

The image features a central cartoon boy with black hair and large black-rimmed glasses, wearing an orange sweater. He is holding a blue fishbowl with two smiling red fish. Surrounding him are various other cartoon characters: a woman with a purple headscarf and grey hair, a woman with brown hair and pink earrings, a man with a beard and a purple cap, a woman with brown hair and a blue jacket, a woman with long black hair and pink glasses, a woman with long brown hair and blue glasses, a man with black hair and a blue jacket, a woman with dark hair and blue glasses, a grey cat, and a brown bear. The background is a solid teal color.

CHARLIE HAS LEUKAEMIA

**YOUNG LIVES
vs CANCER**

CHARLIE HAS LEUKAEMIA

Version 5

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We'd like to say a big thank you to the children, parents and carers who helped us to update this book.

For information about the sources used to create this book, or if you have any comments or questions about it, please contact us at brand@younglivesvscancer.org.uk.

YOUNG LIVES
vs CANCER

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This book belongs to:

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Meet Charlie

This is Charlie. He's 10 years old and he lives with his mum, his stepdad Matt, his stepbrother Ethan, who's eight, and his little sister Ellie, who's four. They have a dog called Millie, a hamster called Fudge and two goldfish called Nemo and Bubbles.

He likes reading stories and playing football with his best friend Omar.

Recently, Charlie hasn't been very well. This book is about what happened to him.

More info

While you're reading Charlie's story, you'll sometimes see a box like this. This is where you can find extra information about *leukaemia** that you might want to know.

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

Finding out what's wrong



For a few weeks Charlie had been unwell with a cough and a cold. He had become very pale.

Charlie felt too tired to play and just wanted to lie down and watch TV.

One day, 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 Charlie needed to go to the hospital straight away.

When they arrived at the hospital, they met Dr Li. She said they needed to find out why Charlie was so poorly, so he'd have to stay in hospital for a few days.



Charlie was upset that he would be away from Ethan and Ellie, but Mum and Matt arranged it so that Mum could stay in hospital too.

Matt, Ethan and Ellie visited every day, which made Charlie feel a little happier.

Charlie had to have a lot of tests. Some of them hurt a bit but Mum or Matt was always there to give him a hug and tell him how brave he was being.



The nurses were very kind and he made some lovely things with Maggie, who was the **play specialist** on the ward. He also had a **social worker** called Simon from Young Lives vs Cancer.

Simon talked to Charlie's family about what help they might need.

Matt had to go to work so Grandma looked after Ethan and Ellie. Everyone was missing each other, and Charlie just wanted to go home.



What's leukaemia?



After a few days, Dr Li saw Charlie, Mum and Matt again, and explained that Charlie had been so poorly because he had **leukaemia**. There were lots of medicines they were going to use to try to make him better.

“What is **leukaemia**?” asked Charlie.

“Well,” explained Dr Li, “**leukaemia** is a type of **cancer**. In this case, it’s when the factory in your body that makes your blood isn’t 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.



Did you know?

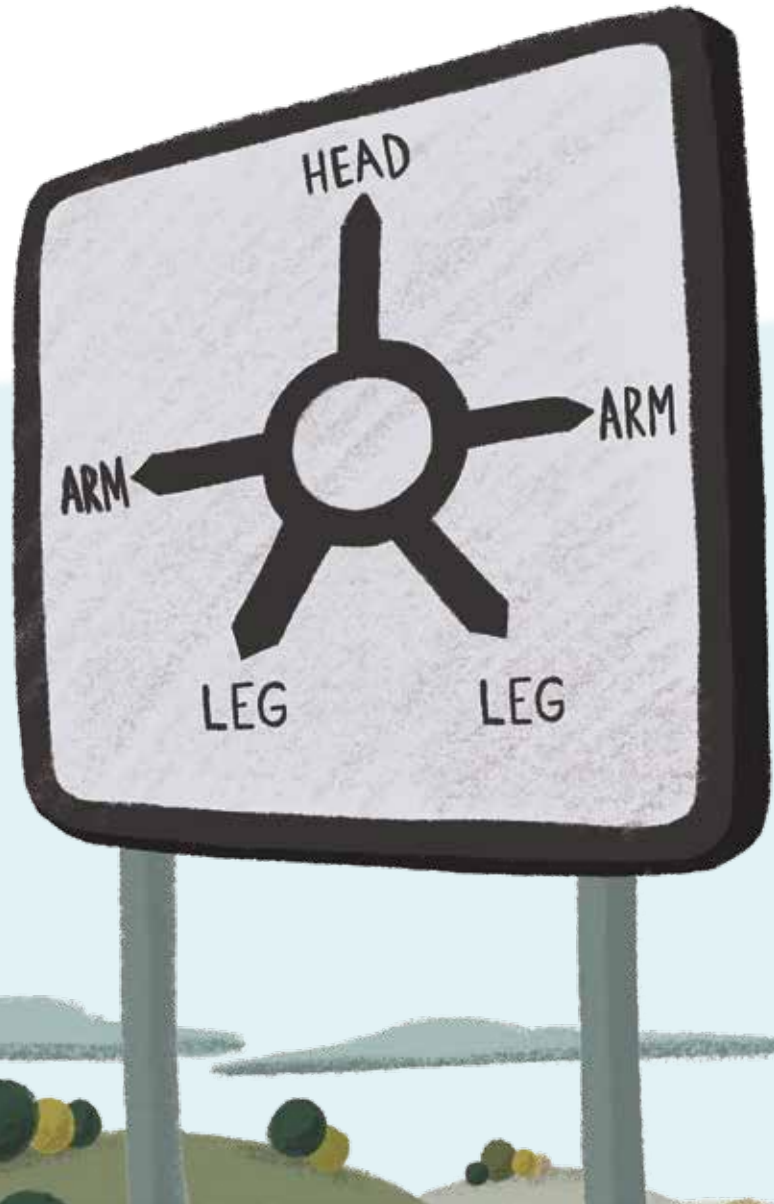
The most common types of **leukaemia** are acute lymphoblastic **leukaemia** (ALL) and acute myeloid **leukaemia** (AML).

Your doctor can help you understand which one you have and how it’s different from the others.

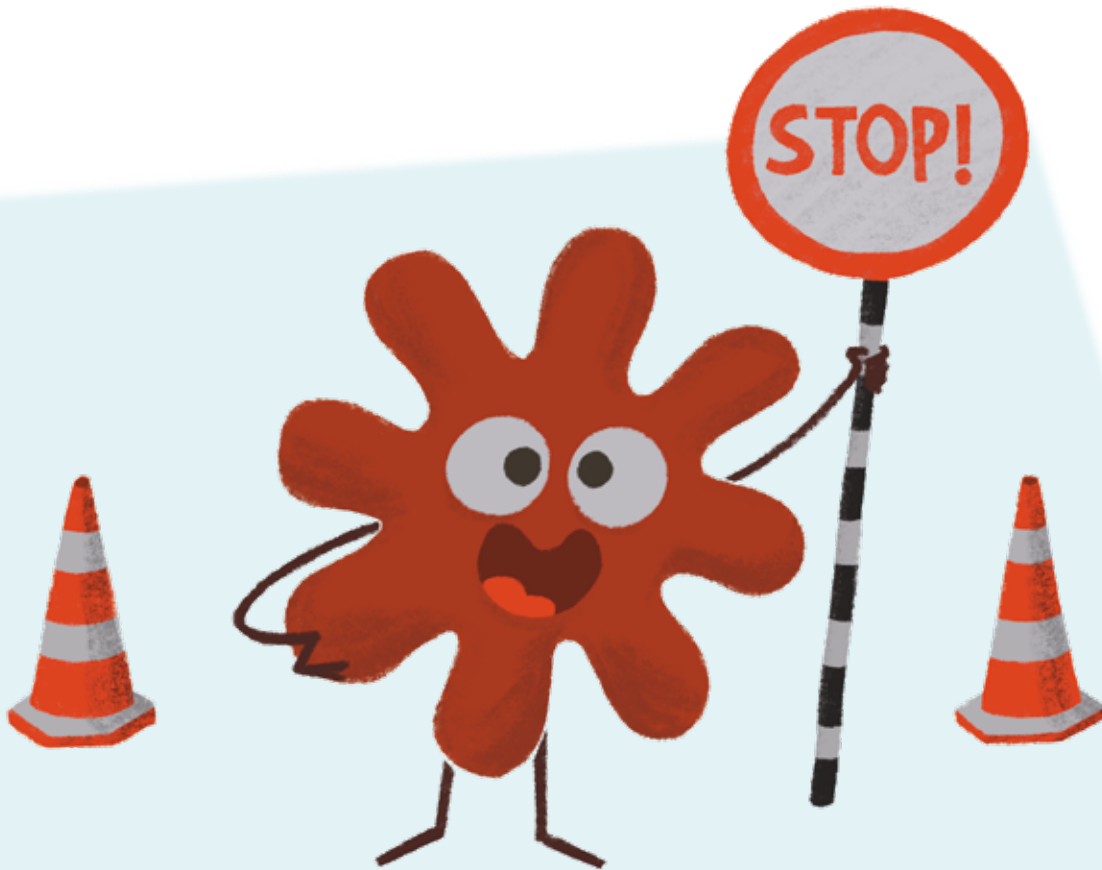


“After the blood has left the factory, it travels through your arteries and veins. These are like roads that go to all parts of your body. The red **cells** carry the oxygen you breathe to all parts of the body. They also help to keep you healthy and full of energy.

“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 don’t work properly and can’t fight infection. That’s why you’ve had a lot of coughs and colds.

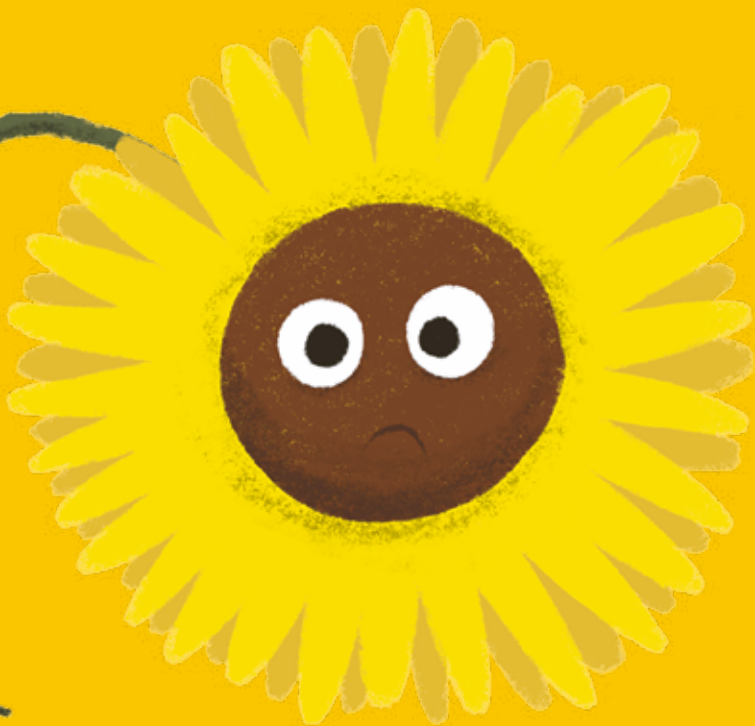


“Because your bone marrow is making far too many of these **leukaemia cells**, there’s not enough room for the healthy **cells** and platelets to grow.

“This is why you’ve felt so tired, and you’ve got lots of bruises when you haven’t even hurt yourself.

“Do you have a garden? If you do, you’ll know that sometimes you get lots of weeds in the garden. These can take over so there’s not much room for flowers or vegetables to grow.





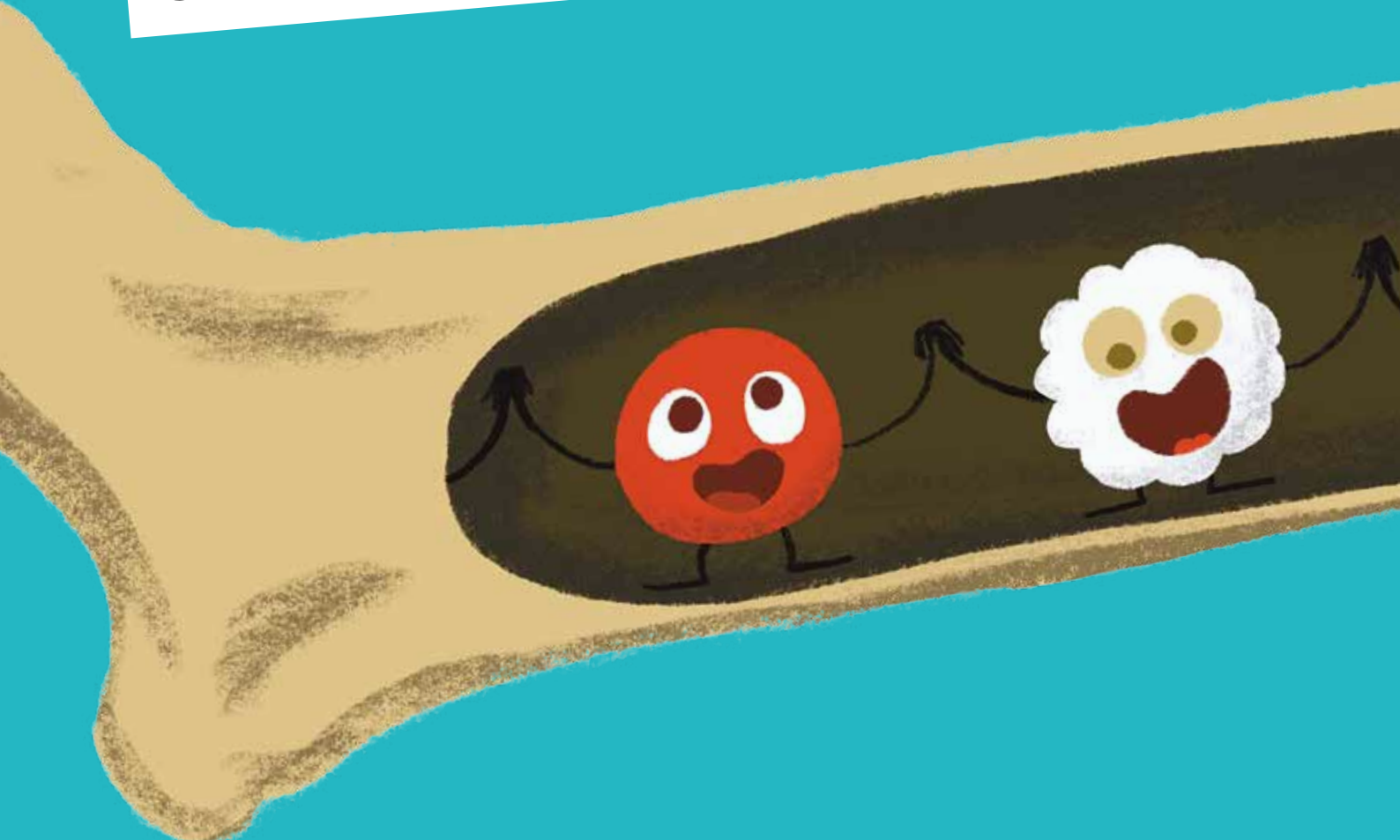
“That’s like the *leukaemia cells* in your bone marrow – they’re taking over and not leaving enough room for healthy *cells* to grow.

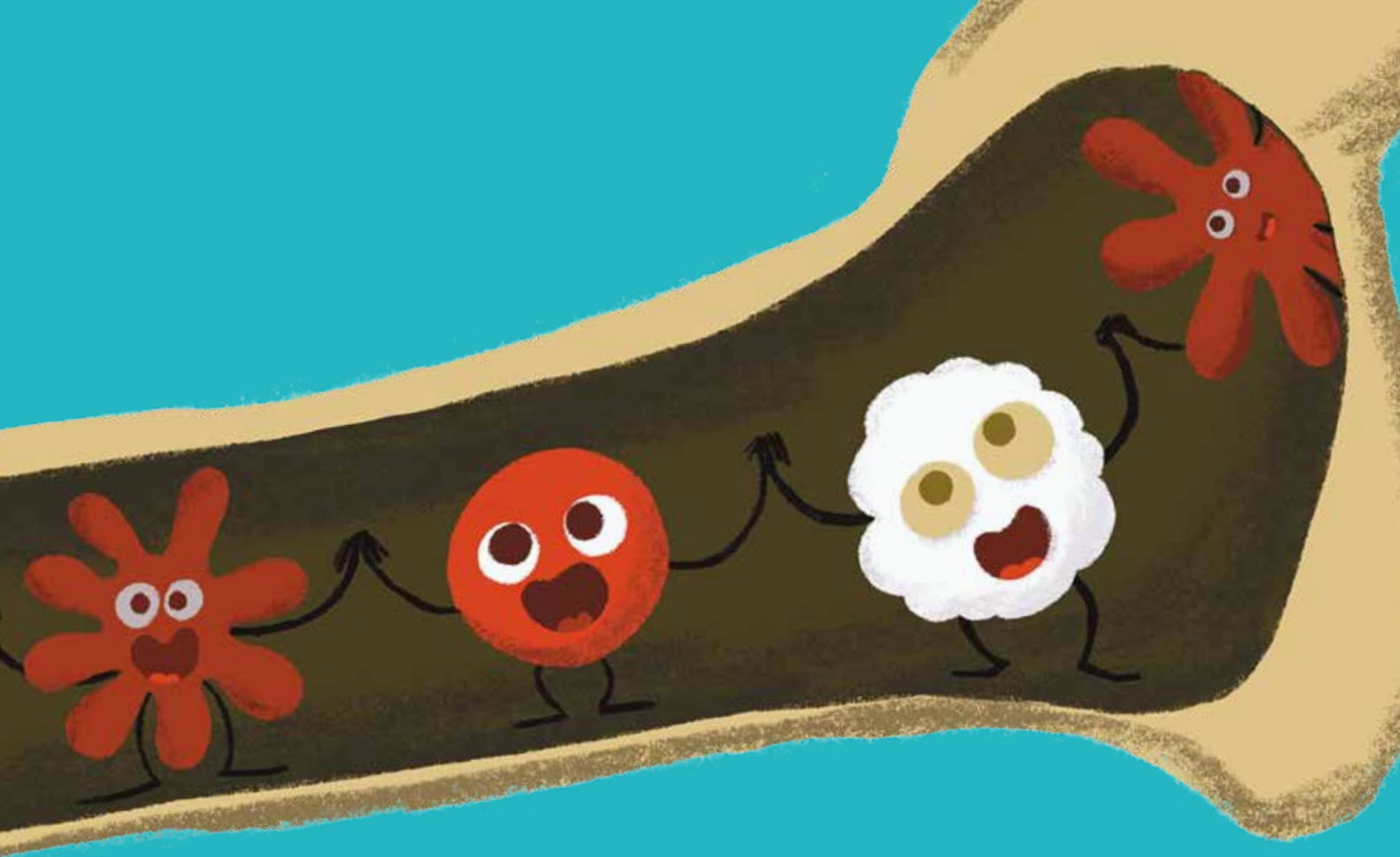
“No one knows why this has happened, but we do know that it’s not your fault or anyone else’s.

“You haven’t done anything to cause *leukaemia*, and you can’t pass it on to anyone else like when you have a cough or a cold.”



Chemotherapy





Charlie asked when he would get better.

Dr Li said, "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. It will make you feel better.

“You’ll have lots of different medicines called **chemotherapy**. You might have to have these for quite a long time, even when you start feeling better.



“Some of these will come as tablets or liquid medicine that you swallow, and some will be medicines that go straight into your body through a **central line**.

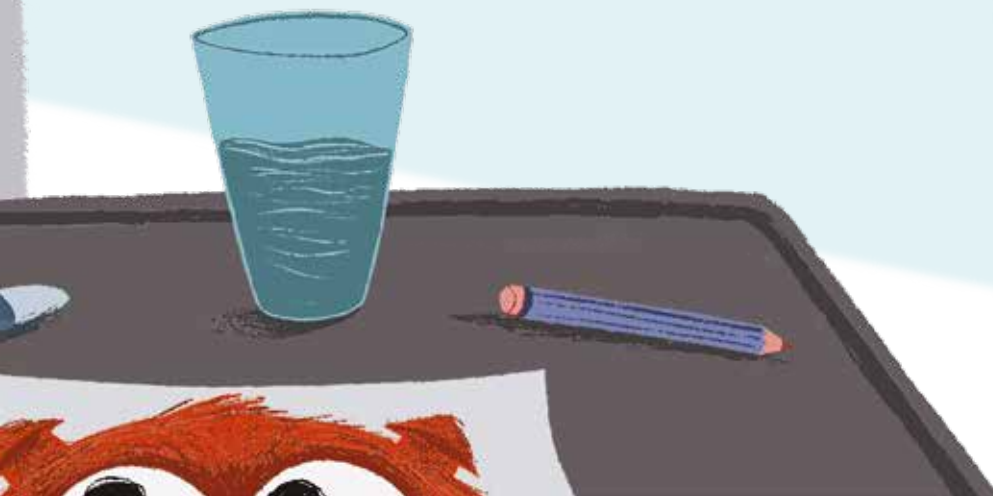
“This is a thin tube that goes into your chest. You’ll have a small operation to put this in, and it won’t hurt because you’ll have medicine called **anaesthetic** to make you go to sleep.

“There are different types of **central line**, like 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.

Did you know?

You might also have a treatment called **immunotherapy**. **Immunotherapy** is medicine that helps your immune system fight the **leukaemia**.





“To make sure that the medicines are working and the **leukaemia cells** aren’t growing again, you will sometimes need to have **blood tests, bone marrow tests**, or a **lumbar puncture**, like you already had when you had your tests.”

Charlie felt a bit worried about having more tests and treatment. He’d never been in hospital before, so it was all new to him. He asked Dr Li lots of questions and talked to Mum and Matt when he felt worried. They helped him feel better.



Did you know?

Usually, children with AML need to stay in hospital more than children with ALL, but everyone's treatment is different. Your doctor or nurse is the best person to ask about this.

Charlie had **chemotherapy** through the drip that was attached to his **central line**. This didn't hurt but sometimes made him feel a bit funny.

When the **chemotherapy** finished the machine beeped! Most of the time, Charlie didn't have to stay in hospital after he had his **chemotherapy**.





Dr Li told Charlie that the **chemotherapy** might make his hair fall out, but that it would grow back when his treatment was finished.

Charlie thought she meant it would fall out all at once, but it didn't. Instead, it fell out quite slowly.



Having no hair made him feel a bit different from everybody else, so sometimes he wore a cap, but a lot of the time he didn't wear anything at all on his head.

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

At the hospital, Charlie saw lots of other children who were also having **chemotherapy**.

Some of them had wigs, and some wore hats, caps or scarves. Some already had their own hair again. They often talked and played together.





Sometimes Charlie didn't feel well when he was having **chemotherapy**. Some days it made him feel very tired, and he sometimes felt sick too. When that happened, the nurses gave him medicine to help him feel better.

He also found that some food tasted different. This was weird, but Dr Li said that **chemotherapy** did that sometimes, and that things would taste normal again soon.

Charlie didn't have to stay still when he was having **chemotherapy**, so sometimes he went for a walk around the ward with his drip stand. Other times, he wanted to read or play games on his tablet instead.

Did you know?

Chemotherapy can sometimes affect your teeth, so your doctor might recommend that you go to the dentist to check your teeth are healthy before you start treatment.

Charlie's treatment

Another treatment Charlie had was a **blood transfusion**. This helped him have more energy and made him feel better.

When Charlie was at home, Mum and Matt gave him his medicine and Hayley the **community nurse** came to take some blood.



Charlie still had to go to the hospital quite a lot and usually Mum came with him, but if Matt could get time off work, he, Ethan and Ellie came too.

Charlie saw Dr Li and the nurses, and sometimes he got weighed and measured. He always had to have some blood taken to make sure the **chemotherapy** was working.

Sometimes Charlie had to stay in the hospital when he had a temperature. Ethan and Ellie went to stay with Grandma.

Charlie made some friends in the hospital. One girl was called Ava and they liked talking and playing together. Charlie knew that Ava understood how he felt about being in hospital and how different you could feel.

Like sometimes, when he was taking a medicine called steroids, he wanted to eat lots of different things and he felt annoyed by little things that wouldn't usually bother him.



Did you know?

Sometimes wards have rules about who can visit and when. If you have questions about visiting, you can ask the nurses on your ward.

Then sometimes he didn't want to eat at all, and had to have some special food through a tube that goes down your nose and into your tummy.

The nurses helped Charlie 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.

Did you know?

You might have steroids as part of your **cancer** treatment. Sometimes they can make your face look puffy, but it will go back to normal when you stop taking them.



When Charlie wasn't at the hospital, he played with his best friend Omar. Omar understood if Charlie was feeling a bit grumpy because of the treatment.

He just waited until Charlie felt better and then they played games, just like they did before he became ill.



Ellie felt a little upset sometimes because Charlie got so many presents, and she felt a bit left out. She didn't want to upset her parents, so she didn't tell them.

One day Ellie 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 Ellie a big hug and then Millie jumped up and licked Ellie's face... and some of the spots disappeared! Mum and Matt realised that Ellie was probably feeling left out.

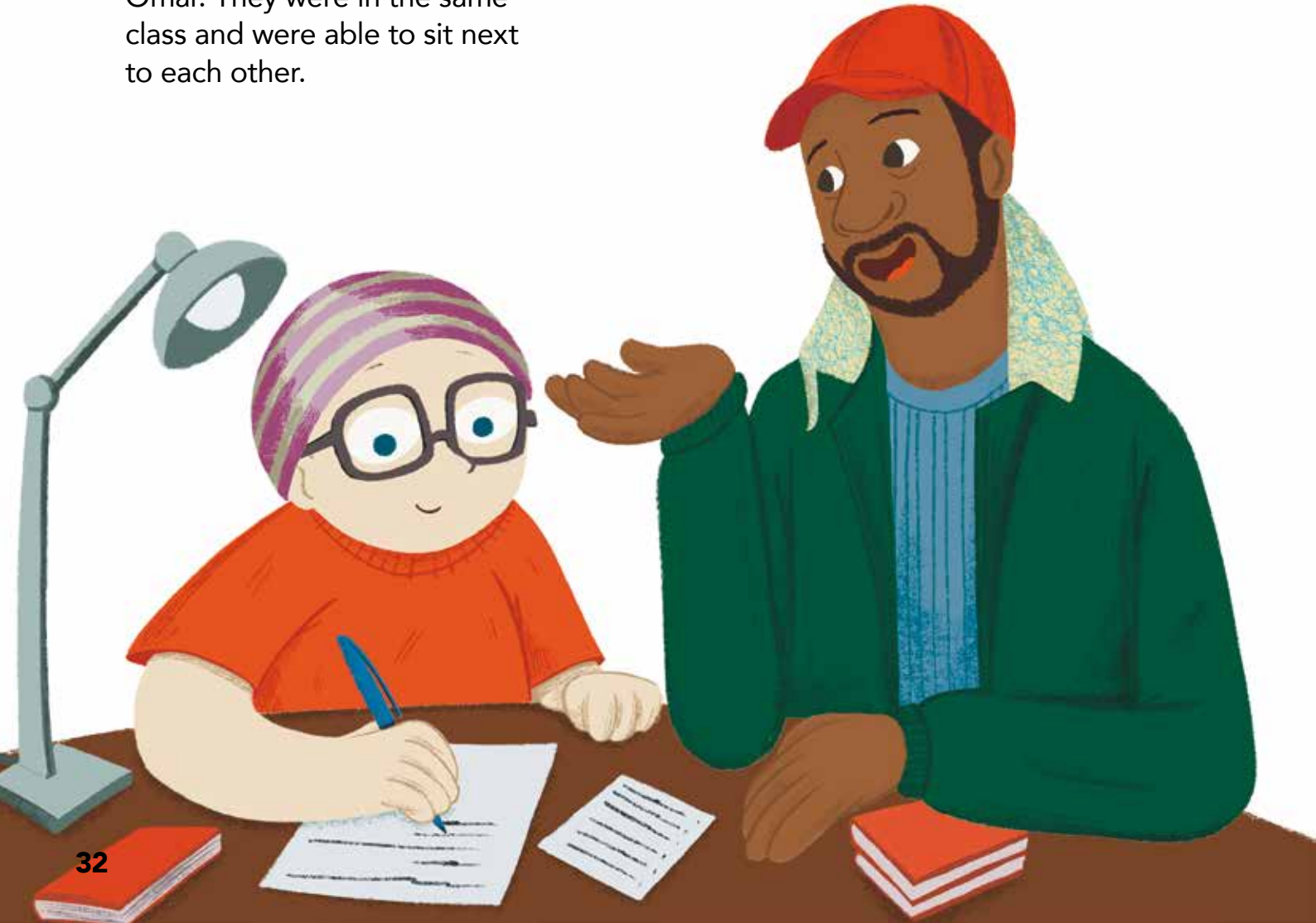
After that they made sure they spent some extra time with her and did more nice things like watching films and going swimming.



Charlie asked Dr Li and the 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.

Charlie went with his best friend Omar. They were in the same class and were able to sit next to each other.

Sometimes when he wasn't well enough for school, Mr Sibanda, a teacher from school, visited Charlie at home.



One day Omar caught chickenpox and Charlie had to take some medicine to stop him from catching it as well. Children with **leukaemia** can be very poorly if they catch chickenpox or measles.

Charlie thought it was strange that you could catch chickenpox but not **leukaemia**.



What

happens next?



After some months, when he was at the hospital, Charlie said to Dr Li, "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 medicine?"

Dr Li said, "I'm really glad that you're 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 won't need to have a line anymore, but you will still need to come and see us at the hospital."



Charlie felt really well. He went to school and played with his friends. At home he helped Mum and Matt and played with Ethan and Ellie.





At last it was the day that Charlie and his family had waited for. He went to the hospital with Mum and Matt, and Dr Li told him, "You've been so brave, Charlie! You've done really well.

You've had all your treatment now and we will take your line out soon. You'll still have to come back and see us regularly for check-ups to make sure that the **leukaemia** hasn't come back."

When Charlie arrived home, he had a big surprise. His Grandma and the family had organised a party. All his friends from school came, and Ellie and Millie were enjoying the balloons.



Everyone had a really great time and Charlie said, "When I'm older, I think I'd 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 anything. 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 and sleep through it, so you won't feel it.

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 your body needs, like blood, muscle or bone.

Central line/Broviac[®] line/ Hickman[®] line/wiggly

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. Sometimes these are called Broviac[®] or Hickman[®] lines. Some people call them wiggles!



Chemotherapy

A mixture of different medicines that treat cancer.

Community nurse

A community nurse is a nurse that visits you at home. They might come to give you some medicine or do a test so you don't have to go to hospital.

Immunotherapy

Immunotherapy medicines help your immune system to recognise and fight cancer cells.

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 your 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.

Play specialist

Play specialists help children in hospital to understand what's happening to them and feel more confident about it. They do this using play and fun activities.

Portacath

A device, or bobble, is inserted under the skin near your armpit under general anaesthetic. A very thin tube (the line) then runs under the skin to the main vein in your 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.

Social worker

A social worker from Young Lives vs Cancer is someone who can help you and your family with things you might need. This could mean explaining medical things so they're easy to understand, helping your family find somewhere to stay near the hospital, arranging for your family to get help with money, or sorting out things to do with work or school. A social worker might have given you this book!

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.



We know that the impact of cancer on young lives is more than medical. That's why we exist.

Young Lives vs Cancer is the only charity in the UK with specialist social workers who provide tailored emotional and practical support to children and young people with cancer, and their families.

We remove barriers, solve problems and prioritise wellbeing. We take the time to understand what matters most to them. And we stop at nothing to make sure their voices are heard and their unique needs understood.

We don't receive any Government funding. Our vital work is made possible thanks to the kindness of our supporters. Together, we make sure children and young people with cancer get the right care and support at the right time.

Registered charity number (1107328) and registered in Scotland (SC039857).
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Further support

Talk to Young Lives vs Cancer:

- through live chat on our website **younglivesvscancer.org.uk** (10am to 4pm, Monday to Friday)
- by calling **0300 303 5220** or emailing **getsupport@younglivesvscancer.org.uk** (9am to 5pm, Monday to Friday).

Please note that everyone's experience will be different and may not follow the order outlined in this book. Services will differ across the UK. Young Lives vs Cancer does not accept any responsibility for information and services provided by third parties, including those referred to or signposted to in this publication.

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YOUNG LIVES vs CANCER

Charlie Has Leukaemia is a story for children with leukaemia to read with their families.

We hope it will help you understand leukaemia and the treatment you might need for it. It might also be helpful for your friends to read so they can find out more about what's happening.



Want to tell us what you think about this book?
Scan the QR code or visit
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storybook-survey](https://younglivesvscancer.org.uk/storybook-survey)

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