. For the same reason, men should not try to become fathers during treatment because the drugs can damage sperm and increase the chance of abnormalities in the baby. Birth control should be used until your specialist has advised that it is safe to try to get pregnant.

“I was in my first proper relationship and had just started having sex before my diagnosis. I would like to have been told when I could have sex again but no one ever spoke to me about it. I was put on the pill to stop me from having periods, which could cause excessive blood loss, but that was the only thing I was told.”

One of the consequences of fatigue and/or anaemia is a lack of sex drive in males - some of whom may have difficulty in achieving an erection. Although this can be a rather embarrassing topic to discuss either with your partner or health-care workers there is plenty of advice available that will help you in your unique situation. Women can also lose their sex drive during cancer treatment. Again there is lots of information and advice available from specialists, books and the Internet.
Can I drink alcohol?

There are many different views regarding whether or not you can drink, and how much, whilst you are receiving chemotherapy. Some drugs though, must be taken on a strictly no alcohol basis. Your doctor will let you know when it is safe to drink again. Where drinking alcohol is allowed, moderation as always, is the key. Unfortunately, that means self-control for a while for the party animals amongst you!

“I wasn’t allowed to drink any alcohol while I was taking my chemotherapy drugs. It made parties a little boring but I spent so much time feeling ill that I didn’t want to risk a hangover anyway.”

Will I be able to get insurance?

Some survivors of cancer, including blood cancer, can find it very difficult to get life and even travel insurance because of their health history. You are obliged to disclose your cancer and treatment when applying for insurance otherwise the policy becomes void.
What about travelling?

When you are in remission you still have to attend regular check-ups, so when is it OK to go travelling? Your consultant is the best person to ask about this and will be able to tell you when it is safe for you to go overseas and help you to organise appointments while you are away if needed.

Parents are normally a little scared when their children decide to skip-off around the world but when they do this after having blood cancer; terrified is a more appropriate description! Explain why you want to go travelling and ask your consultant to reassure your family that it is as safe as it can be for you to go.
FOLLOW-UP

The journey continues...

Getting the ‘all clear’ after your treatment isn’t the end of the story. Follow-up is extremely important for all cancer survivors and as a young person you should attend follow-up care for many years, although local clinics organise things differently from each other. You may never experience any long-term effects of your treatment but these are some of the things your doctors will check:

Fertility

Will I be able to have children when I decide to?

As a young person, becoming a mother or a father may have been the last thing on your mind even before you were diagnosed but you need to know that some chemotherapy and radiotherapy regimes can compromise fertility in both men and women. If you haven’t had total body irradiation the chances are that your fertility will not be affected in the long run but ask your specialist about the impact of your treatment on fertility and any options that are open to you.

Unfortunately, nearly all people who have total body irradiation prior to a stem cell transplant lose their fertility. There is no way to preserve fertility in these cases but when the decision to transplant is made, it is because it gives the best chance of cure for the patient.

Some therapies may also contribute to reproductive problems. In some women it can cause ovarian failure and lead to early menopause. This may require treatment with hormone therapy.

“One of the hardest things for me to accept was the possibility that I might not be able to have kids in the future.”
CAN ANYTHING BE DONE?

Men can have their sperm frozen to be used at a later stage as part of IVF. This option should be offered to all males at diagnosis. For women the options are fewer and less routinely practiced, usually because they take much longer than sperm collection. For women who have a steady partner or husband, it is possible to harvest the eggs and fertilise them with the partner’s sperm. The resulting embryos can then be frozen and stored for use as part of IVF in the future. This is much more effective than simply freezing a woman’s eggs. Freezing of ovarian tissue may be available to some women as part of a clinical trial but this is far from routine practice.

Sometimes there is just not enough time to consider procedures to preserve fertility because rapid treatment is the priority. If this is the case you may want to discuss your options with your doctor further down the track.

“I was offered fertility testing after I recovered but I declined because it is not an issue for me at the moment.”

“It wasn’t until this year when I went for my annual check-up that my doctor asked if anyone had ever spoken to me about fertility. It was only then that she said that the treatment I had probably hasn’t affected my fertility.”

Does my treatment affect the chances of me having a healthy child?

People who have had chemotherapy and radiotherapy often voice concerns 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 in their offspring.
Thyroid function

Radiotherapy to the neck area can sometimes cause damage to the thyroid gland. This is the gland responsible for controlling your metabolism. If it is not functioning properly, a simple daily tablet may be needed to correct the problem.

Secondary cancers

Long-term complications that can occur following treatment for blood cancer include secondary cancers but, thankfully, these are rare. The risk of developing a secondary cancer depends on many factors including:

- Type of treatment received
- Age at diagnosis
- Your sex
- Time since completion of therapy
- Genetic risk factors
- Acquired risk factors e.g. smoking – especially in those who have received radiotherapy to areas including the lungs.

Breast cancer is the most common secondary cancer following treatment for a leukaemia or lymphoma; especially in women who have received radiotherapy to the chest during treatment of lymphoma. Although all women are advised to perform self-breast examinations, it is even more important following the completion of treatment. There are many sources of information detailing when and how a breast examination should be performed.

Heart complications

Some chemotherapy drugs (anthracyclines) can have adverse effects on heart tissue, such as the weakening of muscle. This means that your heart must work much harder to keep up with the demands of your body. Follow-up is important if you have received this type of drug. You may need regular scans if your consultant finds evidence of heart disease.
Weakening of heart muscle doesn’t have to mean a complete lifestyle overhaul, but it does mean that certain sporting activities are not recommended. These include physically demanding sports such as rugby and weight lifting. Activities such as dance, swimming or tennis are encouraged.

**Dental problems**

Radiation to the mouth area can cause an increased risk of dental decay. It is important to attend regular check-ups and inform your dentist that you have had treatment. Generally, problems resulting from lower face irradiation are more severe in children rather than young people, but it is still sensible to be vigilant about dental care.

**WHAT ABOUT MY FUTURE?**

Overall the outlook for a young person with a blood cancer is very promising. The side effects of treatment can be managed and with follow-up for long-term survivors, you have every chance of beating blood cancer. Should you have any concerns or queries, please talk to your doctor, nurse or Leukaemia Foundation support services co-ordinator.
USEFUL WEBSITE LINKS AND OTHER CONTACTS

- Leukaemia Foundation - www.leukaemia.org.au

Information for children

- Challenge Cancer Support Network - www.challenge.org.au
- Children with Leukaemia (UK) - www.leukaemia.org
- Children’s Cancer Web - www.cancerindex.org/ccw/guide2oz.htm
- After Cure (UK) - http://www.aftercure.org
- Children’s Cause for Cancer Advocacy - http://www.childrenscause.org/

Resources for Adolescents and Young Adults (AYAs)

- CanTeen - www.canteen.org.au
- I’m too Young for This - http://imtooyoungforthisthis.org/
- Planet Cancer http://www.planetcancer.org/
- Prepare to Live - www.preparetolive.org
- Teens Living with Cancer http://www.teenswithcancer.org
- Look Good Feel Better - www.lgfb.org.au
- Cancer and Fertility - http://www.cancerandfertilitysociety.org/
- Leukaemia Foundation on-line support group - www.talkbloodcancer.com

Cancer-related websites

- Cancer voices - www.cancervoices.org.au
- Australian Bone Marrow Donor Registry - www.abmdr.org.au
• Association of Cancer Online Resources - www.acor.org
• Can Survive - www.can-survive.org
• Virtual Cancer Centre - www.virtualcancercentre.com
• National Cancer Institute (US) - www.cancer.gov/cancerinfo/eatinghints
• The Lance Armstrong Foundation – www.livestrong.org
• American Cancer Society - www.cancer.org
• Australian Cancer Trials Registry – www.australiancancertrials.gov.au
• The Cancer Council Australia – www.cancercouncil.com.au

Caring for others
• Carers Australia - www.carersaustralia.com.au
• Young Carers - www.youngcarers.net.au
• Living Caring Working - www.livingcaringworking.com
• Working Carers Support Gateway – www.workingcarers.org.au

Mental Health
• Beyond Blue - www.beyondblue.org.au

Relationships
• Relationships Australia - www.relationships.com.au
Please send me a copy of the following information booklets:

- Eating Well: A practical guide for people living with leukaemias, lymphomas and myeloma
- Living with Leukaemias, Lymphomas, Myeloma & Related Blood Disorders: Information & Support
- Understanding Leukaemias, Lymphomas, Myeloma and Related Blood Disorders
- Understanding Acute Lymphoblastic Leukaemia in Adults
- Understanding Acute Lymphoblastic Leukaemia in Children
- Understanding Acute Myeloid Leukaemia
- Understanding Allogeneic Transplants
- Understanding Amyloidosis
- Understanding Autologous Transplants
- Understanding Chronic Lymphocytic Leukaemia
- Understanding Chronic Myeloid Leukaemia
- Understanding Hodgkin Lymphoma
- Understanding Non-Hodgkin Lymphomas
- Understanding Myelodysplastic Syndromes
- Understanding Myeloma
- Understanding Myeloproliferative Disorders
- Young Adults with a Blood Cancer

Or information about:

- The Leukaemia Foundation’s Support Services
- Workplace giving
- Regular deduction scheme
- National fundraising campaigns
- Volunteering
- Receiving the Foundation’s newsletters

Name: ...........................................................................................................................
Street or Postal Address: ...................................................................................................
Suburb ................................................................................................................................
State/Postcode ..................................................................................................................
Email: .......................................................... Tel: (...).....................................
Please send to:
Leukaemia Foundation, GPO Box 9954, In Your Capital City
or Freecall 1800 620 420
or email: info@leukaemia.org.au
Further information is available on the Leukaemia Foundation’s website
www.leukaemia.org.au
Young Adults with a Blood Cancer

A guide for young adult patients, their families and friends

This information booklet is produced by the Leukaemia Foundation and is one in a series on blood cancers and related disorders.

Some booklets are also available in other languages. Copies of this booklet and the other booklets can be obtained from the Leukaemia Foundation in your state by contacting us on

Freecall: 1800 620 420
Email: info@leukaemia.org.au
Website: www.leukaemia.org.au

The Leukaemia Foundation is a non-profit organisation that depends on donations and support from the community.

Please support our work by calling 1800 620 420 or by mailing your donation to:
The Leukaemia Foundation
GPO Box 9954
in your capital city

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