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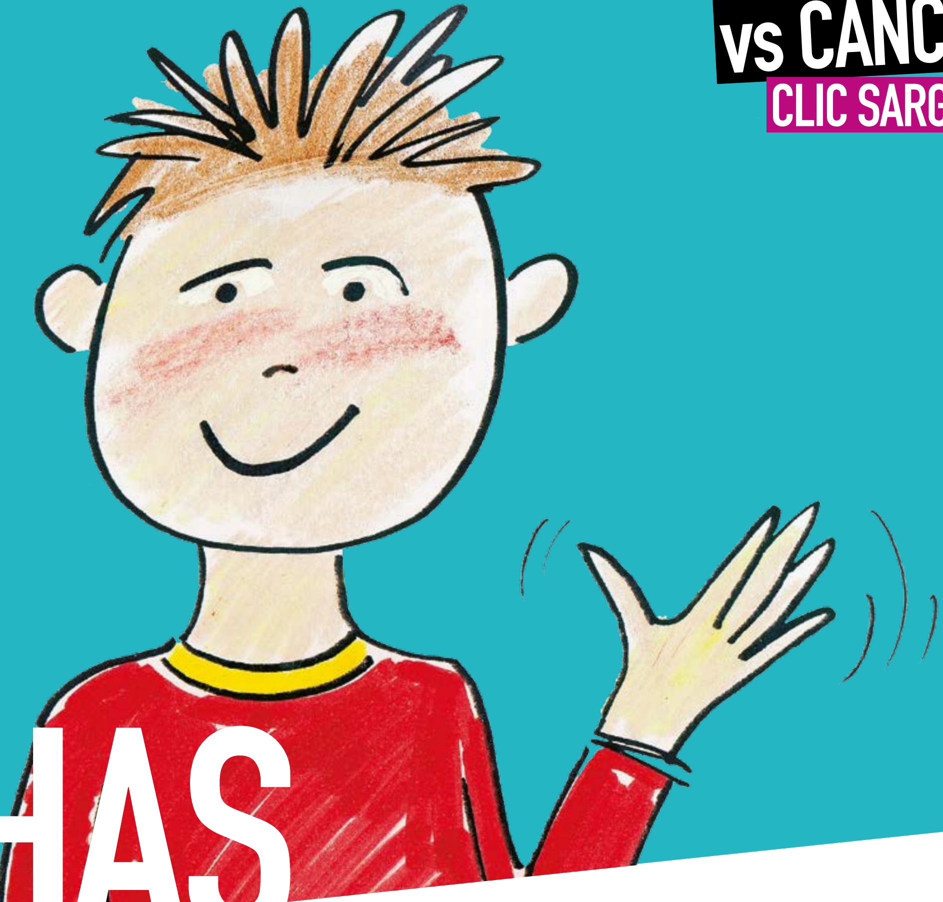

JOE HAS LEUKAEMIA

Joe has leukaemia is a storybook written especially for parents, carers and educational professionals to read with children, to help them understand what leukaemia is and the treatment it involves.

At the back of the book you will find a useful glossary of words you may come across when dealing with doctors and hospitals.

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Medical review by consultant paediatric haematologists Jeanette Payne and Jenny Welch.

For information about the sources used to put this publication together, or if you have any comments or queries about it, please contact us on 0300 300 0803 and ask to speak to the Information Manager.

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JOE HAS LEUKAEMIA

By Victoria Barton

This book belongs to

....

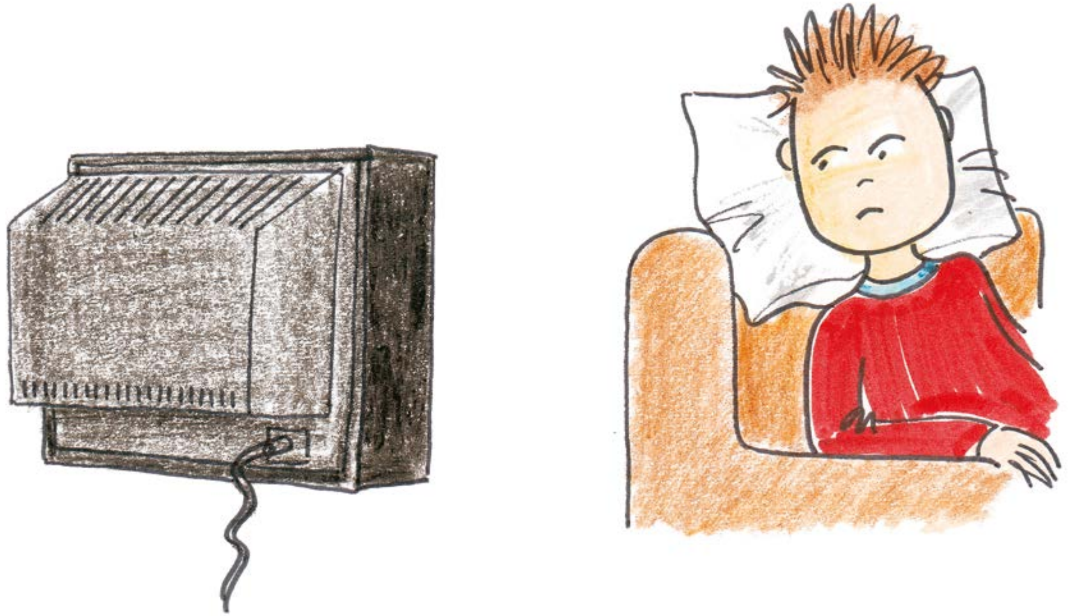
Illustration by Tony Harris

This is Joe. He lives with his mum, dad, sister Hayley, and baby brother Alex.

He has a dog called Scruffy, a hamster called Harry, and two goldfish called Bubbles and Beryl. He enjoys playing football with his friend Omar.

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

For a few weeks Joe had been unwell 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.



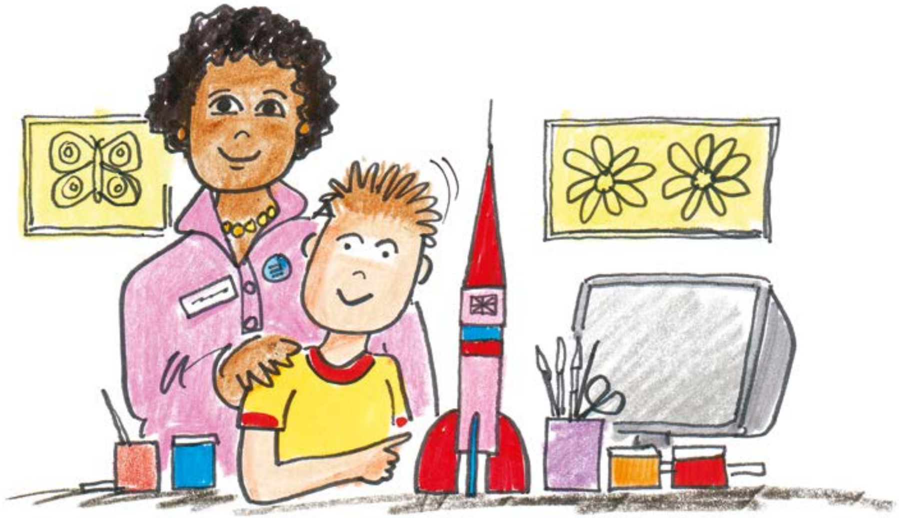
One day his mum noticed that he had lots of bruises on his legs and his body, so she took him to the doctor. The doctor said that Joe needed to go to the hospital straight away.

When they arrived at the hospital, the doctor there said that they needed to find out why Joe was so poorly 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 parents arranged it so that Mum could stay in hospital too. His dad, sister and brother visited each day which 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. He also had a social worker who talked to his family about what help they might need.



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, his mum and dad, and explained that Joe had been so poorly because he had *leukaemia**. There were lots of medicines they were going to use to try to make him better.

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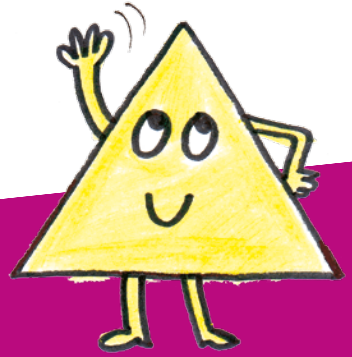
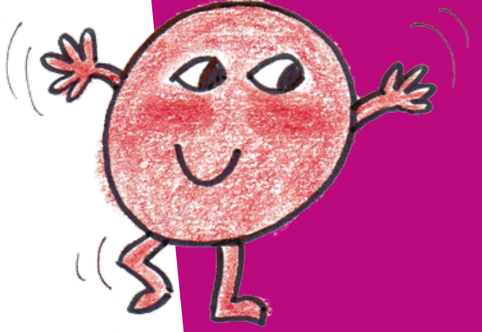
* Words in italics are explained under 'What these words mean' at the back of this book.

Joe asked the doctor **"What is *leukaemia*?"**

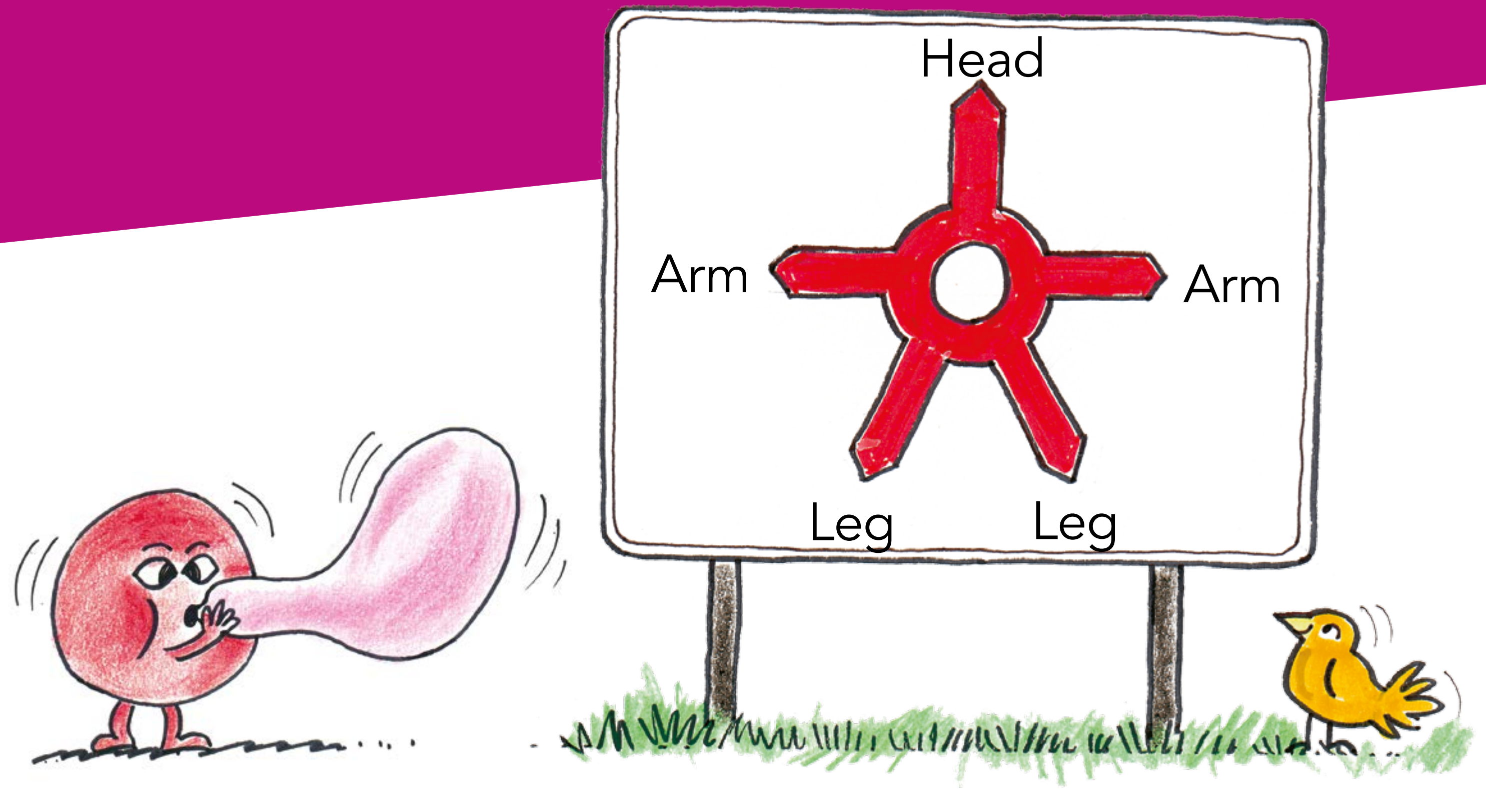


"Well," explained the doctor, "leukaemia is a type of cancer and in this case it is when the factory in your body which makes your blood is not working properly.

There are different kinds of leukaemia. The factory in your body is called the bone marrow which is in the middle of your bones. The factory makes different kinds of blood cells – red cells, white cells and 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. 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 *leukaemia* cells that do not work properly and cannot fight infection. That is why you have had a lot of coughs and colds.

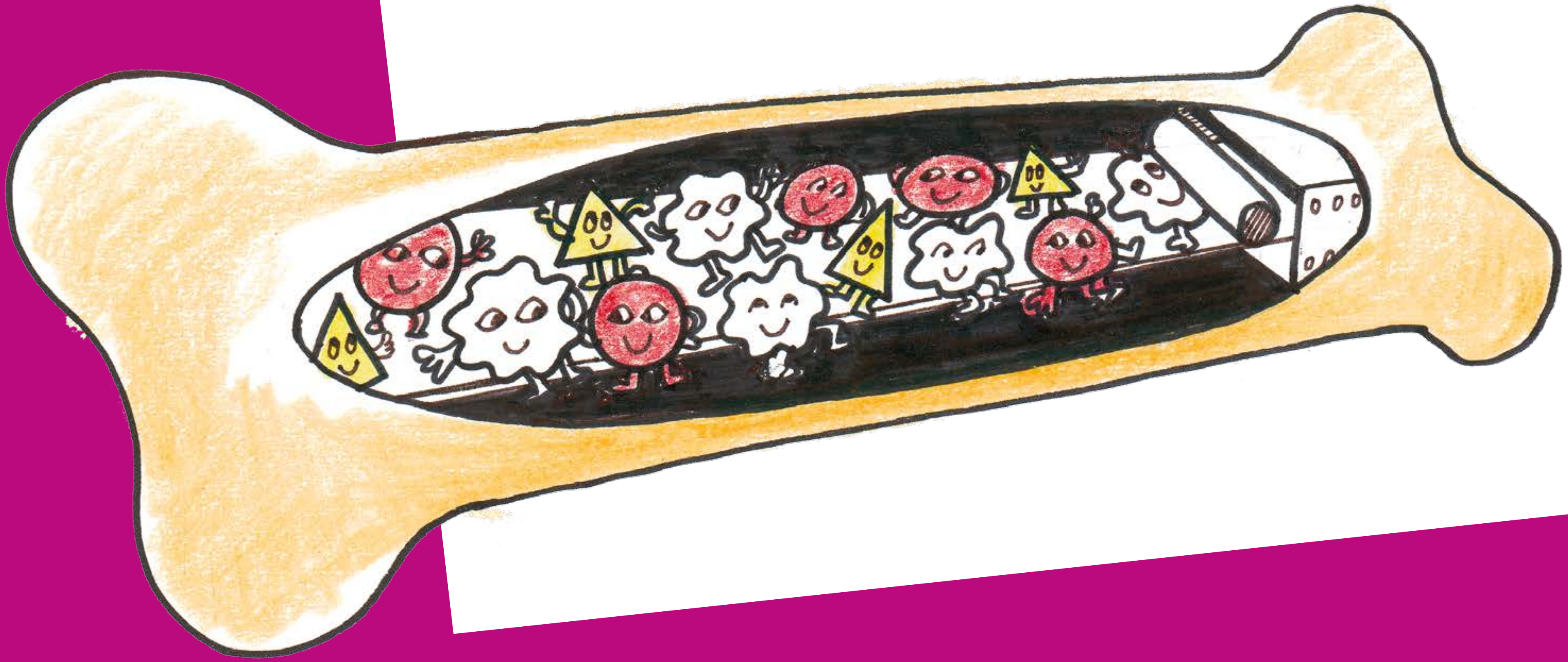
Because your bone marrow is making far too many of these *leukaemia* cells, there is not enough room for the healthy *cells* and the platelets to grow. This is why you have felt so tired, and got lots of bruises when you haven't even banged yourself.

Do you have a garden? If you do, you will know that sometimes you get lots of weeds which can take over so that there is not much room for flowers and vegetables to grow.

That is like the *leukaemia* 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."

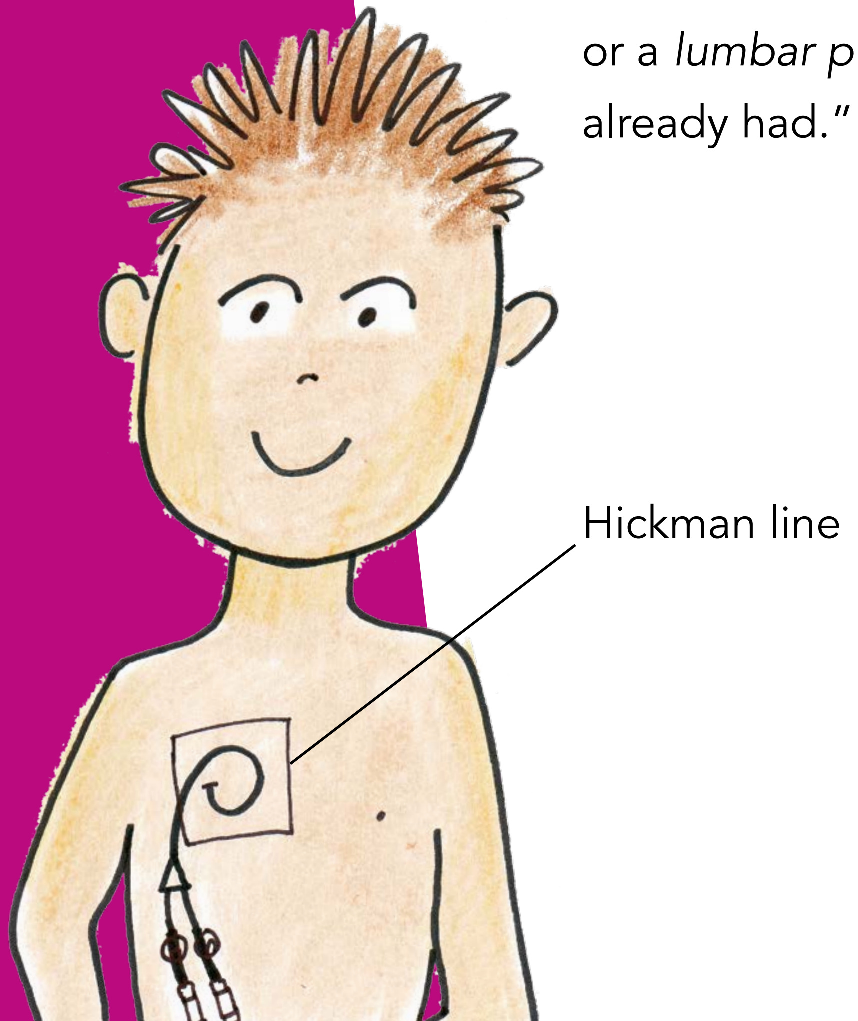
Joe asked when he would get better and the doctor told him, "We hope to make your bone marrow work properly very soon. This will make room for the platelets, the red *cells* and the white *cells* to grow again and will make you feel better.



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 straight into your body through a central line. There are different types, a *portacath*, a *Broviac* and a *Hickman* line. Often the line is called a wiggly! The line is used for giving treatments and taking *blood* tests and saves having some injections.

To make sure that the medicines are working and that the *leukaemia* cells are not growing again, you will sometimes need to have *blood tests*, *bone marrow tests*, or a *lumbar puncture*, like you've 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 bleeped!

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 community 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 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 Granny.

Joe made some friends in the hospital. One girl was called Lucy and they liked talking and playing together. Joe knew that Lucy understood how he felt about being in hospital and how different you could feel. Like sometimes, when you were taking steroids, you wanted to eat lots of different things.

Then sometimes you didn't want to eat at all and had to have some special food down a tube that goes down your nose and into your tummy. The nurse helped Joe get used to the tube and it meant his body could get the food it needed to get better, even when he couldn't eat or drink enough.

When Joe was not at the hospital, he played with his best friend Omar. Omar understood if Joe was feeling a bit grumpy because of the treatment. He just waited until Joe felt better and they then played games, just like they did before Joe became ill.

Hayley felt a little 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 ill too. "Oh dear", said Mum. "Are you poorly too?"

She gave Hayley 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 them.

Joe asked the doctors and nurses if he could go back to school. They told him that he could if he felt well enough. He really liked school and everyone was pleased to see him. Joe went with his best friend Omar. They were in the same class and were able to sit next to each other. Sometimes a teacher visited Joe at home if he could not go to school.

One day Omar caught chickenpox and Joe had to go back to the hospital to have some medicine to stop him from catching it as well. Children with *leukaemia* can be very poorly if they catch chickenpox or measles.

Omar soon got better and before long he was able to play outside again. Omar and Joe thought it was strange that you could catch chickenpox but that you couldn't 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 a lot of the time he did not wear anything at all on his head.

The doctor said the *chemotherapy* made it easier for Joe to get sunburnt, so he wore a hat and sun cream when he was out in the sun.

At the clinic Joe saw lots of other boys and girls, some of them 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 Omar 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 feeling better. We want you to enjoy lots of things, but you do still need your treatment. You need to carry on taking all your medicines to help stop the *leukaemia* coming back. That means you have to have 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. 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 organised a party. All his friends from school came, and Hayley and Scruffy were enjoying the balloons.

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

You may hear lots of strange new words when you're in hospital. Below we explain what some of them mean. If you're unsure about any others, just ask your doctor or nurse.

Anaesthetic

This is a medicine a doctor gives you that makes you really sleepy, so that you fall asleep. You have an anaesthetic before an operation or bone marrow test, so you can sleep right through it without feeling it. Afterwards the doctors will wake you up.

Blood test

When a tiny sample of your blood is looked at to see how many red cells, white cells and platelets you have (this is called a full blood count or FBC).

Blood / platelet transfusion

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

Bone marrow test

When a sample of your bone marrow is removed from the bones in your back using a needle. You will have an anaesthetic sleep, so you won't feel it.

Broviac

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

Cancer

When the cells in your body become abnormal (bad) and continue to grow on their own, out of control.

Cell

Everyone's body is made up of millions of tiny cells. They make different things our bodies need, like blood, muscle or bone.

Chemotherapy

A mixture of different medicines which treat cancer.

Hickman line

A long plastic tube inserted into one of the big veins (blood vessels) in your body, usually your neck. The end comes out through a small hole in the skin on your chest. This is inserted under general anaesthetic.

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

A person is neutropenic when they hardly have any neutrophils (the good white cells that fight infections). Being neutropenic means you are more at risk of getting infections.

Portacath

A device, or bobble, is inserted under the skin near the armpit under general anaesthetic and a very thin tube (the line) then runs under the skin to the main vein in the neck. If treatment is given or blood taken, 'magic cream' is put on to the skin covering the bobble beforehand – to make it go numb so it will not hurt so much when the needle goes in.

Theatre / operating room

This is where you will go if you need to have an operation or bone marrow test. The room has lots of equipment in it that helps doctors and nurses to keep you well.

DO YOU HAVE ANY QUESTIONS, OR NEED SOME HELP?

Talk to your CLIC Sargent care professional, or call us on 0300 330 0803 and we'll put you in touch with someone who can help.
You can also visit our website at **clicsargent.org.uk**

CLIC Sargent is the UK's leading cancer charity for children, young people and their families. From the day the doctor says cancer, CLIC Sargent care teams will step in to provide exceptional care and support to help with the impact on day-to-day life.

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