Why Did I get sick?

What treatment do I need?

How is chemo given?

Where do I go for support?

MY GUIDE to BLOOD Cancer

Who will be my doctor?

When do I go to hospital?

Leukaemia & Blood Foundation
Vision to Cure - Mission to Care

CONTENTS

The Leukaemia & Blood Foundation is grateful to Air New Zealand for sponsoring this booklet. AIR NEW ZEALAND

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My diagnosis

Being told you have a blood cancer at any time is not great, but at your age it can come as a huge shock. The treatment you will receive to fight your blood cancer will not be easy. Although it will disrupt your life, it is not all bad news. The outlook for a young adult 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 young New Zealanders who have been cured of their blood cancers, working, having children 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.

> "ONE THING THAT CAN BE SAID FOR SUFFERING FROM LEUKAEMIA IS IT MAKES YOU APPRECIATE EVERYTHING – EVEN A BAD-HAIR DAY!"

The information contained in this booklet is specifically for young adults and the important issues that are unique to you. You may not wish to read this booklet from cover to cover. It might be more useful to look at the contents and index and read the section which is most relevant to you at the time.

Your parents, families, whānau and friends are also encouraged to read this booklet to gain some understanding of what you may experience.

It is not the aim of this booklet to discuss any disease specific information. The Leukaemia & Blood Foundation (LBF) have a series of disease specific booklets which are available free of charge from your treatment centre, or by contacting LBF using the details on the back of this booklet.

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

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 of development the cell had reached when the controls in the development process go wrong. Your medical team will be able to explain this to you in more detail.

The blood cancers that most commonly affect young adults are:

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

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 (also known as lymph nodes or glands) but in some people the bone marrow can also become involved.

There are also a number of related conditions that affect the blood but these are not leukaemias or lymphomas. Most of them are extremely unusual in young adults. Some of these conditions have similar symptoms to blood cancers and are treated in a similar way.

Related conditions include:

- Aplastic anaemia
- Myelodysplastic syndromes
- Myeloproliferative disorders

For more information please see the Leukaemia & Blood Foundation booklet relevant to your condition.

My diagnosis is: ____________________

My treatment centre is: ____________________

My consultant is: ____________________

Telephone number: ____________________

My AYA worker is: ____________________

Telephone number: ____________________

Why did I get a blood cancer?

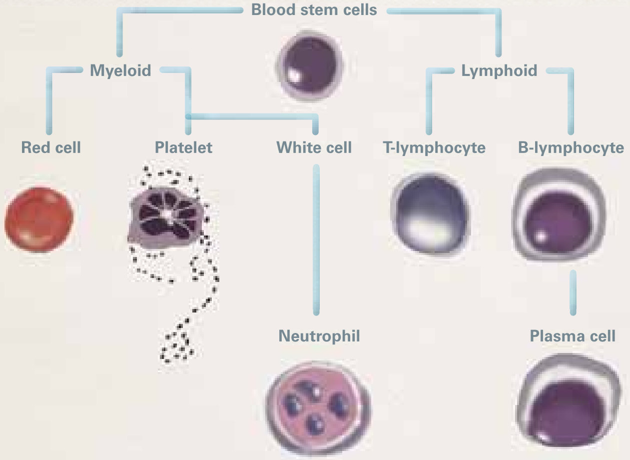
We do not usually know what has caused your blood cancer but one thing is for certain, it is not your fault, you did not do anything wrong. Some important things to remember are:

- You cannot ‘catch’ blood cancers
- There is no evidence that blood cancers can be caused by anything you eat or drink
- Most blood cancers are not hereditary (passed on from your parents or to your children)

How is blood made?

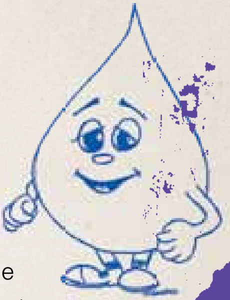
All the cells in blood start their journey in the bone marrow, which is the blood-producing factory where stem cells live. First there is a stem cell (or a ‘parent’ cell) that then divides to form the three main types of blood cells, red blood cells, white blood cells and platelets. White blood cells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

Blood cells



What happens after my initial diagnosis?

Waiting for your treatment to begin can be a very frustrating time. After the initial diagnosis there are often many other tests that help show more about what’s going on with your blood cancer. These tests may include CT scans, bone marrow biopsies, lumbar punctures and genetic testing (done from blood or bone marrow samples). The result of these tests will be really important when your doctor discusses your treatment options. It may also take several days to get the practical side of things sorted out, for example getting your ‘central line’ put in (see page 12).



Genetic analysis – blood tests screening parts of your genetic code (chromosome and molecular tests) to identify the genetic features of your blood cancer and help you plan your treatment.

Staging – a description of how far a lymphoma has spread. Stage I disease is localised whereas stage IV disease has spread beyond the lymphatic system. Staging is not as relevant to leukaemias.

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

How will my blood cancer be treated?

You might have chemotherapy, radiotherapy or a combination of both. Some people also have a stem cell transplant. None of these are pleasant experiences but they are the best treatments available to fight blood cancers.

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.

It is very important that you follow your doctor’s advice and take all the medications for as long as you have been told to. For some of you this can be a long time but it gives you the best chance of fighting your cancer.

Will I have to stay in hospital?

You might hear your doctors talking about being an ‘inpatient’, this means that you stay in hospital. Being an ‘outpatient’ means that you visit a day ward or outpatient department for treatment but you are able to go home afterwards. While there are times you will have to stay in hospital as an inpatient during treatment, how often and for how long depends on your cancer type, treatment regime and how well you are.

Which hospital will I be treated at?

Blood cancers require specialist treatment, which can only be offered in some of the bigger towns and cities of New Zealand. This means that you may need to travel to the centre nearest to where you live for your treatment. Or you may have ‘shared care’ which means you have some treatment at the specialist hospital and some at your local hospital.

If you have to travel and stay away from home (relocate) for treatment, you will be able to bring a support team with you, for example your Mum, Dad, partner or friend. Your treatment centre will also help to organise accommodation for your support team, so they can stay close by.

Currently there are no specialised wards for young adults in New Zealand although there may be dedicated rooms in some of the wards in the hospitals.

Who will look after me in hospital?

Trying to understand who will be looking after you in hospital can be very confusing.

Depending on your age and your location your treatment will be either under the care of the paediatric (children's) or adult cancer services. You will be referred to either a haematologist or oncologist.

Haematologists are doctors who specialise in the care of people with diseases of the blood, bone marrow and immune system. People with leukaemia will be treated by haematologists.

Oncologists are doctors who specialise in the treatment of solid tumor cancers. A medical oncologist specialises in chemotherapy. A radiation oncologist specialises in radiotherapy and a surgical oncologist specialises in surgery.

Lymphoma patients can be treated by either type of doctor, but your treatment will be the same regardless of which team is looking after you.

WHAT DO THEY DO?

The people who you may come into contact with are:

Anaesthetist	specialised doctor who helps you to sleep through an operation
Adolescent and Young Adult (AYA) Key Worker	specialised nurse or social worker who helps young people with cancer
Clinical Nurse Specialist	specialised nurse who assists with aspects of your care
Consultant / Specialist	specialised doctor who coordinates your care – includes haematologists and oncologists (see above)
Dietician	gives advice about your food requirements
Hospital Teacher	helps with continuing your education
House Officers	doctors who will assist with your care
Occupational Therapist	works with you on aspects of daily living in your environment
Phlebotomist	takes blood samples from your veins
Physiotherapist	works with you to help prevent/treat problems with your muscles and joints
Play Specialist	helps to cope with diagnosis and treatment
Psychologist	specialised health professional to help you cope with emotional issues and problems
Radiation Therapists	technicians who give radiotherapy treatment
Registrars	doctors who work with your consultant
Social Worker	provides emotional and practical support for you and your family or whānau
Staff Nurses	nurses at the inpatient ward, day ward and outpatient department

Section summary

- Most people your age survive their blood cancer
- We do not know why blood cancers develop but it is not your fault
- You cannot catch a blood cancer
- There is no evidence it is caused by anything you drink or eat
- Most blood cancers are not hereditary
- You might have chemotherapy, radiotherapy or a combination of both treatments for your blood cancer. The exact treatment you receive, the length of your treatment and how it is administered is unique to you
- Blood cancers require specialist treatment you may find that you need to travel to a bigger town or city for your treatment. You will be able to take a support team with you like your Mum or Dad.
- Depending on your age and type of blood cancer your treatment will be overseen by either the paediatric or adult cancer service. Within these services your doctor maybe a haematologist (specialises in blood, bone marrow and immune system) or an oncologist (specialises in the treatment of solid cancers). Your treatment will be the same regardless of which specialist is looking after you.

MY TREATMENT

New therapies

There has been a lot of progress in the treatment of blood cancers. New drugs are being developed all the time although many do not turn out to be better than existing treatments. Your doctor will be aware of what new treatments are available and you should feel free to ask about your options.

Standard treatment

This refers to treatment which is commonly used in particular types and stages of blood cancers. It has been tried and tested (in clinical trials) and has proven to be safe and effective in a given situation.

Clinical trials

Your doctor may ask you to think about taking part in a clinical trial (also called a research study). Clinical trials 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. Being in a clinical trial may also involve giving blood or bone marrow samples in order to gain a better understanding of your blood cancer.

Clinical trials often give people access to new therapies not yet funded by governments. Taking part in a clinical trial is up to you. You are under no obligation to take part. Your treatment will not be compromised if you decide not to participate. If you are thinking about taking part in a clinical trial, make sure that you understand the reasons for the trial and what it involves for you. You should always take time to think about all aspects of the trial and discuss this thoroughly with your doctor and other support people before giving your informed consent. Your doctor can guide you in making the best decision for you.

There is a separate information booklet about clinical trials available from the Leukaemia & Blood Foundation.

Informed consent

Giving your informed consent means that you understand and accept the risks and benefits of a proposed procedure or treatment. It means that you are happy that you have all the information to make such a decision.

Your informed consent is also required if you agree to take part in a clinical trial, or if information is being collected about you or some part of your care (data collection).

In New Zealand if you are under 16, the written agreement of your parent or guardian may be needed for certain treatments. This written agreement is known as a consent form. If you are 16 or over you can sign your own consent.

If you have any doubts or questions regarding any proposed procedure or treatment, please do not hesitate to talk to your doctor again.

WHAT TREATMENT WILL I HAVE?

What is chemotherapy (chemo)?

Chemotherapy literally means therapy with chemicals. Many chemotherapy drugs are also called cytotoxics (cell toxic) because they kill cells, especially ones that multiply quickly like cancer cells. How much, the timing and types of drugs used will vary depending on your blood cancer, your age, your general health, and the treatment protocol you will be following.

Chemotherapy regimes usually involve a combination of drugs (combination chemotherapy). The names of different combinations of drugs are commonly made up of the first letters of the name of each of the drugs used.

For example **ABVD** chemotherapy (**A**driamycin, **B**leomycin, **V**inblastine and **D**acarbazine) is commonly used to treat Hodgkin lymphoma (HL).

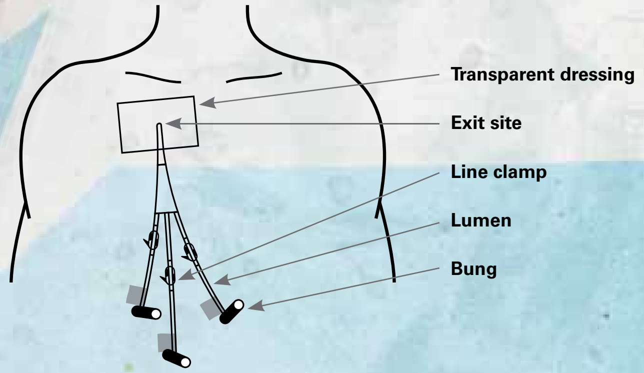
Chemotherapy is usually given in several cycles (or courses) with a rest period of a few weeks in between each cycle. This is to allow the body time to recover from the side effects of chemotherapy. For example a typical chemotherapy regime for acute myeloid leukaemia (AML) might involve four to five cycles of a combination of drugs, given over a period of about six months.

How is chemotherapy given?

There are many ways of giving chemotherapy. It is usually given through a vein (intravenously - IV), in your arm or hand. Chemotherapy can also be given in tablet form, for example, if you have chronic myeloid leukaemia (CML) you may be given a tablet called Glivec.

If you are having several cycles of chemotherapy, your doctor may talk to you about having a central venous catheter (also called a CVC or central line) or portacath inserted. A central venous catheter is a special line inserted through the skin into a large vein in your arm, neck or chest. Once it's in place, chemotherapy and any other IV drugs can be given through the line and blood tests can also usually be taken from the line, without the need for frequent needles in your arms. There are several different kinds of central lines; some are intended for short term use while others remain in place for months or even years. Some examples of different types of central lines include: Hickman line, Peripherally Inserted Central Catheter (PICC line) and Groshong line.

Hickman line



Chemotherapy and kidneys

When cancerous cells die they release high levels of uric acid. Your body makes this waste product normally but the quantities produced during chemotherapy, particularly in the early phases, are very high and can damage your kidneys. If this is a potential problem for you, you will be given a drug to protect your kidneys. It is also very important that you drink plenty of fluid to prevent damage to your kidneys.

This is why you may be given intravenous fluids (IV hydration) with and/or after your chemotherapy to help protect your kidneys. For most people it can be very frustrating to be 'tied up' to your IV pole for what can sometimes be long periods of time. Your doctors and nurses will understand this and will be able to suggest ways to help you through these times. Remember your doctors and nurses are working with you to ensure your treatment is given as safely as possible.

What is radiotherapy?

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 lymphoma as the 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 the cancerous cells, high levels of radiation would be given to healthy cells as well.

Radiotherapy can cause a reddening of the skin, which may also flake and become itchy. The staff at the radiotherapy department will advise you on how to care for your skin during treatment. Gentle washing (avoiding perfumed products like soap) and drying (patting rather than rubbing when drying) is often recommended. You should always avoid moisturisers which contain traces of metal. Check with your radiotherapy department if you are unsure.

What is central nervous system treatment and prophylaxis?

In some conditions like acute leukaemia and lymphoma (particularly acute lymphoblastic leukaemia, ALL) cancer cells are sometimes found in the central nervous system (CNS) - the brain and spinal cord - at the time of diagnosis. In other cases the cancer cells may reappear or relapse within this area at a later stage. Since the blood supply to the CNS is different from the blood supply to other parts of the body, this area can act as a 'sanctuary site' for cancer cells. Here the cells can grow and multiply beyond the reach of standard chemotherapy drugs which normally travel throughout the rest of the body in the blood stream.

Therefore CNS treatment and prophylaxis (protection) will be given at various stages throughout treatment for ALL. This usually involves injections of methotrexate and/or other chemotherapy drugs directly into the spinal fluid (called an intrathecal injection), through a lumbar puncture.

Some types of intravenous chemotherapy and corticosteroid therapy also provide valuable protection for the CNS. On rare occasions, radiotherapy to the head (cranial irradiation) is also used.

> "The team who put in my central line were very careful and now you can hardly see where it was."

What is a bone marrow or peripheral blood stem cell transplant?

For some people very high doses of chemotherapy or radiotherapy are needed to treat their blood cancer. As a side effect of these treatments normal bone marrow and bone marrow stem cells are also destroyed and need to be replaced. In these cases a bone marrow or peripheral blood stem cell transplantation is used.

There are two types of stem cell transplant:

Autologous transplant – An autologous transplant involves collecting your own stem cells, usually from your blood stream, storing them and then giving them back after you have received high doses of chemotherapy.

Allogeneic transplant – An allogeneic transplant is where the stem cells are donated by another person, usually a brother or sister. This type of transplant works by adopting the healthy donor immune system to stop the blood cancer from coming back. Chemotherapy is still necessary beforehand. Total body irradiation (TBI) may be used as well.

The type of transplant you receive depends on a number of factors such as your blood cancer, age and donor matches.

There are separate booklets about stem cell transplants available from the Leukaemia & Blood Foundation.

Complementary therapies

Complementary therapies are therapies which are not considered standard medical therapies. However, many people find that they are helpful in coping with their treatment and recovery from blood cancers.

There are many different types of complementary therapies. These include yoga, exercise, meditation, prayer, acupuncture and relaxation. Complementary therapies should 'complement', or assist with recommended medical treatment for blood cancers. They are not meant to replace your medical treatment. It is not recommended to use complementary treatment alone.

It is important to realise that no complementary or alternative treatment alone has proven to be effective against blood cancers. It is also important that you inform your doctor if you are using any complementary or alternative therapies in case they have interactions with your prescription medications.

Section summary

- Chemotherapy drugs are called cytotoxic (cell toxic) because they kill cells, especially ones that multiply quickly like cancer cells.
- There has been a lot of progress in the treatment of blood cancers and new drugs are developed all the time.
- Chemotherapy can be given through a vein (intravenously - IV) in your arm or hand. It can also be given in tablet form.
- If you are having several cycles of chemotherapy your doctor may talk to you about having a central venous catheter (also called a CVC or central line) or portacath inserted. This is a special line inserted through the skin into a large vein in your arm, neck or chest. There are several different kinds of central lines some are intended for short term use while others remain in place for months or even years.
- Radiotherapy uses very high energy x-rays which are focused on tumours to kill the cancerous cells. This type of treatment may be used for lymphoma.
- There are two types of stem cell transplants.
- An autologous transplant involves collecting your own stem cells and giving them back after receiving high doses of chemotherapy.
- An allogeneic transplant is when the stem cells are donated by another person (usually a brother or sister) and given after receiving high doses of chemotherapy and total body irradiation (TBI).

STAYING in HOSPITAL

As previously mentioned, you may hear your doctors talk about being an 'inpatient'. This means you will be staying in hospital on the ward. Being an 'outpatient' means that you visit the hospital's cancer day ward for treatment and checkups, but you are able to go home afterwards. It is possible you will have to stay in hospital during treatment for your blood cancer. How much time you spend as an inpatient will vary.

If you haven't stayed in hospital before, you may have some rather strange ideas about it. On television and in books people are almost always lying in bed. You will probably spend far more time up and about than you thought.

On the ward there may be a room where you can go to watch television as well as a kitchen where you can make drinks and store food in a fridge. Some hospitals have quiet rooms where you could read or do school work.

> **"I've got my own room at home, so being in a ward with other people around all the time was weird. After a while I just pulled the curtains round my bed when I wanted to be alone."**

Some young adults do not like staying in hospital. They may feel trapped and become frustrated and angry. If you start to feel like this, talk to your doctors and nurses, you will not be the first person to feel this way. By talking to your doctors and nurses you can create a plan which will work best for you. The solution may be something simple like not waking you up too early in the morning (if you are well) or a couple of hours/day leave from the ward. Remember your doctors and nurses are there to help you through your treatment in the best way possible for you.

Below are some tips from other young people to make staying in hospital bearable:

- Wear your own clothes, and get dressed whenever you can.
- Cool pyjamas! They're softer and more comfortable than a hospital gown, they cover your butt, and they make you feel like a human being rather than just a patient. Don't forget the slippers – ones that you can slide in and out of easily.
- Get a couple of beanies or scarves. Hospital rooms can be very cold and most of your body heat is lost from your head. Soft material is best as bald heads are sensitive!
- Keeping in touch with what's going on at school, college or work can help you feel more normal i.e. through emails, texts, Twitter or Facebook.
- Bring stuff to put on the walls. Photos, drawings, pictures – the brighter the better! Cards, decorations or origami could be hung there too. Move things around every so often for a change of scenery. You could even decorate your IV pole and/pump to make your room feel less clinical.
- Listen to music with headphones. Mellow music may be best but more upbeat options can cheer you up. Bring music you know you like.
- Try some light reading. Crosswords are good but you may not have the concentration to tackle them all the time. The same applies for heavy reading so detective thrillers, trashy romances or magazines may be more appropriate.
- Keep a camera handy to take photos of the friends and family who come to visit.
- Watch home videos – they remind you of the people who love you and how much you have to live for. Funny movies will also cheer you up.
- Use stuff to make the room smell nice. It's also relaxing to soak your feet in a basin of warm water with essential oils such as lavender or rosemary. It makes your feet feel great and the room smell wonderful.
- Bring some paper and writing utensils. Good for writing letters, keeping track of questions for the doctor, figuring out the TV channels, or writing lists of things you want from home.
- If you have a laptop, keep in touch with friends, play games, or surf the net. If you're particularly computer savvy you may want to create your own webpage where you can write blogs and post photos.
- Set up voicemail on your phone for when you're too tired or cranky to take calls.
- If you're the creative type – portable hobby kits such as knitting or scrapbooking can keep you occupied in waiting rooms for hours.

> "I'VE GOT MY PHONE AND IPOD
> MY TWO MOST PRECIOUS THINGS IN HERE."

If you're allowed, other things like your own pillow or duvet cover will make the room more homely and less sterile. Staying in hospital isn't fun, but having things you like will make your stay more bearable and even entertaining.

However hard people try, you will almost certainly have to wait at times for doctors, nurses, tests and scans. Here are tips for waiting from other young adults:

- Buy a favourite magazine
- Write down any questions you have – write the answers down too
- If you are studying, take a textbook – it's good distraction
- Take a book that's easy to get into like an adventure, romance or detective novel
- Take some music or a computer game – turn down the sound

Side effects

Understanding side effects

The quality of life during and after treatment has become increasingly important. So, the challenge is to cure your cancer with the fewest possible side effects.

Chemotherapy and radiotherapy kill cells that multiply quickly, such as cancer cells. They can also cause damage to fast–growing normal cells including hair cells and cells in your mouth, stomach and bone marrow. When cells are damaged this can cause side effects.

Radiotherapy side effects usually depend on the area of the body which is being treated. For example radiotherapy to the abdomen is more likely to cause nausea and vomiting while hair loss is usually confined to the areas of the body being treated.

The type and severity of each side effect varies for each person depending on your treatment and how you respond to it. There is no doubt that side effects can be very unpleasant but it is good to remember that most are short term and will usually disappear over time. It is important that you report any side effects you experience to your doctor or nurse because many of them can be treated successfully, decreasing unnecessary discomfort for you.

> " AT A HOSPITAL CHECK-UP I MENTIONED THAT I WASN'T FEELING TOO WELL SO THEY ADMITTED ME ON THE SPOT!"

> "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, but then I got really sick."

Why will I be more likely to get an infection?

Chemotherapy and sometimes radiotherapy can temporarily affect the bone marrow's ability to produce good numbers of white cells, platelets and red cells. As a result, your blood count (the number of white cells, platelets and red cells circulating in your blood) will generally fall within a couple of weeks of treatment. The length of time it takes for your bone marrow and blood counts to recover mainly depends on the type of chemotherapy or radiotherapy you receive.

The point at which your white cell count is at its lowest (nadir) is usually expected 10 to 14 days after starting each cycle of your treatment, during which you will then be at a higher risk of developing an infection. A blood test will be arranged for you during this time to check your blood count. At this stage you will be neutropenic, which means that your neutrophil count is low and you are more at risk of getting an infection.

Neutrophils are important white blood cells that help us to fight infection. While your white blood cell count is low you should take sensible precautions to help prevent infection. These include hand washing before eating and after going to the toilet, showering daily, brushing teeth with a soft toothbrush after meals, avoiding crowds (i.e. malls, movie theatres, public transport and concerts), avoiding people with infections which are contagious (for example colds, flu, chicken pox) only eating food which has been properly prepared and cooked and making sure you do not handle your pet's litter tray.

Your doctor and nurse will advise you on how to reduce your risk of infection while your white cell count is low. If you do develop an infection you may experience a fever which may or may not be accompanied by an episode of shivering – where you shake uncontrollably. Infections while you are neutropenic are serious and need to be treated with antibiotics as soon as possible.

> "I GOT SO FED UP OF TAKING PILLS TO COUNTERACT THE SIDE EFFECTS OF OTHER PILLS THAT COUNTERACTED THE EFFECT OF YET MORE PILLS."

> "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."

"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."

It is important that you contact your doctor or the hospital for advice immediately (at any time of the day or night) if you are feeling very unwell, or if you experience any of the following:

- A temperature of 38°C or over and/or an episode of shivering
- Bleeding or bruising, for example blood in your urine, faeces, sputum, bleeding gums or a persistent nose bleed
- Nausea or vomiting that prevents you from eating or drinking or taking your normal medications
- Diarrhoea, stomach cramps or constipation
- Coughing or shortness of breath
- The presence of a new rash, reddening of the skin, itching
- A persistent headache
- A new pain or soreness anywhere
- You cut or otherwise injure yourself
- If you notice pain, swelling, redness or pus anywhere on your body

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.

Why should I be careful about over the counter medications?

It is important you do not use any drugs to bring your temperature down (i.e. paracetamol) until you are reviewed by a doctor. This could mask an infection which could lead to serious life threatening complications. Do not take aspirin or ibuprofen in any form as this can increase the risk of bleeding if your platelets are low. Always check with your doctor first.

What is G-CSF?

Sometimes your doctor may decide to use a growth factor such as G-CSF (Granulocyte Colony Stimulating Factor) to help the recovery of your neutrophil count. This drug works by stimulating the bone marrow to increase the production of neutrophils. G-CSF is given as an injection under the skin. This is quite a simple procedure and the nurse will teach you or a family member or friend to do this at home. Major side effects are uncommon, but occasionally aching bones may occur.

"I FOUND IT REALLY WEIRD WATCHING SOMEONE'S ELSE'S BLOOD GOING INTO MY VEIN. I ALMOST DIDN'T WANT IT BUT I FELT SO MUCH BETTER AFTERWARDS."

Platelets

Platelets are blood cells which work to clot the blood. After treatment, your platelet count may be affected and you may become thrombocytopenic (a decrease in the number of platelets circulating in the blood). When your platelet count is very low you can bruise and bleed more easily. During this time you should avoid sharp objects in your mouth such as chop bones or potato chips as these can cut your gums. Using a soft tooth brush also helps to protect your gums. In some cases a transfusion of platelets is given to reduce the risk of bleeding until your platelet count recovers.

Anaemia

Red blood cells contain haemoglobin, which carries oxygen around your body. If your red blood cell count and haemoglobin levels drop you may become anaemic. When you are anaemic you may look pale and feel more tired than usual. If your haemoglobin level is very low, your doctor may prescribe a blood transfusion.

You may wish to read about the side effects now or wait to see what happens for you. If so, flick to the back of the booklet and look at the index page.

Nausea and vomiting

Nausea and vomiting are often associated with chemotherapy and some forms of radiotherapy. These days, however, thanks to great improvements in anti-sickness (anti-emetic) drugs, nausea and vomiting are generally very well controlled. You will be given anti-sickness drugs before and for a few days after your chemotherapy treatment. You may find taking your regular anti-sickness half an hour before eating helpful. Some can also feel sick at just the thought of having their treatment, eating or even the smell of food. This is called anticipatory nausea. One way around anticipatory nausea is to try to think in positive terms, such as the treatment you are receiving is destroying all the cancer cells. Be sure to tell the doctors and nurses if you think that the anti-sickness medication is not working or if you still feel sick. There are many different types of anti-sickness drugs that can be tried. A mild sedative may also be used to help stop you feeling sick. This will help you to relax but it might make you feel a little sleepy.

Eating and sickness

You may find that eating smaller meals more frequently during the day, rather than a few large meals, helps to reduce nausea and vomiting. Many find that eating cool or cold food is more appetizing, for example jelly or custard. Eat slowly and try not to watch other people eat. Drinking flat ginger ale or soda water and eating dry toast may also help if you are feeling sick. Get plenty of fresh air and avoid any strong or offensive smells. Keep drinking water even if you feel sick - you may find that you feel worse if you

"AT FIRST CHEMOTHERAPY MADE ME REALLY SICK BUT MY ANTI-EMETICS (ANTI-SICKNESS DRUGS) WORKED WONDERS" don't – sucking on ice cubes could be an alternative. Try sucking a lolly if you get a strange taste in your mouth from any of the drugs you may be given.

Nutrition and diet

A healthy and nutritious diet is important in helping your body to cope with your disease and treatment. Talk to your doctor or nurse if you have any questions about your diet or if you are considering making any radical changes to the way you eat. You may wish to see a dietician who can advise you on planning a balanced and healthy diet.

You may find smoothies or milkshakes work better for you when you don't feel like eating solid food. Depending on hospital policy, if you are in hospital, have someone bring in your favourite meals/food. If you are feeling hungry eat, do not feel as if you have to wait for meal times and on those days when your appetite is good eat a little extra. Eating small frequent snacks is just as good as eating three meals a day.

Why do I need to be careful about what I eat?

When your immune system is low you need to be careful that the food which you prepare and eat does not contain bacteria that could harm you. Depending on hospital policy when you are neutropenic your doctor may place you on a neutropenic diet. The nurses or your dietician will advise you on a list of foods to avoid. Some points to remember are that all your meals should be cooked well and should not be re-heated. Avoid soft boiled eggs and also soft cheeses. Do not eat soft serve ice cream from the machine. Only eat from reputable fast food places or restaurants – make sure everything is cooked fresh and it has not been sitting around for a long time.

"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!"

Changes in taste and smell

Both chemotherapy and radiation therapy can cause changes to your sense of taste and smell. This is usually for a short time but in some cases it lasts up to several months. During this time you may find the foods and drinks that you used to love taste really bland and this can be very disappointing. Some people find that adding a little more sugar to sweet foods and salt to savoury foods can help. Other people find spicy foods more enjoyable to eat.

If you are thinking about using herbs or vitamins it is very important to talk this over with your doctor first. Some of these substances can interfere with the effectiveness of chemotherapy or other treatment you are having.

They gave me lots of mouthwashes. Use them – otherwise you'll be sorry. I didn't bother to start with and my mouth got really sore.

Mucositis

Mucositis (or inflammation of the lining of the mouth and throat) is a common and uncomfortable side effect of chemotherapy and some forms of radiotherapy. It usually starts about a week after the treatment has finished and goes away once your blood count recovers, usually a couple of weeks later. During this time your mouth and throat could get quite sore. Oral pain relief and other topical drugs (ones which can be applied to the sore area) can help. If the pain becomes more severe, stronger pain killers might be needed. Sometimes your salivary glands can be affected causing either a dry mouth or over production of saliva. Using a fizzy drink (such as coke) to rinse and spit out is sometimes useful in clearing gunk from your mouth. Small sips of drinks or ice cubes can be affective with a dry mouth.

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.

Are mouth cares important?

To help prevent infection, it is important to keep your mouth as clean as possible while you are having treatment. It is particularly important to do your mouth care regularly while your mouth is sore. Your nurse will show you how to care for your mouth during this time. This will include mouthwash, using a soft toothbrush and mild toothpaste. Your nurse will recommend which mouthwash to use. Avoid commercial mouthwashes, like the ones you can buy at the supermarket. These are often too strong, or they may contain alcohol which will hurt your mouth. Lastly, it is also helpful to let your doctor know if you have had any problems with your teeth or gums in the past as chemotherapy can sometimes cause old problems to flare up. They may wish you to see a dentist before you start any treatment.

Bowel changes

Chemotherapy and radiotherapy can cause some damage to the lining of your bowel wall. This can lead to cramping, wind, abdominal swelling and diarrhoea. Be sure to tell the doctors or nurses if you experience any of these symptoms. If you develop diarrhoea, a specimen will be required from you to ensure that the diarrhoea is not a result of an infection. After this you will be given some medication to help stop the diarrhoea and/or the discomfort you may be feeling. It is also important to tell the doctor or nurse if you are constipated or if you are feeling any discomfort or tenderness around your bottom (anus) when you are trying to move your bowels. You may need a gentle laxative to help soften your stool.

Fatigue

Most people with a blood cancer experience some form of fatigue. This can be related to your blood cancer, your treatment and/or other complications such as anaemia or infection. In fact, blood cancer patients usually report fatigue to be one of the most common side effects. Fatigue can effect everyone differently. Some may experience fatigue for a short amount of time (days) while others may suffer for longer periods (weeks or months). Fatigue for people with blood cancers is not the same as normal tiredness. This means that the fatigue you may be experiencing can interfere with even small amounts of activity such as showering or even walking around your home. You will even find no matter how much you sleep your fatigue will not go away. This can be especially tough for you, as you may see your friends out enjoying themselves while your life seems to have been put on hold. The feeling of fatigue can be hard to describe - don't be surprised if other people do not really understand. Just remember fatigue is a common side effect and should resolve itself over time.

Chemo brain or chemo fog

Fatigue can also be a factor in affecting the way you think and process information. You may hear some people describing this as 'chemo brain' or 'chemo fog.' Again, this varies from person to person but you may find you have trouble speaking, thinking or making decisions. You may also find it harder to remember things and have trouble concentrating even when you are watching TV or trying to read a book. It can even make you feel more emotional and short tempered. This is usually a temporary effect but for some people it can last for a longer time.

You may find it helpful to keep a diary so you can work out if there is a pattern for your good and bad days. Then you could plan to do more things when you are likely to have more energy. It may sound strange, but having plenty of rest and a little light exercise each day may help to make you feel better during this time. Getting out into the fresh air and doing some gentle exercise is important for your general feeling of wellbeing and it may also help to reduce your fatigue. It is also important to listen to your body and rest when you are tired.

Body image

The physical appearance of a cancer patient is often seen as a minor problem for cancer sufferers but for young adults it can have a huge impact on how you look and feel about yourself. Hair loss, skin changes, weight changes and feeling tired can all interfere with feeling attractive. It is important to remember that these changes will mostly be short term and should resolve once your treatment is finished.

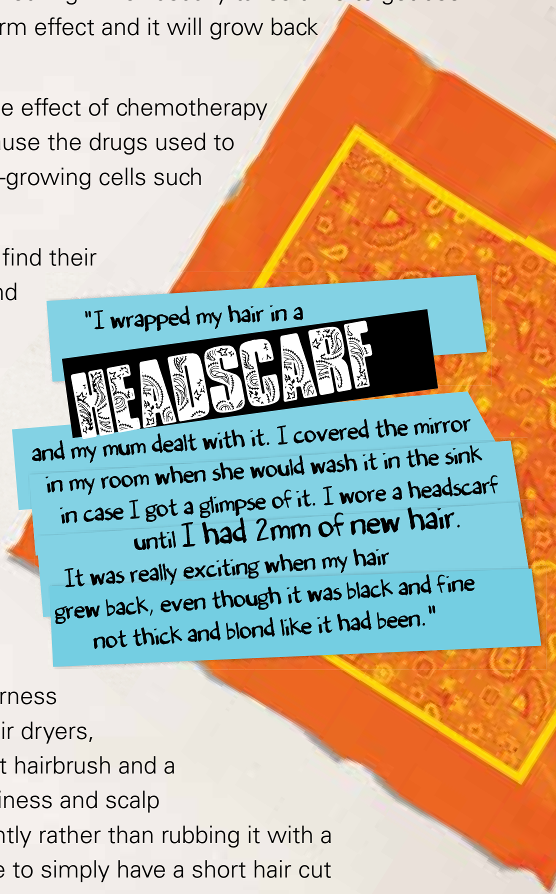
Hair loss

For a lot of young adults losing their hair is one of the biggest challenges they will face. You may feel scared of what you are going to look like or you may feel anxious of what your friends and other people will think. You may feel being 'bald' lets everyone know that something is wrong which can make you feel self conscious. Feeling this way is totally normal and understandable and is something which usually takes time to get use to. And remember that hair loss is a short term effect and it will grow back once treatment is finished.

Hair loss is unfortunately a very common side effect of chemotherapy and some forms of radiotherapy. This is because the drugs used to kill your blood cancer cells also kill other fast-growing cells such as hair cells.

Most people lose all their hair. Others might find their hair thins on top or may fall out in patches and the hair that remains is usually weak. Hair can even be lost from your eyebrows, eyelashes, arms, legs and genitals.

Hair starts to fall out within a couple of weeks of beginning treatment and tends to grow back 3-6 months after finishing. You may find your hair does not grow back exactly the same way sometimes hair grows back thicker, wavier or a different colour.



"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."

You may experience itchiness or scalp tenderness while losing your hair. Avoiding the use of hair dryers, straighters or chemicals and only using a soft hairbrush and a mild baby shampoo can help reduce the itchiness and scalp tenderness. When drying your hair, pat it gently rather than rubbing it with a towel. Some people find it more comfortable to simply have a short hair cut when they notice that their hair is starting to fall out.

You need to avoid direct sunlight on your exposed head (wear a hat) because chemotherapy and radiotherapy makes your skin even more vulnerable to the damaging effects of the sun (i.e. sunburn and skin cancers). Remember that without your hair, your head can get quite cold, so a beanie might be useful, especially if you are in an air-conditioned room like a hospital.

Some people do not like to wear wigs. If wigs are not for you, you could try wearing a bandanna, scarf, baseball cap, hat or a beanie. You may also just prefer to go au naturel which is absolutely fine as well. Finding what works for you is the important thing.

HealthPAC on behalf of the Ministry of Health provides all cancer patients (who are citizens or ordinary residents of New Zealand) with a subsidy for a wig or a hairpiece. Your entitlements depend on age and whether your hair loss is permanent or temporary. Depending on the cost of your wig, if you are under 18 your claim may be paid in full. If you are an adult (18 or over) you might be required to pay an additional cost.

Your treatment centre or the Leukaemia & Blood Foundation can provide you with further information and contact details for wig suppliers and the application process for the subsidy.

Skin

Teenage years can be a difficult time for your skin. Sometimes chemotherapy can make things worse, causing redness, acne and dry skin. Some tips to remember are to use soft cloths and towels, lukewarm water, avoid scratching and don't use a razor. Using razors for a wet shave increases the risk of bleeding and infections if you cut yourself. It is recommended that you use an electric shaver. Makeup may be helpful in covering up areas you may feel self conscious about. Remember to avoid applying makeup to skin if you have had radiotherapy to that area.

Weight

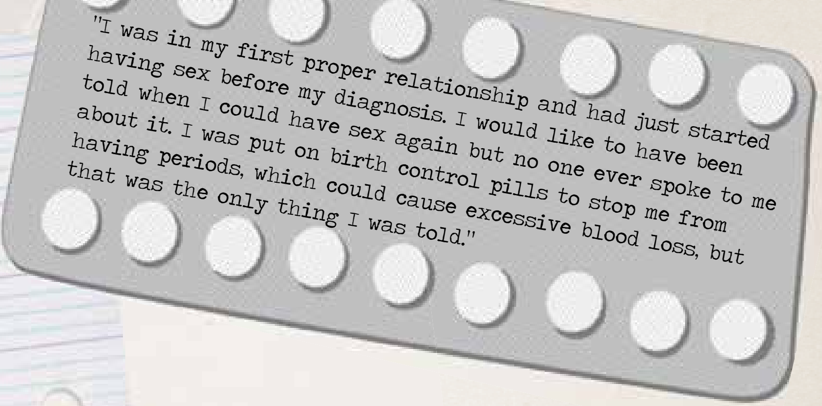
Most blood cancer patients will lose weight due to the cancer and its treatment as well as changes in eating habits. Some will gain weight. Both of which can be upsetting for some as they may make you feel embarrassed about your body. If you have any concerns ask to be referred to a dietician who will be able to review your weight changes and give advice.

Sex

At some time during your treatment you may be advised by your doctor that it is not safe for you to have sexual intercourse. This is because a drop in platelets means you are more prone to bleeding. If you are having sex it is sensible to use a condom and water-based lubricant to minimise the risk of excessive bleeding and, as always, infection. Using a condom is also important to protect your partner from chemotherapy drugs that can be excreted in body fluids in the first few days after they are administered.

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.

Women should not try to conceive 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 birth control pills 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 doctor there is plenty of advice available that will help you in your unique situation. Women can also lose their sex drive during cancer treatment. For further information please discuss with your doctor or nurse, or contact your local LBF Support Services Coordinator who will provide you with accurate up to date information.

Menstruation

If you have started menstruating, you may find your periods stop or are irregular. You may be given a birth control pill to stop your periods. This prevents heavy bleeding and blood loss when your platelets are low. It is best to use pads instead of tampons if you are menstruating as this will reduce the risk of infections. Always let your doctor know if you have your period.

Fertility

Fertility is the ability to produce a child. In males, fertility means having enough healthy sperm to get a female pregnant. In females, fertility is the ability to become pregnant.

Will I be able to have children?

As a young adult, becoming a mother or a father may be the last thing on your mind. However you should know that some types of treatment for blood cancers, such as chemotherapy and radiotherapy, may cause a temporary or permanent damage to your fertility (ability to have children in the future). This means that in the future you may not be able to have a child when you planned. You may need assistance to become pregnant, or you may not be able to have children at all.

Before you start treatment, it is important that you discuss your questions or concerns regarding your future fertility with your doctor. Do not assume you are infertile. Not all treatments cause permanent infertility. The other thing to consider is birth defects. If you are having sex, always use reliable contraception. Chemotherapy can damage your eggs or sperm which may cause birth defects or development problems in a baby conceived during treatment.

"One of the hardest things for me to accept was the possibility that I might not be able to have kids in the future."

While there are some options for preserving fertility you may already have reduced fertility as stress on your body from being unwell causes a decrease in function of the reproductive organs. This may mean that some forms of fertility preservation, such as sperm and egg collection, may not be as successful as hoped for.

Unfortunately, sometimes there is just not enough time to consider procedures to preserve fertility because rapid treatment is the priority. If you are feeling overwhelmed and stressed with this process let your doctor and nurses know as they will be able to help.

Fertility preservation options before treatment

In-Vitro Fertilisation (IVF) is the name given to the process of fertilising ovarian eggs with sperm in a laboratory, then placing the resulting embryos in the female uterus, so a pregnancy may develop. The methods of fertility preservation talked about here are mainly used in combination with IVF techniques.

Males

Sperm banking is where the male donates sperm, which is then stored, with the intention of using it to achieve a pregnancy in the future. The best method for collecting sperm is by masturbation. If possible sperm should be donated on more than one occasion.

It is important to realise that there are many factors that can affect the quality of stored sperm such as amount of sperm collected and if there is any damage from the freezing and thawing process. However, provided there are a good number of healthy sperm after thawing, the fertility of sperm is not affected even after many years of being frozen.

In New Zealand sperm cannot be stored for longer than 10 years unless permission is obtained from the Ethics Committee of Assisted Reproductive Technology (ECART).

Females

Embryo storage involves collecting eggs from your ovaries. This is usually done after taking a course of drugs to help the ovaries to produce a number of eggs, so that more than one egg can be collected. This process can take several weeks which can be a problem if your treatment needs to start straight away. Once collected, the eggs can either be stored, or fertilised with sperm, to be stored and used at a later date.

"The treatment I had for Hodgkin lymphoma did not affect my being able to get pregnant. Louise is 3 months old now, and she is very special"

Ovarian tissue storage is still a new way in preserving fertility and to date there is very little experience with this technique in New Zealand. It involves the removal and storage of some ovarian tissue, but requires surgery and, consequently, a delay in your treatment. It is hoped that at a later date the eggs contained in this tissue can be matured, fertilised and used to achieve a pregnancy. Freezing ovarian tissue in New Zealand is only available to females aged 16-35 years who have a medical indication for ovarian failure. To date this approach has unfortunately shown little success.

Donor eggs may be another option. The eggs are donated from another female, and similar to embryo storage, the eggs are then fertilised in a lab using sperm but instead of putting the resulting embryos into storage, they are implanted in your uterus in attempt to achieve a pregnancy.

In New Zealand, eggs or embryos cannot be stored for longer than 10 years unless permission is granted from the Ethics Committee of Assisted Reproductive Technology (ECART).

Hormonal therapy is being studied to see if this can reduce infertility rates. Usually this involves the monthly injection of a hormone-blocker (a GnRH antagonist) to temporarily turn off the ovaries and make them less susceptible to damage by chemotherapy drugs.

It is important to understand that all these methods are still quite experimental and for many reasons achieving a pregnancy and then a baby is not guaranteed. In addition, some are time consuming and expensive while others may simply not be acceptable to you.

Early menopause

As previously stated some cancer treatments can affect the normal functioning of the ovaries. In some cases this can cause infertility and an earlier than expected onset of menopause (when your ovaries stop producing eggs and your periods stop), even at a young age. Early menopause requires treatment with hormone therapy until the menopausal age, which is normally around the age of 50. The onset of early menopause in these circumstances can be sudden and understandably very distressing.

Young women who have had treatment which may lead to early menopause may be advised to think of having a family before their mid thirties in case of early menopause. It is important that you discuss any changes to your periods with your doctor. He or she will advise you, or refer you on to a specialist doctor (gynaecologist) or clinic that can suggest ways to reduce your symptoms.

Could my treatment affect my future children?

People who have had chemotherapy and radiotherapy often mention 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 have received cancer treatments in the past show no increase in abnormalities or in rates of childhood cancer in their offspring.

If you are considering starting a family it is important to discuss this with your doctor. Due to your cancer treatment there may be extra issues to take into account before you can achieve a pregnancy. For example it may take a while after treatment has been completed to see if your fertility has been permanently or temporarily damaged, and you may also need time to emotionally and physically recover from your treatment. It is usually recommended to wait for at least two years after treatment ends, before trying for a pregnancy. However your doctor may advise you to wait longer depending on your blood condition, treatment you received, and your chances of relapse. Your doctor may refer you to a fertility specialist if there are any fertility concerns.

"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."

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

Section summary

- Chemotherapy and radiotherapy kill cells that multiply quickly, such as cancer cells. They also can damage fast growing normal cells including hair, cells in your mouth, stomach and bone marrow. When healthy cells are damaged you may experience side effects.
- The type of side effects and their severity vary for each person depending on your blood cancer, treatment and how you respond to it. Most side effects are short term and will disappear over time.
- Infections while you are neutropenic can be serious and need to be treated with antibiotics as soon as possible. It is important that you contact your doctor or the hospital for advice immediately (at any time of the day or night) if you are feeling very unwell. See page 20 for further information.
- Eating small frequent meals through the day is as good as eating 3 normal meals.
- To help prevent infection it is important to do regular mouth cares, which includes using a soft toothbrush, toothpaste and mouthwash.
- Fatigue is one of the most common side effects reported by cancer patients. One of the best ways to help overcome fatigue is by getting plenty of rest and gentle exercise.
- Hair loss is a common side effect to treatment but is usually a short term effect and should grow back once treatment is finished.
- A drop in your platelet count means you are at a higher risk of bleeding, at this point your doctor may advise you that it is not safe for you to have sexual intercourse.
- Chemotherapy can damage your eggs or sperm which may cause birth defects or development problems in a baby conceived during treatment. So if you are sexually active always use reliable contraception.
- Some types of treatment for blood cancers may cause temporary or permanent damage to your fertility. Before you start treatment it is important you discuss your questions or concerns regarding your future fertility with your doctor.

LIVING WITH A BLOOD CANCER

Feelings
There is no right or wrong way to feel throughout your diagnosis and treatment. Everyone is different, and your feelings and the way you cope with these feelings may not be the same way as other young adults going through the same experience. You will also find that your feelings change over time and that you have good and bad days.

When you are first told you have a blood cancer you may be shocked or numb – as though it's all happening to someone else. Many people often think why me? Why not someone else? Unfortunately there is no easy answer to this question and often it takes time to grasp and to deal with what is happening to you.

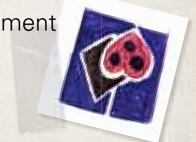
For many, your culture, language, religious or spiritual beliefs can be a very important factor in helping you and family or whānau to cope with your diagnosis and treatment.

Information regarding your diagnosis and treatment can be found in many different languages. Translators can be arranged and your doctor or nurse can help organise any cultural or religious support you need. In New Zealand, most hospitals have kai awhina/ kaumatua, Pacific Island and chaplaincy teams available for visiting support.

Why am I so anxious?
Following the initial diagnosis with a blood cancer you may have some frightening and unsettling thoughts and fears. You may have anxiety about your diagnosis and treatment and what it will mean for you and your family or whānau.

Although it may be overwhelming at first, the truth is, it is unlikely to be as frightening as what you are imagining in your head. Talk to your doctor and nurses; ask questions until you understand this new language and information. Remember that it takes time to absorb new information, so having someone you trust and who will be with you through out your treatment may help.

Do not be afraid to ask the same questions again if you have forgotten what they may have said, or what things mean – your doctors and nurses understand that it is a lot of information to take on board all at once. You will probably find that as your treatment progresses your anxiety will lessen over time.



Why am I so emotional?
You may find you are more emotional than usual and your moods can swing from one to the other (i.e. anger to sadness). This is very normal. You are coming to terms with having a blood cancer. Medications including steroids and sedatives involved with chemotherapy and radiotherapy can also influence your mood.

There will be days when you are feeling positive and other days when you are feeling not so positive. Feeling this way is OK and normal. Many young adults find that taking one step at a time, and one day at a time, is a great way to help with dealing with your diagnosis and treatment.

Many young adults who have experienced a blood cancer find that they are mentally tougher than they thought. They also develop more of an awareness of what matters the most to them in life.

Why do I feel out of control?
All of a sudden you may feel as though decisions are being made about your life, which you have no control over, either because you feel people have made these decisions for you or you do not feel able to make the decisions required. This can make you feel vulnerable and less sure about yourself.

One of the ways you can take back control of your life is by focusing on what you can control. For example you could decide to find out more about your blood cancer or simply decide not to. You can even discuss with your nurse when would be the best time for you to receive your treatment, or simply decide on jelly or no jelly. No matter how big or small your decision may be, you have taken control.

Confidence
The treatment involved with fighting your blood cancer can change how you physically look and feel and can sometimes decrease your confidence in going out and seeing your friends. If you are worried about going out, take things slowly. To start with, ask people round to your place. Then go out with friends you can rely on – get them to come to your place first, rather than meeting up somewhere else.

Loneliness
Blood cancers in a young adult are rare. To meet other young adults, your age, with your specific blood cancer in New Zealand, can be even rarer. You may have also had to travel to another town or city leaving behind the familiarity of home, family, whānau, and friends. All of these things can leave you feeling lonely and isolated, like no

one understands what you are going through. This time can be just as difficult for family, whānau and friends as they will want to be there to support you but may be scared to talk to you about your diagnosis.

Remember, talking about your feelings to family, whānau, friends or your doctors and nurses is one of the best ways to deal with your emotions.

If you wish, you can be referred to CanTeen – an organisation which supports young adults and their siblings experiencing cancer. It is a great way to meet other young adults with cancer around New Zealand.

There are also websites dedicated to young adults with online cancer forums you can join. Please check out the recommended website section at the end of this booklet.

Am I depressed?
If you are feeling sad and low most of the time, and you or other people can't lift you out of your despair, you may be depressed. Other signs of depression include not being able to sleep night after night, and feeling that everything is hopeless.

If you think you may be depressed, talk to someone you trust, perhaps your doctor or nurse. Sometimes it may be helpful to have counselling as depression is not something you can easily get over by yourself.

Below are some tips from other young adults for coping with your emotions:

- You know best how you feel, and what will help you through
- Talk – you may find sharing how you feel is helpful
- Do things that you like – watch a favourite TV show, listen to music, play computer games
- Try not to get stuck in your own room, a change of scenery may really help you
- Don't take too much on, try to do things in easy steps
- Try to meet your friends or workmates even just for a little while say at lunchtime
- Remember that mood swings are normal
- If you are tense try to find a good way to release it
- Try not to get too tired, it can make you more emotional

> "Talk to people, especially your family and friends, 'cos sometimes you're being strong for them, but it's better to tell them how you actually feel"

Relationships

> "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."

What do I tell my friends and family or whānau?
When you receive your diagnosis you may find it difficult to tell friends, family or whānau. 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, family or whānau – after all you know them better than anyone.

The important thing in any family, or friendship is to talk about how you are feeling. 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. You don't have to talk about having cancer all the time.

When you are used to your treatment pattern, you will have a good idea of which days are likely to be good and bad. Plan to do things with friends on the good days. Friendships can change when you are ill. You might find that some people are more supportive and understanding than others.

"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…"

"When I didn't feel like going out, I'd ask friends round to watch DVDs or play computer games – that way I didn't feel I was missing out on everything."

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 or whānau to be part of the decision-making process. It is really important to discuss issues like this with your family and let them know how you would like them to be involved.

How do I get along with my family?
For most people with cancer, your family or whānau becomes an important support network. They will 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. Everyone 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. If you would like to talk to a counsellor your doctor and nurses can arrange this for you.

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

As mentioned, some drugs, called steroids, can sometimes make you feel more emotional than usual. This can affect your relationships with friends, family or whānau. It will be easier to deal with this if you explain that the drugs are to blame for your emotions.

"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."

"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."

Will it affect my siblings?

Brothers and sisters, especially those who are younger than you, can find it very difficult to cope with your blood cancer diagnosis. The attention that you need from the rest of your family can make siblings confused and resentful.

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

What about my boy/girl friend?

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 to about hopes and concerns. However, being diagnosed with a blood cancer is a major life-changing event, for both you and your partner; it can take a lot of energy to keep a relationship going especially if you haven't been together for very long.

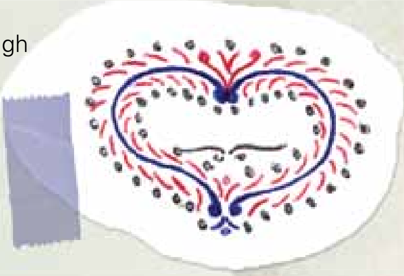
"I was in a relationship all the way through my diagnosis and treatment. It only affected us when I had to go away to have a stem cell transplant. Other than that our relationship became stronger."

"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."

Living alone with a blood cancer

Living as an independent person is important to many young people but it may be very challenging to keep up your spirits and continue to be positive if you are living alone with a blood cancer. You may be someone who normally appreciates your independence; however being unwell may make you feel lonely and isolated. The possibility of having to sacrifice your current living situation on top of the diagnosis of a blood cancer is all very overwhelming.

There are aspects of living with a blood cancer that can make it difficult to manage everyday life, such as grocery shopping and cleaning. Some young adults may feel comfortable with temporarily moving home with family or whānau whilst they undergo treatment for their blood cancer. For many young adults this is simply not an option, and for those individuals there is support available to help them through this time and remain living independently. Ask to speak to your social worker who will be able to help you to remain as independent as possible.



If you are living alone it is important that you:

- Put together a list of emergency contacts in case you do unexpectedly become unwell.
- Let friends, family, whānau and neighbours know about what could happen so if you call them in an emergency, they will know what to do and who to call. Your doctors and nurses will also give you a list of 24 hour emergency contact numbers to use in such circumstances.

It is okay to accept help. Family and friends who care about you may want to help in any way they can, and it is sometimes difficult to accept this help when you have previously lived so independently. Some family, whānau and friends may find it difficult to talk openly about your blood cancer, but would be happy to help in more practical ways, such as doing your shopping or helping with your house cleaning and transporting you to doctors' appointments. Accepting support offered may make living alone easier, and therefore enable you to retain your independence.

Although you may want to stay independent for as long as possible, remember that it is okay to ask for help when you need it. Being independent is about finding the right balance between acknowledging when you need support and looking after yourself.

"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."

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

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 that due to your cancer treatment your immune system may be low, making it easier for you to catch infections and harder to fight them off. You should stay away from school if any students have chickenpox, measles, shingles, flu or a bad cold.

You can discuss with your teachers/tutors a plan for your education while you are being treated for blood cancer. It may include doing schoolwork by correspondence, 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.

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.

"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."

"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."

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

Tertiary education

Going to polytechnic or university can be quite daunting for anyone but it can be really scary if you've just been treated for a blood cancer. Some people find they feel more attached to their family or whānau 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.

Treatment for a blood cancer 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. Some students take a year off to travel overseas or spend a year working and re-enter their course with a different group of peers. While this may appear scary, there will be many other people in a similar position.

Work

For those of you who work, it is hard to know before treatment starts how it will affect you. Whether your job is full or part time, you may find your treatment affects your ability to work. Some have no problem, while others need to stop working altogether in order to focus on having their treatment and then recovering sufficiently enough to return to work.

Often the biggest concerns for work are telling your employer that you have a blood cancer and worrying whether this will affect your job or pay.

The majority of employers are supportive. With improved knowledge and education about blood cancers, discrimination in the workplace is less common. If you have any questions regarding employment issues contact the Department of Labour, (www.dol.govt.nz) they will be able to advise and guide you through your concerns.

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

It can be helpful for you to talk to your employer about your blood cancer and treatments. You can explain how long you think it will last and what tasks you will be able to do. With this in mind, your employer will be able to make allowances for you while you are receiving treatment so that you can either take some time off or have a flexible working pattern. If you are worried about telling your colleagues, your employer can also help to support you in this matter.

Letting your colleagues know what is happening makes it easier for them to support you. For example it may help them to understand why you might be taking time off work. Try keeping in touch with colleagues from work, let them know how you are. A quick email or phone call can help reassure everyone that you are coping and have every intention of coming back to work.

You can ask to speak to the hospital social worker as you maybe entitled to benefits. Your social worker can also assist you with employment issues.

Exercise

It may sound strange, but keeping active is one of the best ways to make you feel better as well as healthy through your treatment.

As mentioned previously, blood cancers and their treatment affect people differently. Gentle daily exercise (such as walking) is better for you than sudden bursts of activity. When you are on treatment, your energy levels will vary according to your treatment regime.

Some things to remember are:

- Not to exercise in excessive heat – use an air-conditioned room
- Do not exercise if you have a fever
- If experiencing any shortness of breath stop exercising immediately
- If experiencing any nausea or dizziness stop exercising immediately
- Only use quality exercise equipment to reduce the risk of injury
- Above all, listen to your body

Avoid doing any power lifting or heavy weights if your chemotherapy included anthracyclines. Anthracylines are a group of very powerful chemotherapy drugs that can affect the strength of your heart. Ask your doctor whether this applies to you.

If your platelet count is low, you will bleed and bruise easily, so sports where you are likely to get injured are not a good idea. If you want to take part in energetic sports such as rugby, soccer, netball, basketball or mountain-biking you should ask your doctor for advice.

You are likely to have a lower white cell count than normal; this means you are at more risk of getting infections. The warm damp conditions in swimming or spa pools make them a very good place for bacteria to breed. You should ask your doctor for advice. They will be able to tell you whether you have enough white cells to fight infection to go swimming. You may be advised not to if you have a central line.

For your safety, it is best to check with your doctor if you want to go scuba diving as some chemotherapy drugs, such as bleomycin, can affect your lungs.

If you would like further information on developing exercise programmes, you can ask to be referred to your hospital physiotherapist.

What about alcohol and recreational drugs?

Alcohol and drugs are broken down and processed by your liver and kidneys, as are all the medications and chemotherapy you are having as part of your treatment. Whether you are able to drink alcohol during your treatment and recovery will depend partly on what medications you are receiving, how your liver and kidneys are responding to that treatment and how you are feeling. It is strongly advised that you do not take any recreational drugs while having treatment as this will only add extra stress to your body.

Some of your chemotherapy drugs can interact with alcohol and drugs, not only making any side effects you are experiencing worse, but could also create new ones. Drugs can mask serious symptoms and side effects of your treatment, such as neurological (brain) complications, infection and pain. Smoking/inhaling any drug increases risk of fungal infections in your lungs which can create serious complications with your treatment. When you are fighting so hard to get well from your blood cancer why risk further complications?

Excessive and prolonged consumption of alcohol is known to lower the body's immunity, which for you could mean a difficult and longer recovery – meaning more time in hospital. Also due to the treatment and side effects your body is experiencing, the tolerance for alcohol, that you may have had before treatment will be significantly lower. The occasional glass of beer or wine may not impact significantly on your treatment. However, it is best to speak with your doctor often about this issue and keep checking throughout treatment.

It is always best to be open and honest with your doctor and health care team. Anything you tell them will be confidential. Your health is a priority and they will only have your health and safety in mind.

For further information on alcohol and drugs please see the recommended websites listed at end of booklet.

Please note: Drinking alcohol under the age of 18 and taking any illicit drugs in New Zealand is illegal.

What about smoking?

There is no doubt about it – smoking is unhealthy. If you are a smoker this is a good time to quit – as previously mentioned, why give your body more work?

If you would like further information on giving up smoking please talk to your doctor or nurse. Free quit smoking programmes are available.

> "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."

Tattoos and piercings

For anyone, getting a tattoo or piercing can be a health risk. Tattoos and piercings both break the skin barrier and create a risk for infection and other complications, such as bleeding, scarring and reactions to the chemicals (such as the ink and metal used).

For someone whose immune system is compromised these risks increase. While you are receiving treatment for your blood cancer, your immune system, which is your body's defence against infection, will be low. This means it is harder for your body to fight infections and it also can take longer for your body to heal from wounds.

An average piercing can take 6–8 weeks or longer to heal. For anyone who has decreased immunity this could take longer, which increases your chances of developing infections. This could potentially lead to complications and a longer stay in hospital.

Your treatment will decrease your platelet count and as platelets help to form clots to stop bleeding, this means you may bleed more easily from a cut or any break in your skin. During a tattoo procedure a small amount of bleeding may occur. For someone who is receiving treatment for a blood cancer this bleeding and resulting bruising could potentially be more significant. This can also be an issue for piercings.

In some cases a tattoo (or permanent makeup) may interfere with the quality of a Magnetic Resonance Imaging scan (MRI scan). In other very rare occasions a tattooed area may swell or burn during a MRI scan. It is best to let your doctor know if you do have a tattoo so precautions can be taken before the scan.

It is safest for you to wait until after your treatment finishes before getting a tattoo or piercing. However if you are considering a tattoo or piercing during treatment please discuss this with your doctor or nurse. To limit the risks of these procedures your medical team can advise you on when would be the best time to have a tattoo or piercing and can also monitor you through the healing process. It is important your tattoo or piercing is done correctly, at a safe/clean establishment and proper care is taken afterwards to reduce the risk of infection and other complications.

What about travelling?

In New Zealand travelling is often seen as a rite of passage for young adults. You may have been dreaming and planning since you were little about when and where you would go. You may also have friends travelling, working and living overseas. When you have been diagnosed with a blood cancer these plans will often have to be put on hold.

So when is it safe to travel? As always it is a good idea to talk to your doctor about the best time for you to travel. Even when you have completed treatment you will still need to have regular checkups. Your doctor will be able to recommend when the best time would be as well as sorting out any follow up appointments you may need to have while you are away.

Depending on your blood cancer and treatment you may need to choose where you will travel very carefully. If you want to travel to places which require vaccinations it is best if you discuss this with your doctor for advice. There are some live vaccines which you should not have, such as yellow fever, typhoid and live oral polio.

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

Immunisations

After chemotherapy or a stem cell transplant, your doctor may advise you to have a repeat course of some of your childhood vaccines. This is because the immunity that you gained from your childhood vaccines may be lost during treatment.
Check with your doctor to find out which immunisations you should get.

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 (doesn’t count). Larger and more established insurance companies are more likely to be able to provide insurance for you but may charge a higher premium.

Sun protection

Chemotherapy permanently affects your skin, making it much more sensitive to the sun. It is very important that you always cover up, wear a sunhat, sunglasses and use a high factor sunscreen when you go outside.

Remember New Zealand burn times are a lot faster than the rest of the world and you can also be burnt on cloudy days. So best to play it safe and ‘slip slop slap’. If you have had radiotherapy, you should always protect the area of skin exposed to the x-rays regardless of the time of year.

It is strongly advised that you do not use sun beds. The very intense rays will damage your skin.

Section summary

- There is no wrong or right way to feel throughout your diagnosis and treatment. Everyone is different and your feelings may not be the same as other young adults going through the same experience. You will also find that your feelings change overtime and that you have good and bad days.
- The important thing in any family, whānau, friendship or relationship is to talk about how you are feeling. 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.
- If you are living alone with a blood cancer remember it is okay to ask for help. Being independent is finding a balance between acknowledging when you need support and looking after yourself.
- 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.
- Treatment may affect your ability to work. The majority of employers are supportive. With improved knowledge and education about blood cancers, discrimination in the workplace is less common.
- Keeping active is one of the best ways to make you feel better as well as healthy through your treatment. Gentle daily exercise is better for you than sudden bursts of activity. When you are on treatment, your energy levels will vary according to your treatment regime.
- Alcohol and recreational drugs are broken down and processed by your liver and kidneys, as are all the medications and chemotherapy you are having as part of your treatment. It is strongly advised that you do not drink alcohol or take any recreational drugs while having treatment as this will add extra stress to your body.
- It is safest for you to wait until after your treatment finishes before getting a tattoo or piercing due to risk of infection or bleeding.
- Chemotherapy affects your skin making it more sensitive to the sun. It is very important that you cover up, wear a sunhat, sunglasses and use a high factor sunscreen when you go outside.

Survivorship

The concept of survivorship and the term survivors has progressively changed over the years. Today survivorship is defined as beginning at diagnosis, the moment you start living with a cancer and continues through treatment, recovery and beyond. A cancer survivor is seen as anyone living with a cancer, including family, whānau, friends and or caregivers.

As well as physical well-being, a blood cancer diagnosis threatens a person's overall enjoyment of life. In past years, doctors focused on treating the cancer as effectively as possible, and so the quality of life often was overlooked. This is beginning to change. Many healthcare providers are grappling with the challenge of helping survivors maintain or regain a sense of wellbeing.

Surviving blood cancer is different from many other health issues, in that recovery may not be the end of the cancer experience. Some people may live with cancer as a chronic condition, requiring ongoing treatment. Others may go into long-term remission and will move on to lead normal lives, reporting few or no side effects.

However, treatment for blood cancer can also be very toxic, leaving some with unique health needs that require lifelong check ups. Also, many report that recovering from the social and emotional trauma of the blood cancer can take longer than getting better from some of the treatments.

Psychological, social, emotional, and spiritual impacts sometimes can be difficult to separate from the physical effects because they can be closely intertwined.

After finishing treatment

Some young adults have a feeling of isolation once treatment is finished. This is often described as the loss of a security blanket or safety net. Many may feel anxious about stopping treatment and uncertain of how effective the treatment was.

Finding a new 'normal'

Regaining a sense of normality and coming to terms with a new or possibly changed outlook on life can be challenging. As a young adult you may be apprehensive about returning to work or school, which can include dealing with friends, colleagues' reactions or finding new employment. For some people, this change in outlook presents an opportunity to travel or become involved in new activities.

Fear of relapse

Fear of relapse and anxiety associated with follow-up appointments is experienced by the majority of blood cancer survivors. Even if it has been years since you were successfully treated, no one, not even your doctor, can be sure that the cancer will not return. At some point, all survivors have to find a way to live this fear of relapse.

Relationships with family, whānau and friends

Survivors have differing experiences with their family, friends and partners once treatment is finished. Some do not experience any changes; others experience increased closeness, while others encounter difficulties in their relationships. Understanding and realising that different people will react in different ways is important. Open and honest communication is very important.

Dating

Many people find dating difficult whether they have a blood cancer or not. Young adults with a blood cancer deal with many issues related to their blood cancer which can make dating even more complicated, such as:

- Body image – change in physical appearance can cause you to feel unattractive.
- Confidence – difficulty in starting and maintaining conversations
- Uncertainty of future
- Coming to terms with your blood cancer experience
- Fertility

It is important to remember if you are finding dating difficult you are not alone and many others with a blood cancer have felt this way. Talking to people you feel comfortable with and allowing time to recover from your blood cancer experience can help to overcome theses issues. Many young adults find talking to others who have experienced similar issues can help as well.

Tips to help with dating:

- Getting involved with activities to meet other people and to practice your social skills
- Attend support groups with other young adults to discuss these issues.
- Check out the internet support available from reputable websites (see list of recommended websites at end of this book)
- Counselling, talk to your doctor or nurse or someone you feel comfortable with.

When should you tell someone you are dating that you have/had a blood cancer?
Some young adults like to tell people straight away as they feel that cancer is a very big part of their life, and if someone cannot accept this, it will not work out. Some take a more 'sooner rather than later' or 'case by case' approach and tell when the moment is right for them. Whatever you decide it is always good to use the option which is most comfortable for you.

How to tell someone that you have/had a blood cancer
Many young adults suggest that you should think about what you want to say to them before you go on the date. Being prepared may help you to feel more confident about the conversation. It is also a good idea to ensure you set aside enough time for your talk. This way you can say as much or as little as you would like too. Depending on your relationship some find that writing a letter helps you to think about what you would like to say. It can also give them time to respond to your letter.

Unfortunately some people may react badly to your news. This may upset you and make you feel as if you have done something wrong. Just remember you have done nothing wrong. Others may also surprise you and be supportive and understanding of your blood cancer experience.

Physical impacts of treatment

Fatigue
Physical, mental or emotional fatigue after finishing treatment is quite common. The duration and intensity will vary but it is important to find ways to cope, such as through exercise and meditation. See page 24 for more information.

Sexuality and relationships
Changes in body image and self esteem can occur as a result of treatment and may impact relationships. Physical changes from the cancer or treatment can be difficult to come to terms with. A decrease in sexual activity and anxiety about sexual performance may occur. See page 26 for more information.

Fertility
The effects of treatment on fertility vary widely. Understanding options for fertility preservation is important and coping with potential infertility by talking with experts is critical. See page 27 for more information.

Menopause
Onset of early menopause is a potential side effect of some cancer treatments. Hormone replacement therapy may need to be considered to prevent side effects such as osteoporosis. See page 30 for more information.

Late effects
These will vary depending on the type of cancer and treatments. Discussing a long term care plan will ensure that any long term effects are managed. Examples of some late effects are secondary cancers, heart complications, thyroid problems and difficulty with concentration and learning.

Surviving survival
There are no guidelines for how to survive survival. Many of these impacts may come and go and play different roles at different times throughout the cancer experience. Ways for coping with the changes associated with survivorship may include completing goals (e.g. finishing a degree, travelling), joining groups, faith/spirituality, moving forward, or finding a new appreciation for life and meaning of the blood cancer experience.

QUESTIONS TO ASK YOUR DOCTORS

Finding out you have cancer is devastating news. It can be difficult to know what to ask your doctor when you're still in a state of emotional shock!

You are encouraged to bring along a family member, partner, or close friend when you visit the doctor as it's difficult to remember everything. A notepad or recording device can also help. Keep all the information you collect in a file for future reference. Remember that knowledge is power, so ask as many questions as you need until you fully understand your diagnosis and the options available to you.

If you're not happy with the way the doctor is communicating with you, or you're unsure about the information they are providing, it is well within your rights to seek a second opinion. It is important that you trust the person that will be treating you – after all, they have your life in their hands!

TIPS

> "There's nothing worse than waiting for ages to see someone and then forgetting to ask them a question"

- If you have a question ask it
- If you have several questions, write a list
- If you don't understand the answer, say so
- Write down the answer
- If you forget the answer, don't be embarrassed to ask again

Here is a list of some questions you could ask:

- What kind of cancer do I have?
- How does the cancer affect my body?
- In your opinion, what is my prognosis?
- What is the success rate of this line of treatment?
- What are the pros and cons of treatment?
- What if I decide not have treatment?
- Are there other treatment options for me to consider?
- How long will treatment take?
- How long will I be in hospital?
- What are the common side effects of the treatment?
- How are the drugs administered?
- Will this line of treatment affect my fertility? What can be done to protect it?
- Who will be in charge of my treatment and care?
- Do I have to stay in hospital for treatment?
- Can my parent/sibling/partner stay with me if I have to be in hospital overnight?
- Will my friends be able to visit?
- Will I be able to continue studying/working throughout treatment?
- Is there anything I can do to help me get better? Should I eat differently? Should I exercise?
- What are your thoughts about complementary therapies? Are there any you would advise against?
- Will drinking alcohol effect my treatment? Can I go to parties/nightclubs?
- Can I have sex with my partner? Are there any 'dos' and 'don'ts'?
- Can I be around animals and pets?
- Will I have any long-term effects of the cancer or treatment?
- If the treatment works, what are the chances that the cancer will return?
- Will my lifestyle be affected by my cancer experience?
- Will I be able to work full-time, have kids, travel etc?

Recommended websites

The value of the internet is widely recognised; however, not all the information available may be accurate and up to date. For this reason, we have selected some of the key sites that you might find useful.

With the exception of our own websites, the Leukaemia & Blood Foundation does not maintain these listed sites. We have suggested sites we believe may offer credible and responsible information, but we cannot guarantee the information on them is correct, up to date or evidence based medical information.

Leukaemia & Blood Foundation	www.leukaemia.org.nz
LifeBloodLIVE – the online support and information forum	www.lifebloodlive.org.nz

Information for children:

Children with Leukaemia (UK)	www.leukaemia.org
After Cure (UK)	www.aftercure.org
Child Cancer Foundation	www.childcancer.org.nz
Ronald McDonald House	www.rmhc.org.nz
Starship Foundation	www.starship.org.nz

Information for adolescents and young adults:

Teenage Cancer Trust (UK)	www.teenagecancertrust.org
Teen Info on Cancer (TIC) (UK)	www.click4tic.org.uk
CanTeen	www.canteen.org.nz
Team Revive – Leukaemia Foundation Australia's online forum for 18–35 year olds	www.teamrevive.org
Planet Cancer (USA)	www.planetcancer.org

Cancer-related websites:

MacMillan Cancer Support	www.macmillan.org.uk

Other websites:

The Correspondence School	www.correspondence.school.nz
Youthline	www.youthline.co.nz
Department of Labour	www.dol.govt.nz
Ministry of Health	www.moh.govt.nz

JARGON BUSTERS

Acute leukaemias rapidly progressing cancers of the blood and bone marrow usually of sudden onset. Characterised by uncontrolled growth of immature blood cells which crowd the bone marrow and spill out into the blood stream.

Allogeneic from a donor's body.

Alopecia hair loss. This is a side effect of some kinds of chemotherapy and radiotherapy. It is usually temporary.

Anaemia shortage of red blood cells in your blood.

Antibody a protein that fights infection and disease.

Antiemetic a drug which prevents or reduces feelings of sickness (nausea) and vomiting (emesis).

Antigen a substance, usually on the surface of a foreign body such as virus or bacteria, which stimulates the cells of the body's immune system to react against it by producing antibodies.

Autologous from your own body.

Blast cells immature cells in the bone marrow which go on to mature into blood cells.

Blood count also called a **Full Blood Count (FBC)** or a **Complete Blood Count** (**CBC**). A routine blood test that measures the number and type of cells circulating in the blood.

B-lymphocyte a type of white cell normally involved in the production of antibodies to combat infection.

Bone marrow the tissue found at the centre of many flat or big bones of the body. The bone marrow contains stem cells from which all blood cells are made.

Bone marrow biopsy a procedure to collect a sample of the bone marrow. This is usually from the back of the hip bone, or occasionally from the breastbone (sternum). This procedure is often down under local anaesthetic or light sedation and incorporates either or both of the following. **Aspirate:** A procedure that involves removing (or aspirating) a small sample of bone marrow fluid for examination in the laboratory. **Trephine:** A procedure that involves removing a small core of bone and bone marrow for examination in the laboratory.

Cancer a disease characterised by uncontrolled production, accumulation and maturation of cells; often called malignant disease or neoplasm. Cancer cells grow and multiply eventually causing a mass of cancer cells known as a tumour.

Cannula a plastic tube which can be inserted into a vein to allow fluid to enter the blood stream. Often referred to as the 'drip', 'IV' or 'leur'.

Central line a flexible plastic tube inserted into a vein to give chemo, or take blood. Can be left in place for weeks or months.

Chemo short for chemotherapy.

Chemotherapy drug treatment with cytotoxic drugs.

Chromosomes chromosomes are made up of coils of DNA (deoxyribonucleic acid). DNA carries all the genetic information for the body in sequences known as genes. There are approximately 40,000 genes on 23 pairs of chromosomes. The chromosomes are contained within the nucleus of a cell.

Chronic leukaemias a group of cancers that affect the blood and bone marrow. Chronic leukaemias usually develop gradually and slowly progress, particularly in the early stages of disease. The leukaemia is called chronic because the leukaemia cells divide and increase in number more slowly than in acute leukaemia. Typically, chronic leukaemic cells are more mature than those found in acute leukaemia. Chronic leukaemias are sometimes diagnosed by chance, during a routine blood test.

Clinical trials a controlled and carefully monitored assessment of new forms of treatment. Trials can vary in design and size from small-scale trials of experimental treatments to large international trials that compare subtle variations in current therapies. Patients can opt not to join a trial or can opt out of a clinical trial at any time.

Complete remission anti-cancer treatment has been successful and so much of the disease has been destroyed that it can no longer be detected using current technology. In people with leukaemia this means that proportion of blast cells present in the circulating blood and the blood count has returned to normal.

Computerised axial tomography (CT scan or CAT scan) a specialised x-ray or imaging technique that produces a series of detailed three dimensional (3D) images of cross sections of the body.

Cure this means that there is no evidence of disease and no sign of the disease reappearing, even many years later.

Cytogenetic tests the study of the structure of chromosomes. Cytogenetic tests are carried out on samples of blood and bone marrow to detect chromosomal abnormalities associated with disease. This information helps in the diagnosis and selection of the most appropriate treatment.

Cytokines chemicals excreted by the immune system to communicate with other cells during the coordination of the body's immune response.

Cytotoxic poisonous to cells.

Diaphragm a layer of muscle under the ribs that separates the stomach from the chest and assists with breathing.

Disease progression this means that the disease is getting worse despite treatment.

Drip referring to an intravenous infusion (IV) of fluid; the slow, drop-by-drop infusion of a liquid.

DNA molecules found in the centre of the cell that carries all the genetic information for the body. There are four different chemical compounds of DNA (deoxyribonucleic acid) arranged in coded sequences called genes, which determine an individual's inherited characteristics.

Echocardiogram special ultrasound scan of the heart.

Electrocardiogram (ECG) Electrical trace of the heart.

Erythrocytes a red blood cell containing haemoglobin and transporting oxygen.

Genes collections of DNA. Genes direct the activity of cells. They are responsible for the inherited characteristics that distinguish one individual from another. Each person has an estimated 100,000 separate genes.

Groshong line a hollow tube inserted into a vein to give chemo, or take blood. See central line.

Growth factors a complex family of proteins produced by the body to control the growth, division and maturation of blood cells by the bone marrow. Some can be produced synthetically and are now available as drugs used to stimulate normal blood cell production following chemotherapy or bone marrow or peripheral blood stem cell transplantation.

Haemoglobin the oxygen-carrying part of an erythrocyte.

Haemopoiesis (also called haematopoiesis) the formation of blood cells.

Haematologist a doctor who specialises in diseases of the blood and blood marrow.

Hickman line a hollow tube inserted into a vein to give chemo, or take blood. See central line.

High-dose therapy the use of higher than normal doses of chemotherapy to kill off resistant and left over cancer cells.

High-grade lymphoma a fast-growing lymphoma.

Hodgkin lymphoma a type of lymphoma-cancer of the lymphatic system. All other types of lymphoma come under the heading of non-Hodgkin lymphoma.

Hypothyroidism a reduction in the normal function of the thyroid gland.

Immune system the body's defence mechanism to fight infection and disease.

Immune suppression the use of drugs to reduce the function of the immune system.

Immunocompromised when the function of the immune system is reduced.

Immunophenotyping specialised laboratory test used to detect markers on the surface of cells. These markers identify the origin of the cell.

Inversion where parts of a chromosome turn upside down or when two parts of a chromosome reverse their positions.

Leukaemia cancer of the blood and bone marrow characterised by the widespread, uncontrolled production of large numbers of abnormal and / or immature blood cells. These cells crowd the bone marrow and spill out into the bloodstream.

Leukaemic blasts abnormal blast cells which multiply in an uncontrolled manner, crowding out the bone marrow and preventing it from producing normal blood cells. These abnormal cells also spill out into the bloodstream and can accumulate in other organs.

Localised disease disease that is confined to a small area or areas.

Low-grade lymphoma a slow-growing lymphoma.

Lymph clear fluid that carries white blood cells around the lymphatic system.

Lymph node a gland that acts as sieve in the lymphatic system – fights infection.

Lymphatic vessels tubes which carry lymph and connect lymph nodes.

Lymphocyte a type of white blood cell that fights infection.

Lymphoid to do with the lymphatic system.

Lymphoma cancer that arises in the lymphatic system.

Magnetic Resonance Imaging (MRI) a body scanning technique which uses a very strong magnet and radiation waves to produce very clear and detailed three dimensional (3D) images of internal organs and structure.

Malignancy a term applied to tumours characterised by uncontrolled growth and division of cells (see cancer).

Matched unrelated donor (MUD) transplant an allogeneic stem cell transplant where the donor is unrelated to the patient, but with a similarly matched tissue type. Also called voluntary unrelated donor (VUD) transplant.

Mucositis an inflammation of the lining of the mouth throat or gut.

Mutation a change in the DNA code of a cell, caused, for example, by exposure to hazardous chemicals or copying errors during cell division. If mutations effect normal cell function this can lead to the development of disease due to the loss of normal function or the development of abnormal functions of the cell.

Myeloid term used to describe a pathway of maturation of blood cells in the bone marrow. Red blood cells, white blood cells (neutrophils, eosinophils, basophils and monocytes) and platelets are derived from the myeloid stem cell line.

Nausea feeling sick.

Neutropenia a shortage of white blood cells in your blood. When this occurs you are 'neutropenic'.

Neutrophil a type of white blood cell – fights infection.

Oncologist a doctor who specialises in treating solid tumor cancers.

Partial remission the tumour shrinks to less than half its original size after treatment. In people with leukaemia this means that the proportion of blast cells in the marrow has been reduced, following treatment but not necessarily below five per cent. There are still some leukaemic cells present.

Pathologist a doctor who specialises in the laboratory diagnosis of disease and how disease is affecting the organs of the body.

Petechiae Red or purple flat pinhead sized spots on the skin, especially on the legs. They are caused by tiny bleeds under the skin, usually as a result of a severe shortage of platelets.

PICC line peripherally inserted central venous catheter (see central venous catheter). It is inserted in the arm. PICC lines are sometimes used for people having chemotherapy.

Platelets a type of blood cell that stops bleeding.

Positron Emission Tomography (PET scan) a special type of x-ray or imaging technique capable of distinguishing between normal tissue and areas of cancer deep in the body.

Prognosis an estimate of the likely course of a disease.

Purpura purple spots on the skin, often accompanied by bleeding from the gums. It is caused by a shortage of platelets as well as fragile skin.

Radiographer a person who takes x-rays.

Radiologist a doctor who interprets x-rays and scans.

Radiotherapist someone who specialises in giving radiotherapy.

Radiotherapy treatment by x-rays.

Relapse the return of the original disease.

Resistant or refractory disease this means that the disease is not responding to treatment.

Regimen a programme of treatment including drugs, how much of each you have, and when you have them.

Leukaemia &
Blood Foundation
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WOULD YOU LIKE MORE INFORMATION?...

Leukaemia &
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Vision to Cure - Mission to Care

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Remission is when your blood cancer no longer shows up in any test.

Sedation medicine to make you feel sleepy.

Spleen an organ that accumulates lymphocytes, acts as a reservoir for red blood cells for emergencies, and destroys red blood cells, white blood cells and platelets at the end of their lifespan. The spleen is found high in the abdomen on the left-hand side. It is often enlarged in diseases of the blood or bone marrow.

Splenomegaly enlargement of the spleen.

Stage the extent or spread of disease in the body.

Staging an assessment of the extent or spread of disease in the body.

Standard therapy the most effective and safest therapy currently being used.

Stem cell a young blood cell that the body hasn't yet turned into a red, white or platelet cell.

Stem cell transplant general name given to bone marrow and peripheral blood stem cell transplant. Typically a transplant involves taking early blood/bone marrow cells from one person and giving them to another to restore normal bone marrow function in the recipient.
These treatments are used to support the use of high-dose chemotherapy and/or radiotherapy in the treatment of a wide range of cancers including leukaemia, lymphoma and other serious diseases.

Steroid a type of drug used to relieve swelling and inflammation.

T-lymphocyte a type of white cell involved in controlling immune reactions.

Thymus a gland found behind the breast bone involved in the maturation of T-lymphocytes (T-cells).

Thrombocytopaenia shortage of platelets in your blood.

Tumour an abnormal mass of cells which may be non-malignant (benign) or malignant (cancerous).

Ultrasound pictures of the body's internal organs built up from the interpretation of reflected sound waves.

Vomiting being sick, throwing up, spewing to eject some of the contents of the stomach through the mouth.

White cells specialised cells of the immune system that protect the body against infection. There are five main types of white blood cells; neutrophils, eosinophils, basophils, monocytes and lymphocytes.

X-ray a form of radiation used in diagnosis and treatment.

INDEX

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Vision to Cure - Mission to Care

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☐ Dictionary of Terms
☐ Acute Myeloid Leukaemia
☐ Chronic Myeloid Leukaemia
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☐ Myeloproliferative Disorders
☐ Multiple Myeloma
☐ Autologous Stem Cell Transplants
☐ My guide to blood cancer – for adolescents and young adults
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