

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?

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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.

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.

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

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: _____

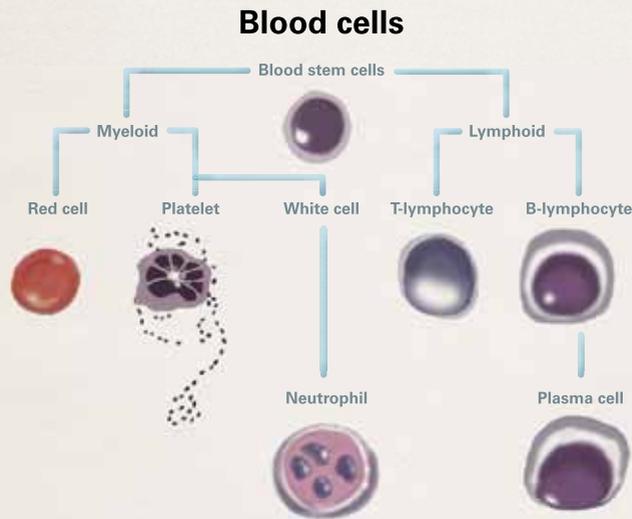
Why did I get a blood cancer?

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).



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 |

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.

| | |
|-----------------------------|---|
| 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 |

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).

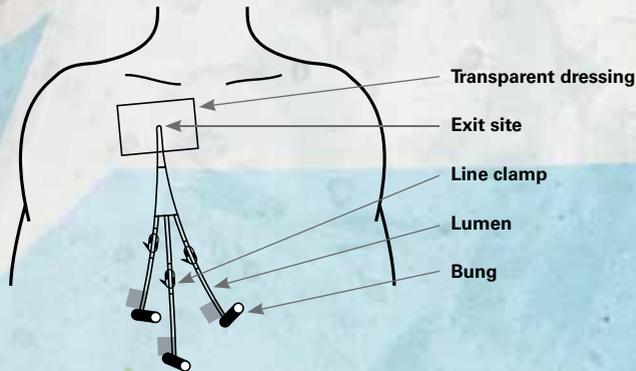
Chemotherapy is usually given in several cycles (or courses) with a rest period of a few weeks in between each cycle. This is to allow the body time to recover from the side effects of chemotherapy. For example a typical chemotherapy regime for acute myeloid leukaemia (AML) might involve four to five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

"I'VE GOT MY PHONE AND IPOD

MY TWO MOST PRECIOUS THINGS IN HERE."

- 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.

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

"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."

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.

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.

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

"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."