

Joe has Leukaemia



 leukaemia &
blood cancer
new zealand

our mission is to care, our vision is to cure



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Joe has Leukaemia

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This is Joe. He lives with his Mum, Dad, sister Hayley, and baby brother Alex.

He has a dog named Scruffy, a cat named Harry, and two goldfish called Bubbles and Beryl.

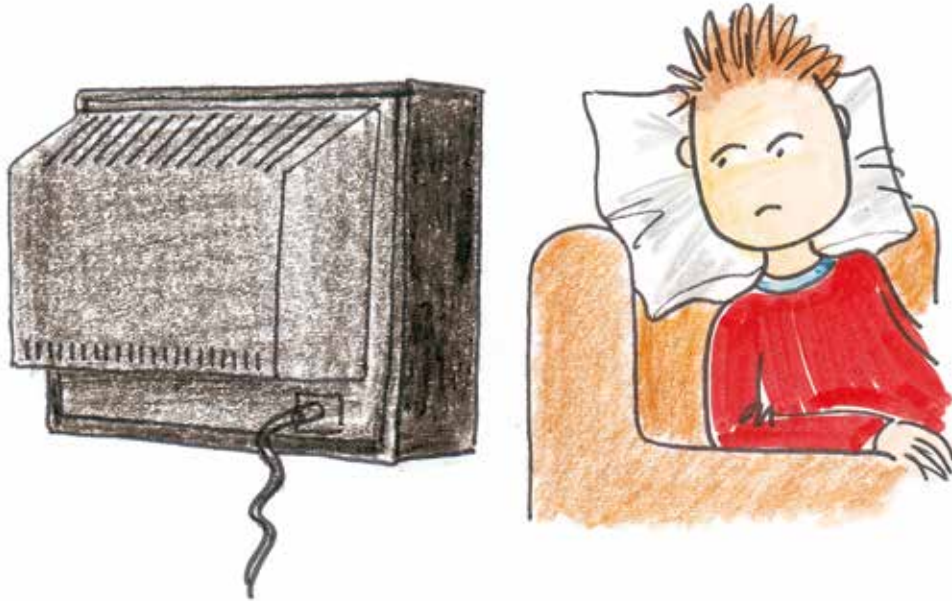


He enjoys playing soccer with his friend Matt.

Joe became unwell during his first year at school, and this is the story of what happened to him.



For a few weeks Joe had been sick with a cough and a cold. He had become very pale.



Joe had felt far too tired to play and he just wanted to lie down and watch TV. One day his mum noticed that he had lots of bruises on his legs and his body, so she took him to the doctor. The doctor said that Joe needed to go to the hospital straight away.

When they arrived at the hospital, the doctor there said that they needed to find out why Joe was so sick and he would have to stay for a few days.

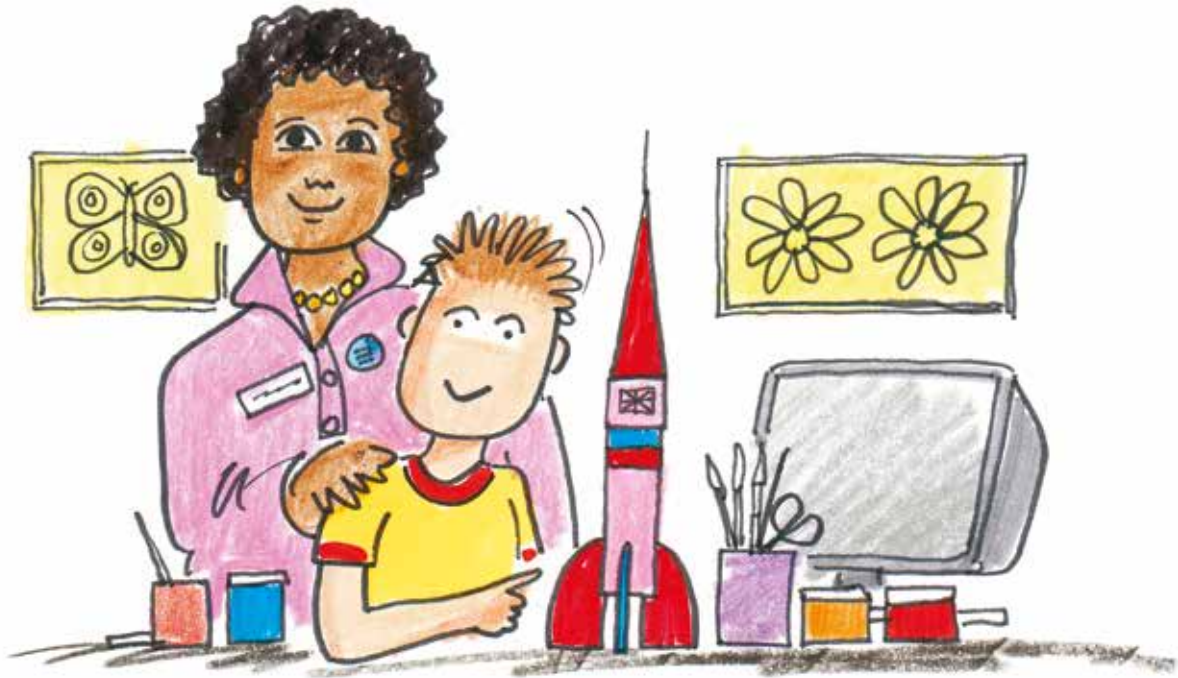


Joe was really upset that he was leaving his sister and baby brother, but his mum and dad arranged it so that Mum could stay in hospital too, and Dad, his sister, and baby brother visited each day – this made Joe feel a little happier.

Joe had to have a lot of tests, some of them hurt a bit but Mum or Dad were always there to give him a cuddle and tell him how brave he was being.



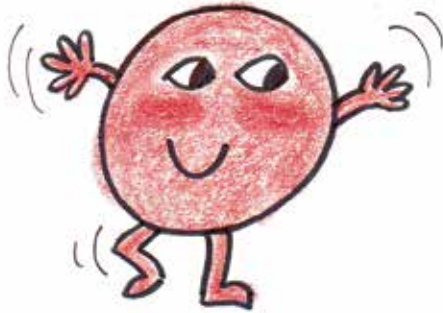
The nurses were very kind and he made some lovely things with the play specialists and teachers on the ward.



Dad had to go to work so Grandma looked after Hayley and Alex. Everyone was missing everybody else and Joe just wanted to go home.

After a few days the hospital doctor saw Joe, Mum and Dad, and explained that Joe had been so sick because he had leukaemia. There were lots of medicines they were going to use to try and make him better.





Red Cells

Joe asked the doctor "What is leukaemia?" "Well", explained the doctor, "Leukaemia is a form of cancer and in this case it is when the factory in your body which

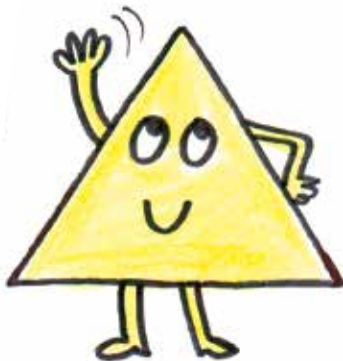
makes your blood, is not working properly. There are different kinds of leukaemia. The factory in your body is called the bone marrow and



White Cells

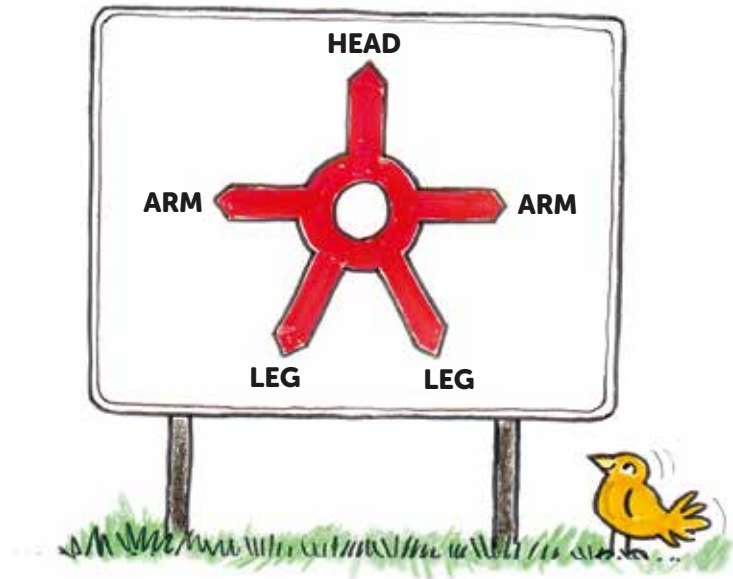
this bone marrow is in

the middle of your bones. The factory makes different kinds of blood cells – red cells, white cells and platelets."



Platelets

"After the blood has left the factory it travels through your arteries and veins. These are like roads that go to all parts of your body.



"The red cells carry the oxygen you breathe to all parts of the body; they also help to keep you healthy and full of energy."



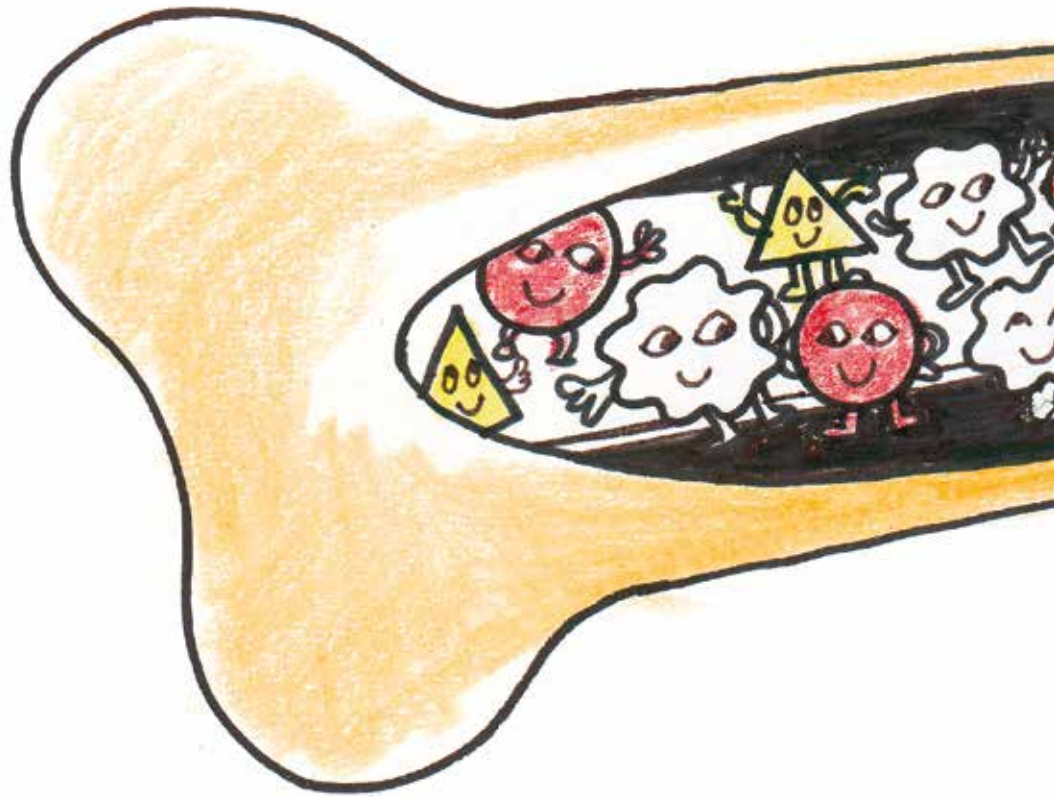
“The platelets, or mending cells, help the arteries and veins to stop any bleeding if you cut or bruise yourself and the white cells help to fight infection.

“When you have leukaemia, your bone marrow has trouble making healthy blood cells. Instead, it makes a lot of damaged cells that do not work properly and cannot fight infection. That is why you have had a lot of coughs and colds.”

“Because your bone marrow is making far too many of these damaged cells, there is not enough room for the healthy cells and the platelets to grow. This is why you have felt so tired, and got lots and lots of bruises when you have not even bumped yourself!”

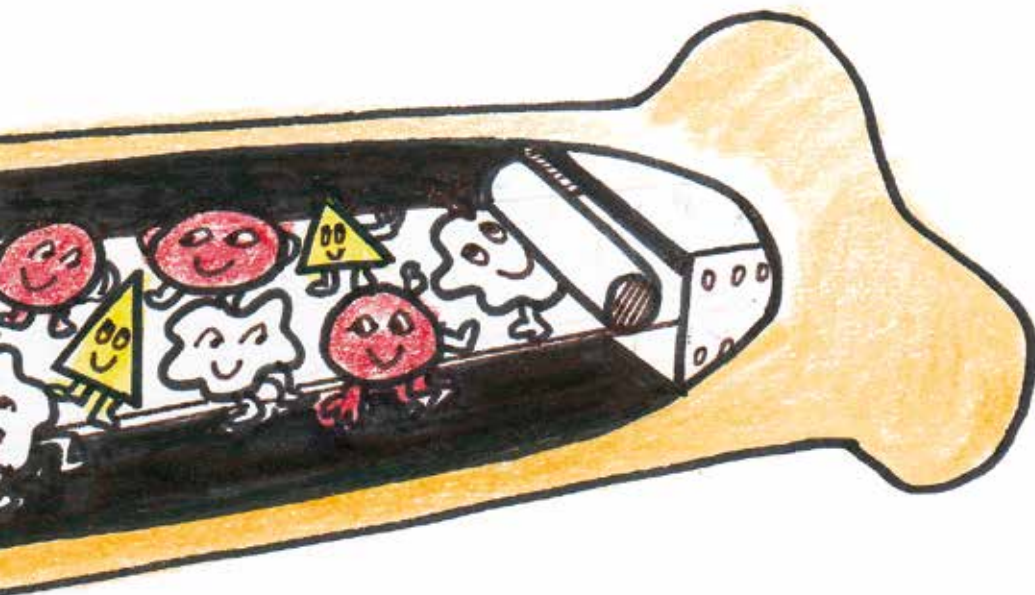
“Do you have a garden? If you do, you will know that sometimes you get lots of weeds and the weeds can take over so that there is not much room for flowers and vegetables to grow. That is like the damaged cells in your bone marrow; they are taking over and not leaving enough room for healthy cells to grow.”





"No-one knows why this has happened, but we do know that there is nothing you or anyone could have done that could have caused it."

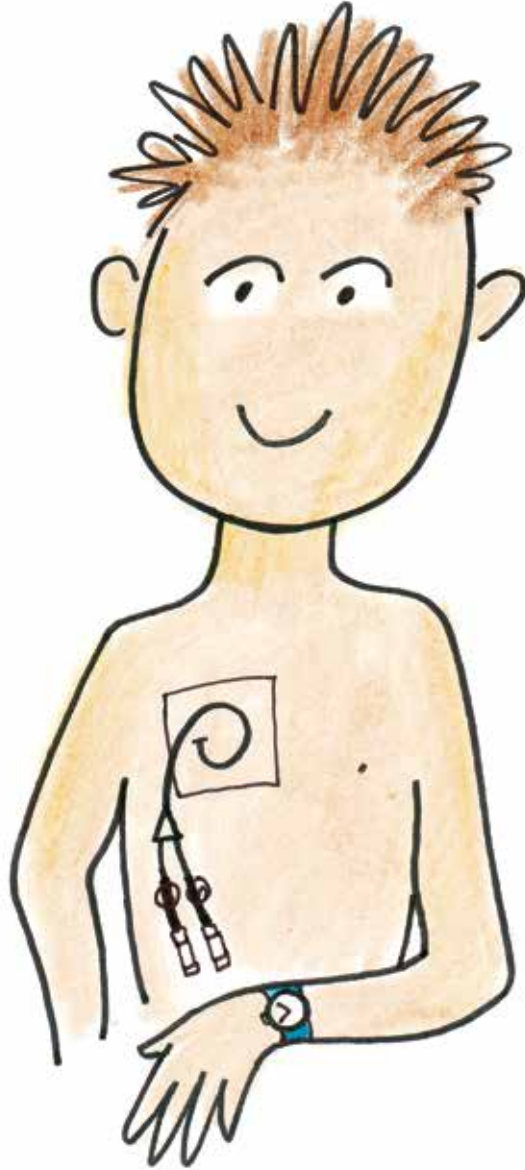
Joe asked when he would get better and the doctor told him,



"We hope to make your bone marrow work properly very soon. This will make room for the platelets, the red cells and the white cells to grow again and will make you feel better."

“You will have lots of different medicines called chemotherapy for a long time, even when you feel quite well. Some of these will come as tablets and some will be medicine which will go through a central line – there are different types, a Portacath, a PICC line and a Hickman line. The line is used for giving treatments and taking blood tests and saves some injections.”

“To make sure that the medicines are working and that the damaged cells are not growing again, you will sometimes need to have blood tests, bone marrow tests, or a lumbar puncture, like you have already had.”



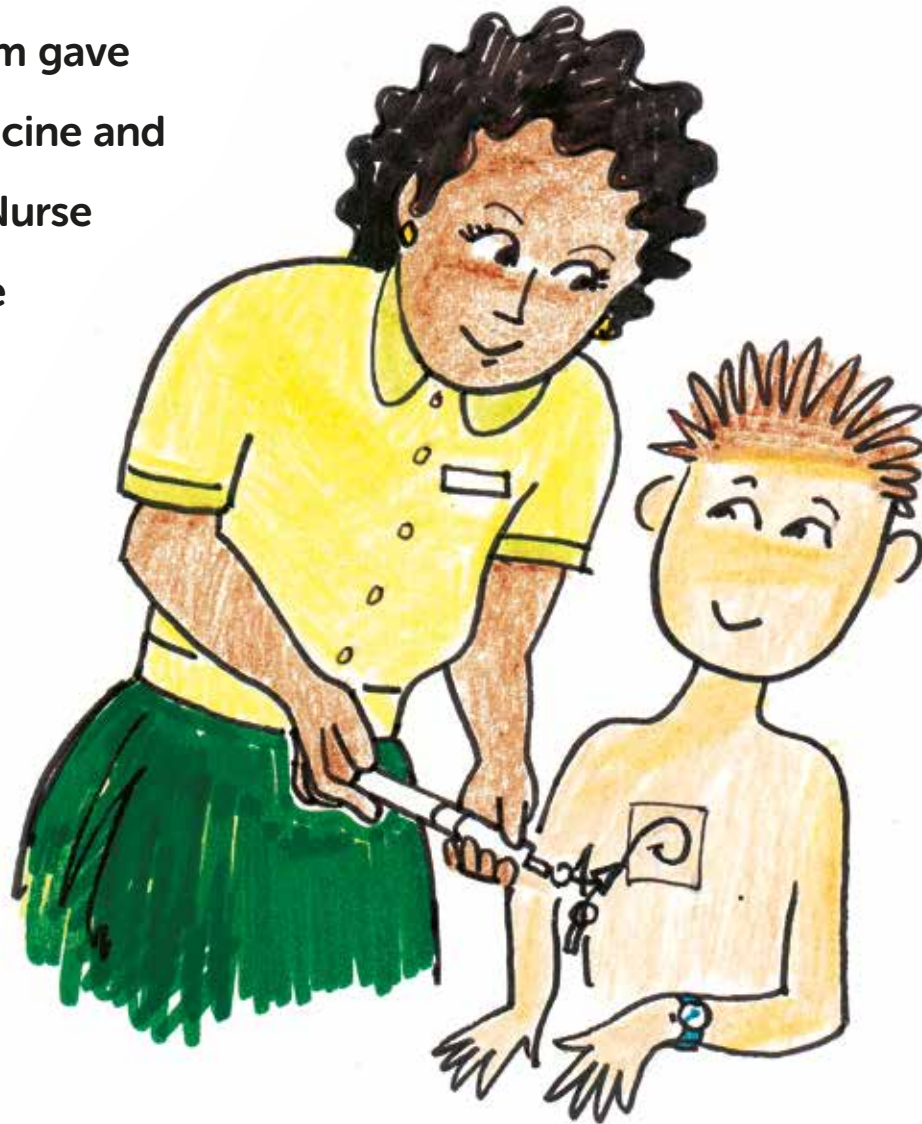


Later Joe had chemotherapy through the drip that was attached to the line.

This did not hurt but sometimes made him feel a bit funny. When the chemotherapy had finished the machine beeped!

Joe also had to have a blood transfusion which helped him to have more energy and made him feel better.

When Joe was at home
Dad and Mum gave
him his medicine and
the District Nurse
came to take
some blood.





Joe still had to come to the hospital quite a lot and usually Mum came with him, but if Dad could get time off work, he, Hayley and baby Alex came too. Joe saw the doctor and the nurses, sometimes he got

weighed and measured. He always had to have some blood taken to make sure the chemotherapy was working. Sometimes Joe had to stay in the hospital when he had a temperature. Hayley went to stay with Grandma.



Joe made some friends in the hospital, one of whom was called Lucy; they liked talking and playing together and Joe knew that Lucy understood how he felt about being in hospital.

When Joe was not at the hospital, he played with his best friend Matt. They played games, just like they did before Joe became sick.



Hayley felt very upset sometimes because Joe got so many presents, and she felt a bit left out. She did not want to upset Mum and Dad so she did not tell them.



One day Hayley felt so jealous of her brother and all his presents that she painted spots all over her body, so that people would think she was sick too. "Oh dear", said Mum, "Are you sick too?" She gave her a big hug and then Scruffy jumped up and licked Hayley's face ... and some

of the spots disappeared! Mum and Dad realised that Hayley was probably feeling left out. After that she had lots of 'special times' with Mum and Dad.



Joe asked the doctors and nurses if he could go back to school. They told him that he could if his blood counts were OK. He really liked school and everyone was pleased to see him. Joe went with his best friend Matt. They were in the same class and were able to sit next to each other. When Joe could not go to school, he was given some school work that he could do at home.





One day Matt caught chicken pox and Joe had to go back to the hospital and have some medicine to stop him from catching chicken pox as well. People with leukaemia can be very sick if they catch chicken pox or measles. Matt soon got better and before long he was able to play outside again.

Matt and Joe thought it strange that you could catch chicken pox but that you could not catch leukaemia.

For a while Joe had no hair. Mum told him that the chemotherapy had caused his hair to fall out but that it would grow back.

This made him feel a bit different from everybody else, so sometimes he wore a cap, especially in winter, but most of the time he did not wear anything at all on his head.





At the clinic Joe saw lots of other boys and girls, some of the girls had wigs, some wore hats or caps or scarves, and some already had their own hair again. They often talked and played together.

After some months, when he was at the hospital clinic, Joe said to the doctor, "I feel much better now and I can do everything that Matt can do, so why do I still have to have my line and take my tablets?"



The doctor said, "I am really glad that you are so well. We want you to enjoy lots of things, but you do still need your treatment. Your bone marrow will not be able to work properly unless you take all your medicines and that means that you have to take them for a long time yet."



"One day the medicines will stop and you will not need to have a line or take tablets anymore, but you will still need to come and see us at clinic."



Joe felt really well. He went to school and played with his friends there and at home he helped his mum and dad and played with his sister and baby brother.



At last it was the day that Joe and his family had waited for. He went to the hospital with Mum and Dad, and the doctor told him, "What a brave boy you have been, you have done really well! You have had all your treatment now and in

a while we will take your line out. You will still have to come back and see us regularly for check-ups to make sure that the leukaemia has not come back".

When Joe arrived home he found that Grandma and the family had arranged a party. All his friends from school came, including Matt.

Everyone had a really great time and Joe said, "When I am older, I think I would like to become a doctor or a nurse and help other children like me".





What would you like to be when you're older?

What these words mean

ANAESTHETIC

When the doctors give you some medicine that makes you go to sleep during an operation, so you don't feel any pain

BLOOD TEST

When a tiny sample of your blood is looked at to see how many red cells, white cells and platelets you have

BLOOD TRANSFUSION

When your blood count is low you may need extra blood to help you feel better

BONE MARROW TEST

Under anaesthetic a sample of your bone marrow is removed from the bones in your back using a special needle

CANCER

When cells in your body do not work properly

CHEMOTHERAPY

A mixture of different medicines which treat cancer

HAEMATOLOGIST

A doctor who looks after people with blood diseases like leukaemia

What these words mean

HICKMAN LINE

One or two lines are inserted under anaesthetic, the end comes out of a small hole in your skin on your chest

LEUKAEMIA

A form of cancer when the factory that makes your blood is not working properly

LUMBAR PUNCTURE

Under anaesthetic a needle is used to take liquid from the spine and sometimes medicines are put in

NEUTROPENIC

When you hardly have any neutrophils (the white cells that fight infections).
Being neutropenic means you are more at risk of getting infections

PICC LINE

One or two lines are inserted under anaesthetic. The end comes out of a small hole in your skin on your arm

PORTACATH

A device that is inserted under the skin under anaesthetic near the armpit, then runs under the skin to the main vein in the neck.

If treatment is given or blood taken, 'magic cream' is put on the skin covering the portacath one hour before this happens – this means it will not hurt so much when the needle goes in



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Leukaemia & Blood Cancer New Zealand is a national organisation in New Zealand dedicated to supporting patients and their families living with leukaemia, lymphoma, myeloma and related blood conditions.

**Every family's experience is different;
living with a blood cancer or condition is not easy,
but you don't have to do it alone.**

0800 15 10 15

www.leukaemia.org.nz





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**If you have any questions
or if you are unsure about anything,
please ask a member of your treatment team
or contact Leukaemia & Blood Cancer New Zealand.**

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