



**LUCA
HAS LYMPHOMA**

**YOUNG LIVES
vs CANCER**

**Lymphoma
action** 

LUCA HAS LYMPHOMA

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For information about the sources used to create this book, or if you have any comments or questions about it, please contact either Young Lives vs Cancer **brand@younglivesvscancer.org.uk** or Lymphoma Action **publications@lymphoma-action.org.uk**

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Meet Luca

This is Luca. He's nine years old and he lives with his dad and their dog, Coco.

His favourite things to do are drawing and making things. He also likes to spend time with his best friends, Izzy and Arun.

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

More info

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

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

Luca's lymph node

One evening when Luca was brushing his teeth, he noticed he had a lump in his neck. He showed it to his dad and asked him what it was. Dad wasn't sure, so he made an appointment for Luca to see their family doctor.



The doctor said she thought it was just a **gland** in his neck, but she said that Luca and his dad should keep an eye on it.

A few weeks later, the lump was still there, so they went back to the doctor. This time, she sent them to the hospital to see another doctor, Dr Prabhu.

Did you know?

Glands are small organs that you have all over your body. They help your body fight infection. They get bigger when you have an infection and get smaller again when the infection is gone.



Finding out what's wrong

Dr Prabhu said Luca would need a small **operation** to take the lump out. Luca was worried that the **operation** would hurt, but Dr Prabhu explained that he would have a medicine called **anaesthetic** which would make him go to sleep, so he wouldn't feel anything.





A doctor called a pathologist would then look at the lump under a microscope. Pathologists can tell if there's something wrong with the **gland** because healthy **glands** look different to unhealthy ones.

"What could be wrong with it?" asked Luca. Dr Prabhu said that another name for a **gland** is a **lymph node**. You have them all over your body, not just in your neck. Their job is to help the body fight off infections like sore throats or earache. They get bigger when they are doing this, which is normal.

But sometimes **lymph nodes** get bigger when there is no infection. That's because the **cells** inside them stop working properly. We call these 'abnormal' **cells** because they are not behaving normally. The abnormal **cells** multiply and grow, making the **lymph node** get bigger too.

When the **lymph node** is full of these abnormal **cells**, we call this **lymphoma** (lim-foh-muh). **Lymphoma** is a type of illness called **cancer**. Dr Prabhu wanted to find out if Luca had **lymphoma**.

Soon, Luca went back to the hospital to have his **operation**. The nurses checked his temperature and blood pressure. They also measured his height and weight. While they did this, they asked Luca about school and he told them about his green uniform and his favourite subject, art.

Did you know?

Some people feel ill when they wake up after having an **anaesthetic**. Some people feel cold and shivery, while others feel dizzy or sick. This doesn't last long – you'll usually feel better by the next day.



Luca had his **anaesthetic** and went to sleep for the **operation**. When he woke up, Dad was there. Luca was still a bit sleepy, so they watched a film together while he woke up a bit more. Then a nurse brought him a sandwich – he chose a cheese one. After that, he was allowed to go home.







A few days later, Luca went back to the hospital for some scans, so that the doctor could see if there were any big **lymph nodes** in other parts of his body. Sometimes people get them in their armpits, at the very top of their leg (which is called the groin), or in their tummy or chest.

There are lots of different types of scans, like **CT**, **MRI**, **PET** and **ultrasound**. For most of these, you need to lie on a kind of bed that moves into a big machine. This machine takes a picture of the inside of your body.

Luca felt a bit nervous before his scans because he'd never had one before. Being nervous made his tummy feel funny.

While he was waiting for the scans, he met Lisa, the **play specialist**.

She had lots of fun things to do, and she suggested he could draw a picture of what he thought a big **lymph node** might look like.

He gave the **lymph node** a very funny face and Dad laughed when he saw it. This helped Luca feel less nervous.

Lisa said he could bring a toy to the scans too, so he brought his favourite teddy.

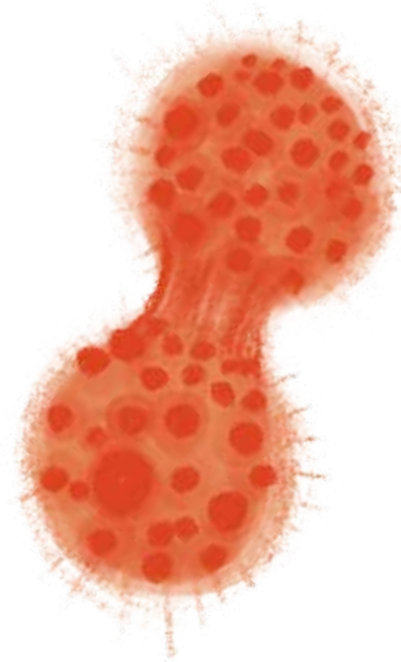
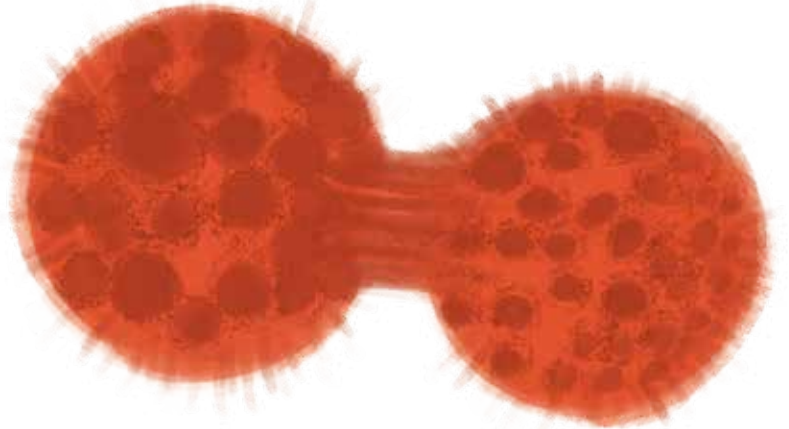
Luca had to lie very still during the scans so the doctors could get a clear picture. The scans didn't take too long and he didn't feel anything. Afterwards, he was able to go home and go out to play with Izzy and Arun.



What's cancer?

The next week, Luca and Dad went back to the hospital to see Dr Prabhu. The results had come back from the pathologist and they said that Luca's lump was **lymphoma**.

Dr Prabhu explained that **lymphoma** is a type of blood **cancer**. **Cancer** is an illness where some of the **cells** in your body aren't working as they should. They divide up to make new **cells** too quickly and damaged **cells** are made. This is what had happened in Luca's blood **cells**.



Some children with **lymphoma** don't feel as well as Luca. Sometimes they have lots of high temperatures and sweat a lot, especially at night. Some children lose weight, and some feel really itchy all over their body.

Luca asked why he had got **lymphoma**. Dr Prabhu said that doctors didn't know why some children got **lymphoma**, but what they did know was that it was nobody's fault. "You haven't done anything to get **lymphoma**," he said, "and you can't give it to someone else like a cough or a cold."

Did you know?

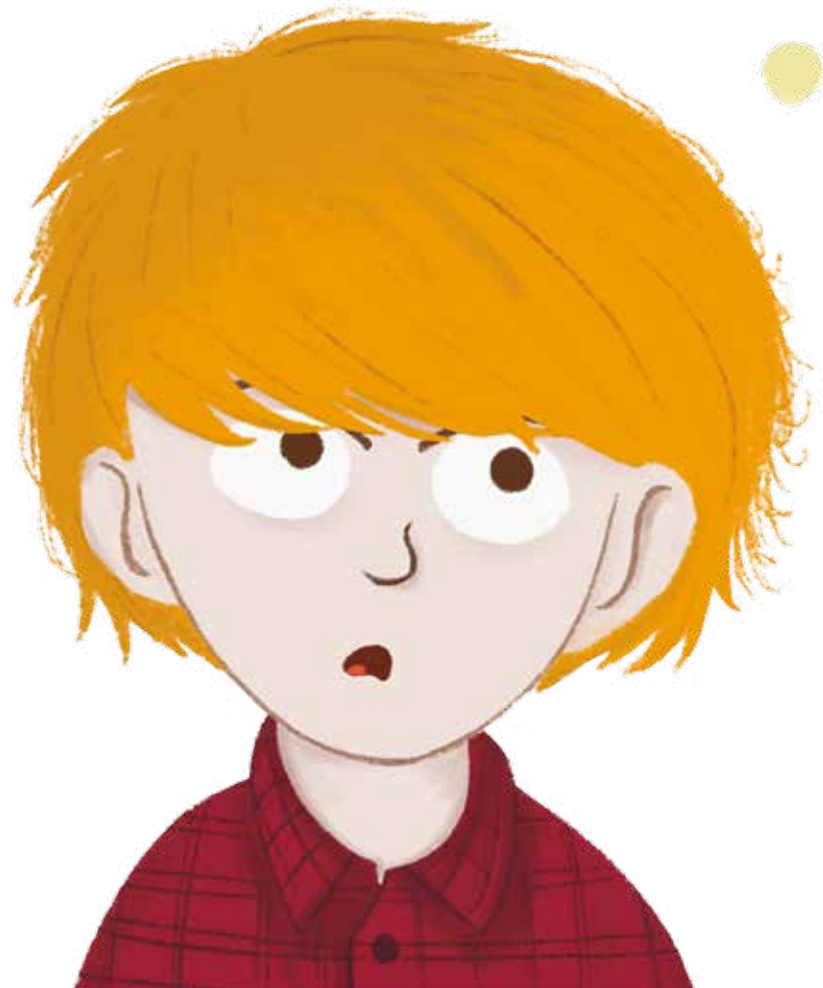
There are lots of different types of **lymphoma** and they are all treated a bit differently. Luca had a type of Hodgkin lymphoma. Some people have a type of non-Hodgkin lymphoma.





Luca felt scared when he found out he had **cancer**, and he thought Dad looked worried too. But Dr Prabhu said there were things they could do to try to make the **lymphoma** go away. He called this 'your treatment'.

Dr Prabhu said that although some of the **lymphoma** had been removed when Luca had his **operation**, the scans showed that there was also some inside his chest. The treatment should get rid of this bit, which would stop the **lymphoma** growing back.





Luca asked if his hair would fall out and how long it would take him to get better. Dr Prabhu told him, "We'll try to shrink the **lymphoma** and make it go away, which will make you better. Sometimes the treatment can also make your hair fall out, but it will grow back when your treatment has finished."



Luca had a **PET scan** to see which bits of the **lymphoma** were growing. He was able to bring his teddy with him, just like last time.

Other children, like those with non-Hodgkin lymphoma (NHL), can have different types of scans. The growing **lymphoma** looks much brighter on the scan.

Luca would have another scan after he'd had some of his treatment to see if all the bright **lymphoma cells** had gone away.

Now the doctors could see where the **lymphoma** was in his body, he could start having his treatment.



Chemotherapy



As part of his treatment, Luca needed medicine called **chemotherapy** (kee-mo-ther-uh-pee) to get rid of the **lymphoma**. He had a tube called a **central line** put into his chest to make it easier to give him the medicine. There are different types of **central lines**. Luca had a **Hickman® line**, but some children have a different kind of line, like a **portacath** or a **Broviac®**.

Blood for **blood tests** can come out of a **central line** – that means the nurse doesn't have to use a needle every time they need to take your blood to be tested. Luca had his **chemotherapy** in his **central line** so it could go straight into his body.

Luca needed another small operation to put the **central line** in the right place, so he had an **anaesthetic** and went to sleep again like he did for his first **operation**. He wasn't so nervous this time because he'd had an **anaesthetic** before.

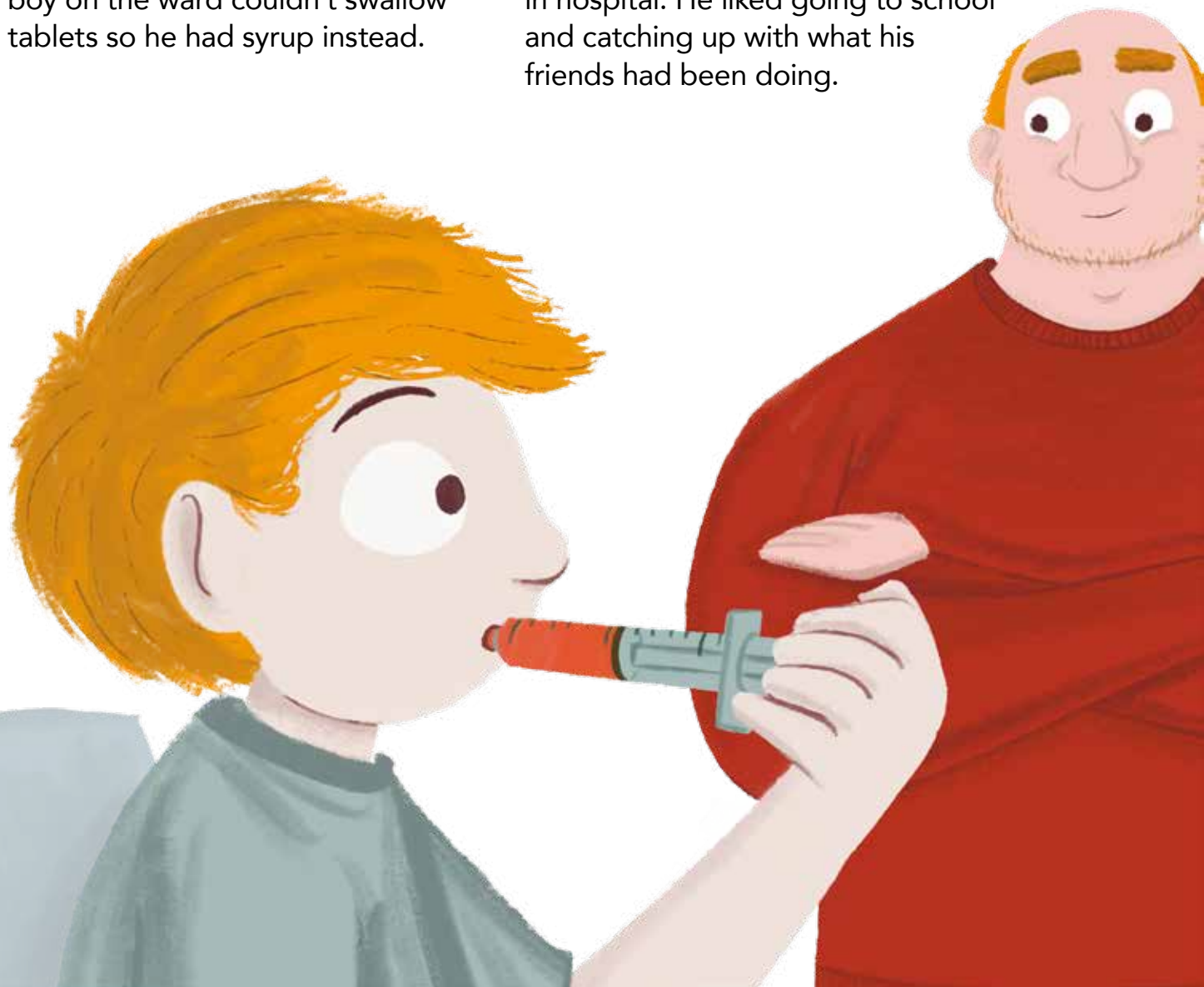
When he woke up, the new line was safely in place. Luca heard some of the other children call their lines 'wiggles' because they looked a bit like wiggly worms. He thought that was funny!

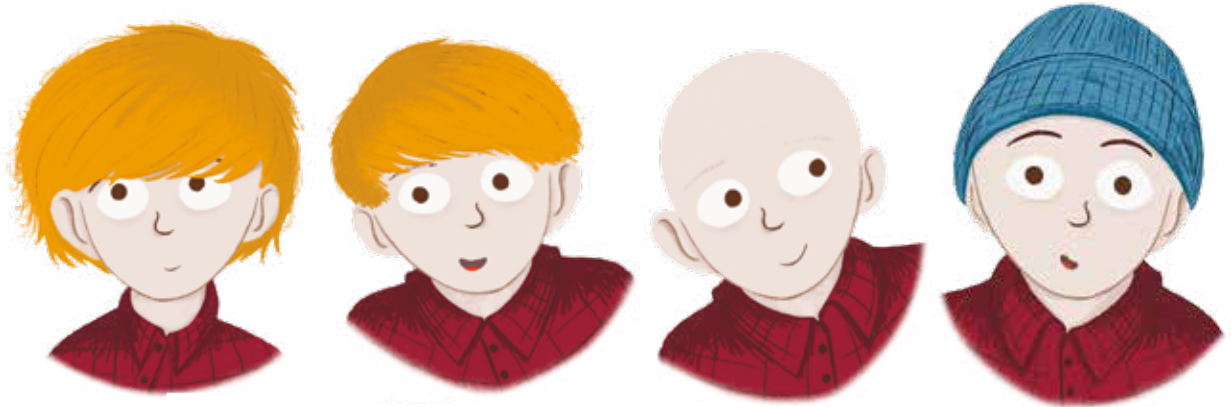
Dr Prabhu said that Luca would have **chemotherapy** on some days over the next two weeks. "Why can't I just have it all now?" Luca asked. He wanted it to be done quickly so things could go back to normal.

Dr Prabhu said he might feel unwell for a bit after **chemotherapy**, so he needed to have a rest before he had more. "Some people feel very tired when they have **chemotherapy**," he explained, "and some people feel sick. If that happens, we can give you some medicine to help you feel better."

Not all the **chemotherapy** that Luca had went through his **central line**. Some of it came as tablets or as a runny syrup, like cough medicine. He preferred the tablets, but another boy on the ward couldn't swallow tablets so he had syrup instead.

Luca had to keep going back to the hospital for his treatment, but he didn't have to stay long or spend the night there. He could go to school when he was well enough and wasn't in hospital. He liked going to school and catching up with what his friends had been doing.





Some of the other children having treatment stayed in the hospital a couple of nights each time, especially the ones who lived far away. One of Luca's friends needed a different type of treatment to Luca. She had to stay in hospital to have all of hers.

Over the next few weeks, Luca sometimes didn't feel very well and was quite tired. Gradually, his hair started to fall out, so he decided to have it all cut off. One of the nurses at the hospital asked if he'd like a wig to wear, but he preferred wearing his favourite blue beanie hat when his head was cold. Some of the other children wore headscarves and one of his friends in hospital had a pirate bandana.



Sometimes Luca wasn't well enough to go to school. His teacher Mrs Blaker sent him some work to do at home when he felt a bit better, and everyone in his class signed a 'get well soon' card for him. Izzy and Arun drew him a picture and he put it up on the wall in his bedroom.

Did you know?

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

One day, Luca had a fever and he had to go to hospital. A **blood test** showed that he didn't have enough of the right sort of white **cells**, called neutrophils (nyoo-truh-fils), to fight infections. So the doctors and nurses gave him some antibiotics through his **central line** to make the fever go away and kill off any bugs causing the infection. Antibiotics are special medicines to treat infections.

Luca felt very unwell and he had to stay in hospital for a few days. He missed his friends, who weren't allowed to visit in case he caught another infection from them. Dad arranged for him to have a video call with Arun and Izzy so he could hear about what they were doing. Luca was allowed to watch lots of films and play games on his tablet until he felt better.

Although Luca missed his friends a lot when he couldn't go to school, he started to feel worried about going back. He and Dad talked about it with Abby, their **social worker** from Young Lives vs Cancer, and the psychologist at the hospital.

A psychologist is someone you can talk to about how you're feeling. Luca told her he was excited to finish his treatment and join the new drawing club at school, but worried he wouldn't be able to do sports day next month because he felt tired a lot.



What

happens next?

After a few more weeks, Luca had another **PET scan** to see if all the **lymphoma** had gone. If there were still bright bits on the scan, he would need to have another treatment called **radiotherapy** to make sure all the abnormal **cells** were gone. Some children with Hodgkin lymphoma need to have **radiotherapy** after their **chemotherapy**. Children with non-Hodgkin lymphoma don't usually have **radiotherapy**.

If Luca needed to have **radiotherapy** for his Hodgkin lymphoma, he would meet the **radiotherapy** doctors who would plan the treatment. Then he would have **radiotherapy** at a **radiotherapy** centre a few weeks after he finished **chemotherapy**.

Did you know?

Radiotherapy is another kind of **cancer** treatment. It's done by pointing powerful rays like X-rays at the **lymphoma** to get rid of any tiny bits that are left after **chemotherapy**.



Luca didn't have any bright bits on his second **PET scan**. Once he'd finished his **chemotherapy**, that would be the end of his treatment.

Even after Luca finished his treatment, he still had to go back to hospital sometimes to make sure that everything was OK. This gave him a chance to talk to Dr Prabhu about how he was feeling. All Luca's hair grew back and he was back at school and having fun with his friends.



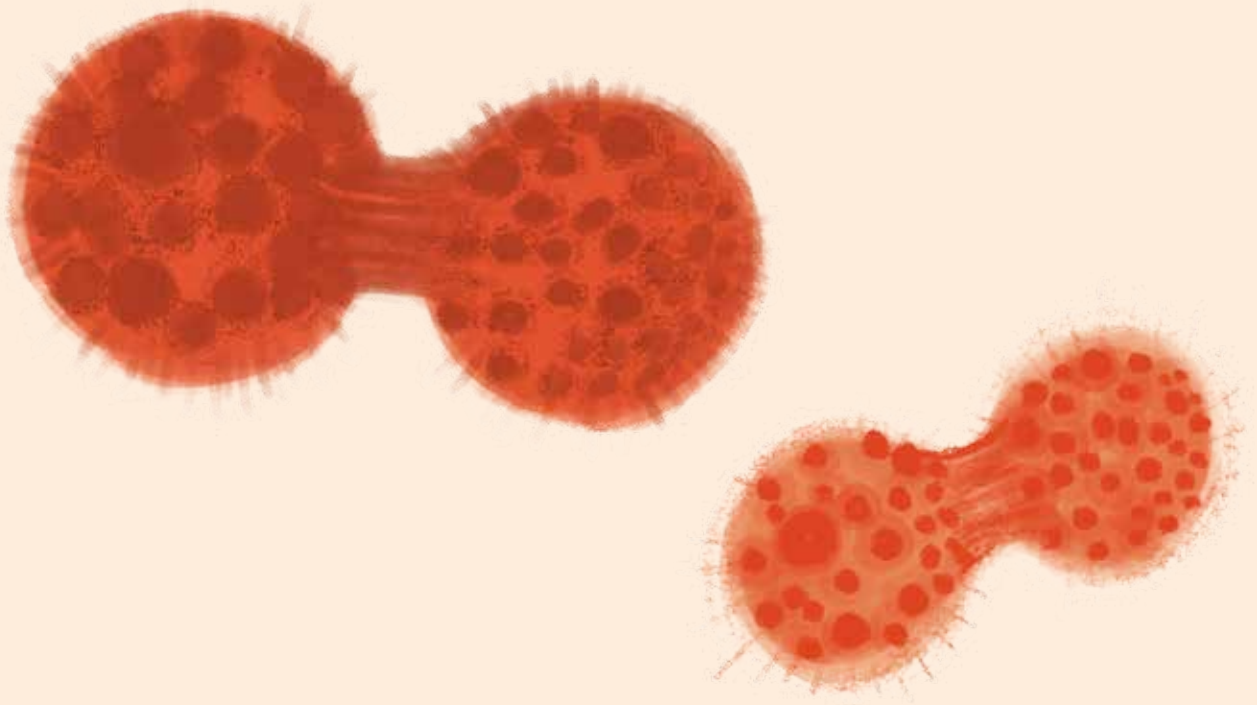
A year later, Luca was doing really well and only had to go back to the hospital occasionally for check-ups. He felt nervous about the check-ups sometimes and worried that the **lymphoma** would come back. He told Dad how he was feeling, and Dad said they would make sure to do something nice after each check-up so Luca had something to look forward to.

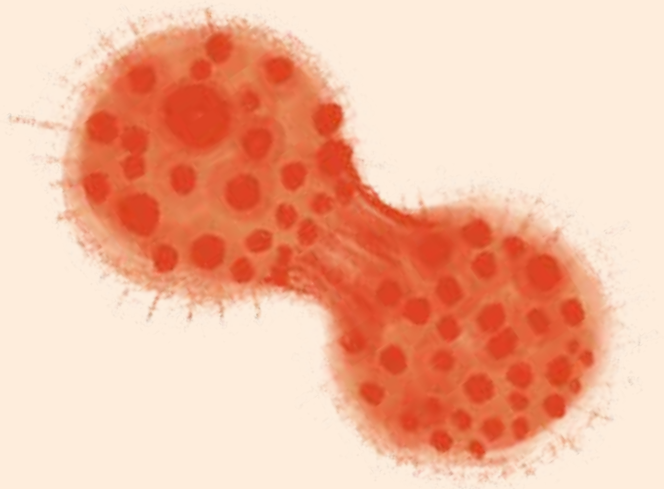
There was an art competition at school and he drew a big picture of his **cells** fighting **lymphoma**. He won first place!



What are

**Hodgkin lymphoma and
non-Hodgkin lymphoma?**





There are two main types of **lymphoma** – Hodgkin lymphoma and non-Hodgkin lymphoma. Both affect the **lymphatic system**, which helps fight against disease and infection. The **lymphatic system** is made up of **lymph nodes** that are linked together, like a chain. The **lymph nodes** get bigger when they fight disease and infection. They shrink back down when the disease or infection has gone.

Although Hodgkin lymphoma and non-Hodgkin lymphoma affect the same part of the body (the **lymphatic system**), they are different and are treated differently.

The most common type of Hodgkin lymphoma is called classical Hodgkin lymphoma, and it's usually treated the way Luca's Hodgkin lymphoma was treated. There's another type of Hodgkin lymphoma that might be treated differently.

There are lots of different types of non-Hodgkin lymphoma. Treatment depends on the type, but most people have **chemotherapy**, one of the medicines described in this book. Some people might have other treatments, like CAR-T or proton beam therapy. Your doctor will tell you about the treatments you'll have.

What these words mean

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, 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. In lymphoma, a blood test is usually used to see how many red cells, white cells and platelets you have (this is called a **full blood count** or FBC).

Cancer

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

Cell

Your 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.

CT scan

A scan like an X-ray where the doctor can look inside your body.

Febrile neutropenia

When you are neutropenic and have a fever (a higher temperature than normal). This is a sign of infection.

Gland

Another name for a lymph node.

Haematologist

A doctor who looks after people with blood or lymph node problems or diseases.

Lymphatic system

Part of your immune system. Cells that fight infection and disease travel around your body in the lymphatic system. These are the cells that go wrong in lymphoma.

Lymphoma

This is cancer of lymph nodes, or the lymphatic system. It's a type of blood cancer.

Lymph nodes

The cells that fight infections and disease live in the lymph nodes. Lymph nodes become bigger when they are fighting infection.

MRI scan

A scan using strong magnets to take pictures of the inside of your body. It can be quite noisy. It doesn't hurt, but you might be given an anaesthetic or some medicine to help you relax and lie still.

Neutropenic

A person is neutropenic when they have too few neutrophils (the good white cells that fight infections) in their blood. Being neutropenic means you are more at risk of getting infections.

Oncologist

A doctor who treats people with cancer, including lymphomas.

Operation

Where you have some medicine called anaesthetic to make you go to sleep and then the doctors can have a look at your body without hurting you. An operation is sometimes called surgery.

PET scan

Another scan which lets the doctors see a picture of the inside of your body. Areas where there is lymphoma show up on the scan as bright spots.

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. This makes it go numb so it will not hurt so much when the needle goes in.

Radiotherapy

Special, powerful rays like X-rays are pointed at the lymphoma to kill any tiny bits left after chemotherapy.

Side effect

A side effect is something that may happen during your treatment, like feeling sick or your hair falling out.

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!

Ultrasound scan

A scan that uses sound waves to see inside your body. It doesn't hurt.

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

We remove barriers, solve problems and prioritise wellbeing. We take the time to understand what matters most to young people with cancer and their families. 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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Bristol, BS1 2NT

Lymphoma Action is the UK's only charity dedicated to lymphoma, the fifth most common cancer. We've been providing in-depth, expert information and wide-ranging support for over 35 years, helping thousands of people affected by lymphoma, their families and loved ones. We're here to make sure no one faces lymphoma alone.

We would like to thank our incredible supporters, whose generous donations enable us to offer our essential support services free of charge. As an organisation, we do not receive any Government or NHS funding, so every penny received is truly valued.

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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).

Talk to Lymphoma Action:

- by calling their freephone helpline on **0808 808 5555**
- by clicking on the Live Chat icon at **lymphoma-action.org.uk** (both services open 10am to 3pm, Monday to Friday)
- You can also email them at **information@lymphoma-action.org.uk**

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 and Lymphoma Action do 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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Luca Has Lymphoma is a story for children with lymphoma to read with their families.

We hope it will help you understand lymphoma 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.



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