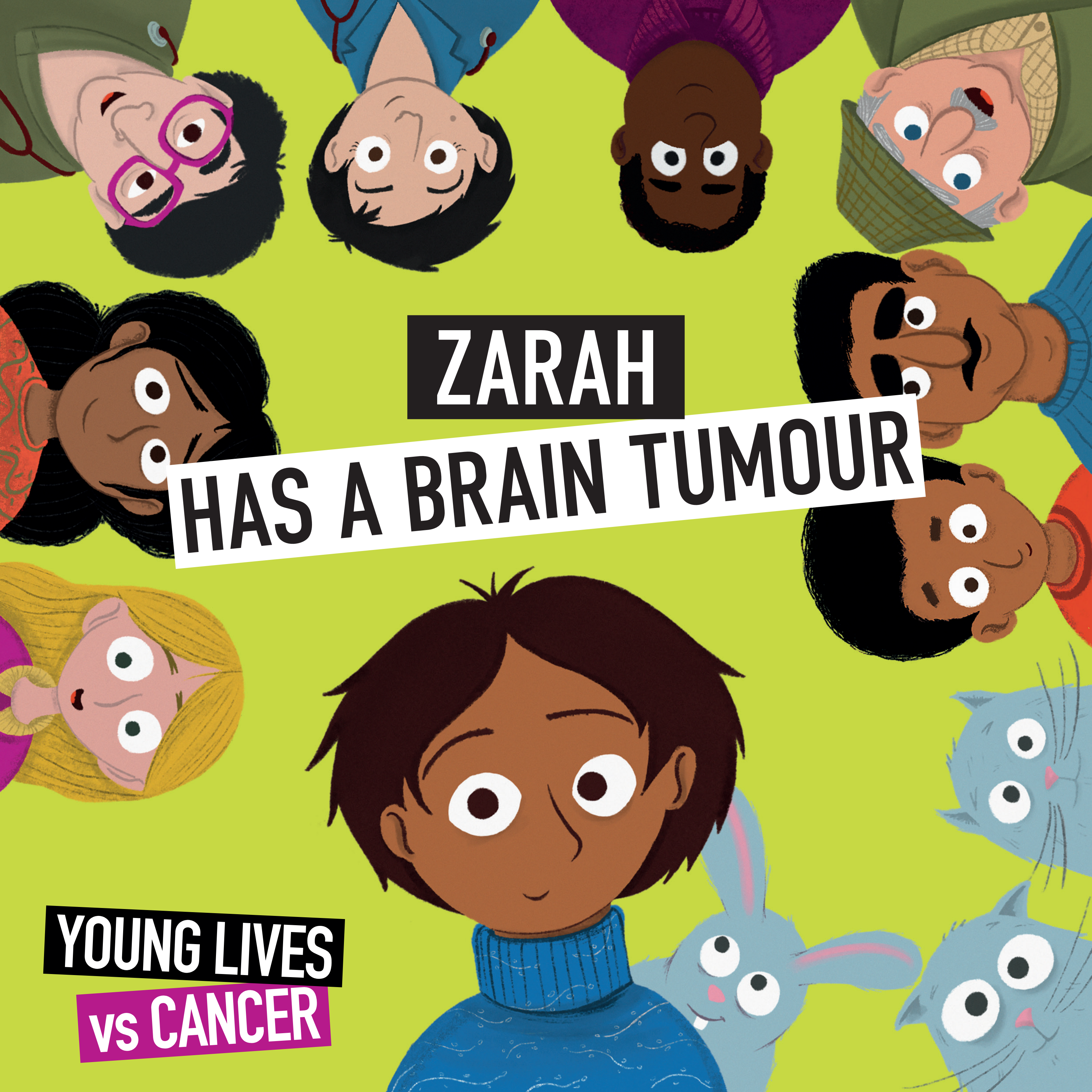

ZARAH
HAS A BRAIN TUMOUR

YOUNG LIVES
vs CANCER

ZARAH HAS A BRAIN TUMOUR

Version 5

Updated: December 2024

Next planned review: December 2027

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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

Registered charity number 1107328 and
registered in Scotland (SCO039857). 24033d

This book belongs to:

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Illustration by Allen Fatimaharan

More info

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

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

Meet Zarah

This is Zarah. She's eight years old and lives with her mum, dad and big brother Ali, who's 13. They have a rabbit called Buzz. She likes swimming and writing stories, but most of all she likes to play with her best friend Ruby, who has two kittens.

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

Finding out what's wrong

Zarah had been feeling unwell for a few weeks. She felt very tired and was a little bit grumpy. Sometimes she was sick when she got up in the morning and often she had bad headaches.

Mum was worried so she took Zarah to the doctor. He looked in Zarah's eyes and checked her thoroughly and then he said that she needed to go to hospital straight away. There they met Dr Rees, who examined Zarah again and said that she would need to have some tests. One of them was called a ***scan****.

The ***scan*** took pictures of the inside of Zarah's head. Zarah needed to lie very still inside the scanner, which was like a big tube that took the pictures. This was so the scanner could take a clear picture for the doctors to look at. The scanner was quite noisy, but Zarah could listen to some music or a story, and it didn't hurt at all. She took her favourite teddy with her too.

Soon after the ***scan***, Dr Rees saw Zarah and her mum and dad. He told them that Zarah had a lump in her head and this was causing the headaches and sickness. The lump was called a brain ***tumour*** and was a type of ***cancer***.

Did you know?

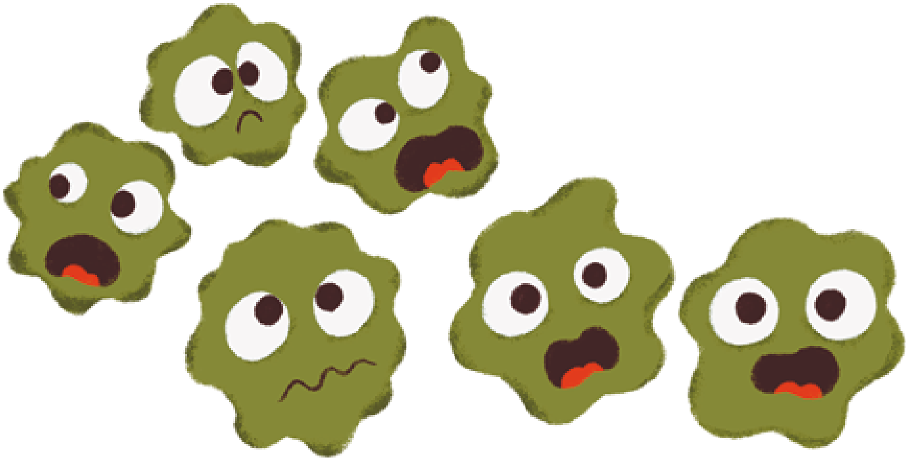
Not all brain ***tumours*** are ***cancer***. ***Tumours*** that aren't ***cancer*** are called benign. Doctors aren't always able to tell what kind of ***tumour*** it is from a ***scan***, so you will need some other tests as well. Your doctor can tell you more about the tests you will need.

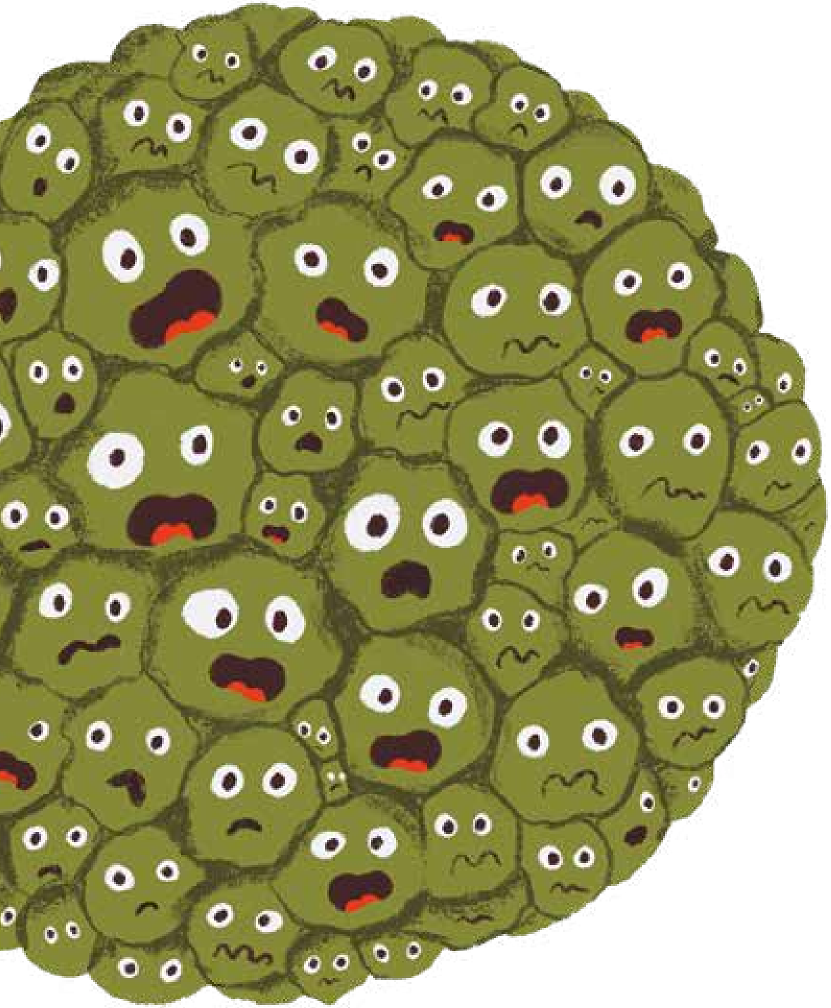
What's cancer?

"What is ***cancer***?" Zarah asked.

Dr Rees explained, "Everyone's body is made up of millions of tiny cells, so tiny that you can't see them without a microscope. These cells make up different things our bodies need – like blood, muscle or bone.

"Sometimes the cells start to multiply to make new cells too quickly and they don't do their job properly. Lots of damaged cells are made and they stop the good cells from working properly. This is called ***cancer***. Some ***cancers*** grow more quickly than others."





"When the damaged cells do not know what they should do, they begin to stick together to form a lump, which is called a ***tumour***. There are different types of brain ***tumour***. Some are treated with an ***operation***, and others need to be treated with an ***operation*** and ***radiotherapy***, or with an ***operation***, ***chemotherapy*** and ***radiotherapy*** together."

Did you know?

Chemotherapy and ***radiotherapy*** are treatments for ***cancer***. We'll learn more about them later in this book.

Zarah's operation

Dr Rees said Zarah would need to have an ***operation*** to take the ***tumour*** out and she would need to stay in hospital. Zarah was a bit worried about the ***operation*** because she'd never had one before. But Dr Rees explained that she would have a medicine called an ***anaesthetic*** so she'd be asleep and wouldn't feel anything. Then she'd wake up when the ***operation*** was finished.

He explained that sometimes children find it difficult to talk or walk for a little while after this kind of ***operation***. If this happened to Zarah, there would be specialists to help her. Once Dr Rees knew what kind of brain ***tumour*** Zarah had, he would be able to tell her what treatment she would need.

Zarah was unhappy about staying in hospital, but she felt a bit better once she saw the ward. A ward is a place in the hospital where children stay while they're poorly. Zarah thought it seemed like a nice, friendly place and there were other children to play with. She also met Simon, her Young Lives vs Cancer ***Social Worker***. He talked to Zarah and her family about anything they might need. Mum and Dad took it in turns to stay with her and look after Ali at home.

Did you know?

When people find it difficult to walk or talk after a brain ***operation***, ***physiotherapists*** and ***speech and language therapists*** can help them.

The next morning Zarah was not allowed to have anything to eat because she was going to have her ***operation***. Another doctor, Dr Monye, came to see her. He was an ***anaesthetist*** and his job was to look after Zarah and make sure she stayed fast asleep during her ***operation***. Mum and Dad would be with her when she went to sleep and when she woke up.

Then another doctor came to see Zarah. Her name was Ms Garcia and she was a ***neurosurgeon***. She was going to do Zarah's ***operation***. Zarah wanted to know what would happen. Ms Garcia explained that she would have to shave a little hair off Zarah's head when she was asleep so she could see her head properly. Then she would be able to remove the ***tumour***.

Zarah would have a big bandage on when she woke up and she might feel a bit tired and sore. Ms Garcia said that she would wake up in another ward called intensive care.

Did you know?

You might need to have a medicine called a steroid before and after your ***operation***. This medicine can make you feel very hungry and sometimes a bit grumpy too, but this should get better quite quickly.

When the nurses came to take Zarah for her ***operation***, she had to put on a hospital gown with an opening at the back. She could wear her dressing gown over the top to stay warm. She also had some cream put on the back of her hand. It made it go numb, so when she had a tube put in, it didn't hurt so much.

The tube was called a cannula, and it was used to give Zarah the ***anaesthetic*** to make her sleep through the ***operation***. Mum was with her and she held her hand until the ***anaesthetic*** made her go to sleep.

The next thing Zarah knew, she was lying in bed, with Mum sitting by her on one side and Dad on the other. There were a lot of machines bleeping and she felt very tired, so she went back to sleep.

Soon Zarah was feeling better and she was able to sit up and have something to eat. Mum and Dad were very proud of her because she'd been so brave. The nurse came and said it was time to go back to her ward so Mum, Dad and the nurse pushed Zarah along the corridor in her bed.

Did you know?

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

Chemotherapy

A week later, Dr Rees came to see Zarah, Mum and Dad. He told Zarah that she would need to have some medicine called ***chemotherapy*** and she might need a treatment called ***radiotherapy*** as well.

Some ***chemotherapy*** would be tablets and some would be medicine that would go straight into Zarah's body through a ***central line*** – a small tube that went into her chest. There are different types of ***central line*** – these include a ***portacath***, a ***PICC line*** and a ***Hickman® line***. Often the line is called a wiggly!

The wiggly line is very useful because as well as giving medicines, it can be used for taking ***blood tests***. Dr Rees said that Zarah would not be in hospital all the time but she would need another small ***operation*** to put the ***central line*** in.

When she had the ***operation***, she would have ***anaesthetic*** again, so she would be asleep and wouldn't feel anything. But first she could go home for a while to get a little bit stronger.

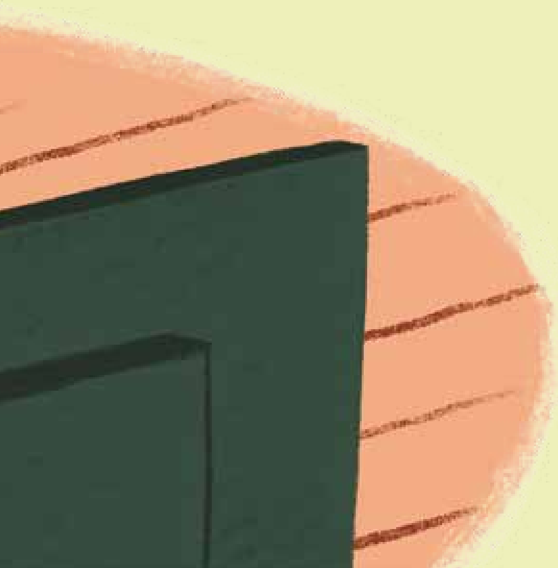

BUZZ

When Zarah went home, everybody made a fuss of her and brought her presents. Her brother Ali was really pleased to see her – he'd been worried about her when she was in hospital.

Talking to Mum and Dad helped him feel better about his worries, and he was glad that Zarah could come home for a while. They watched a film together like they did before she was ill. Ruby also came round to visit and she and Zarah made cakes together.

Soon it was time to go back to hospital. Zarah didn't want to go back, but it was nice to see her friends on the ward and the doctors and nurses. She had her wiggly line put in and then she could start her ***chemotherapy***.

The ***chemotherapy*** would take a few days each time she needed to have it, so she would have to stay in hospital for a little while each time.



Did you know?

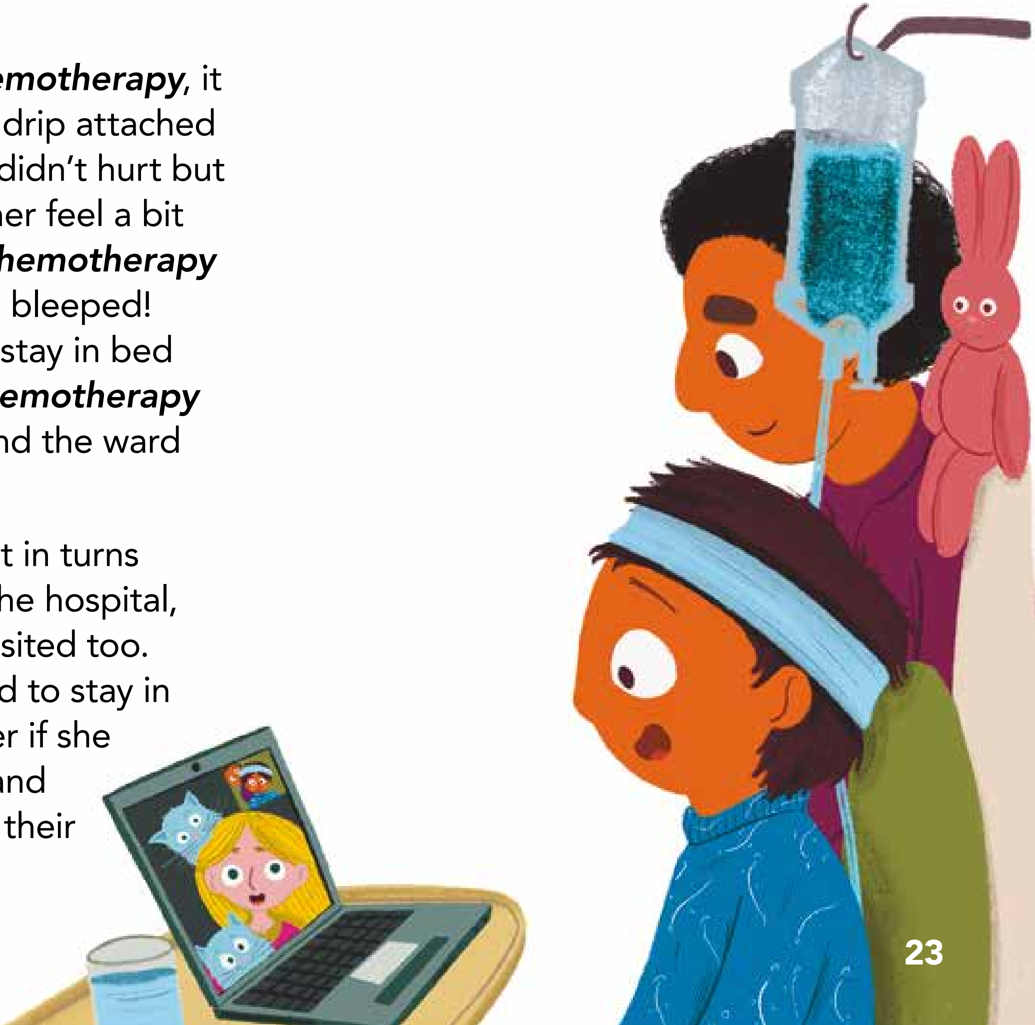
Sometimes wards have rules about who can visit and when. If you have questions about visiting, you can ask the nurses on your ward.

Zarah was usually weighed and measured when she came to the hospital for treatment, and a ***blood test*** was always taken too. Dr Rees could then decide if she should have her treatment that day or if she needed a ***blood transfusion***. The transfusion helped Zarah to have more energy and made her feel better.

When Zarah had ***chemotherapy***, it was given through a drip attached to the wiggly line. It didn't hurt but sometimes it made her feel a bit strange. When the ***chemotherapy*** finished the machine bleeped! Zarah didn't have to stay in bed while she had her ***chemotherapy*** and could walk around the ward if she wanted.

Mum and Dad took it in turns to be with Zarah at the hospital, and sometimes Ali visited too. Sometimes Zarah had to stay in hospital a little longer if she had a temperature, and Ali went to stay with their aunty and cousins.

Zarah didn't mind being on the ward, as she made friends with the other children. If she felt well enough, the teachers and ***play specialists*** always had things she could do or make so she didn't get bored. She also had video calls with Ruby and her kittens.



When she was at home, Zarah was given her medicine by Mum and Dad, and Maria the ***community nurse*** came to take blood. Zarah liked it when Maria came round because she got to show her Buzz the rabbit!

After a few weeks of ***chemotherapy***, Zarah's hair started to fall out. Dr Rees had told her this would happen and that it would grow back once the treatment had stopped. He also told her that it wouldn't hurt and, although Zarah hadn't believed him, he was right.

Mum gave Zarah a pretty, silky scarf to wear on her head. They practised different ways of tying it together. Zarah saw other children in hospital without hair – some had wigs, hats or scarves like hers, and some didn't wear anything on their heads.

Sometimes Zarah felt well enough to go to school for a little while and see her friends. When she was not well enough for school, Mr Slater, a teacher from her school, sometimes came and gave her lessons at home.

Zarah really enjoyed that, especially when she got to write stories. Dad said the lessons would help her to keep up with the work her friends were doing at school.

Did you know?

People who are having ***chemotherapy*** can be unwell if they get infections. Because of this, they usually have to have their temperature taken quite a lot to check if they have an infection.

One day, Zarah heard that Riley, a child she'd met on the ward, was having to take some extra medicine at home to stop them catching chickenpox from a friend at school. People who are having ***chemotherapy*** can be very unwell if they catch chickenpox or other bugs. Zarah thought it was strange that you could catch chickenpox, but you couldn't catch ***cancer***.

Radiotherapy

It took a long time to finish all the ***chemotherapy*** treatment, but at last it was finished. Zarah had another ***scan*** and then Dr Rees said she would need to go to a different hospital and have ***radiotherapy***. Dr Rees explained that ***radiotherapy*** was like having an X-ray or another ***scan***. It wouldn't hurt but Zarah might feel tired or a bit sick, so Dr Rees would give her medicine to help with this.

Like when she had the ***scan***, Zarah would need to lie very still for a few minutes. A special mask, a bit like a space helmet, would be made for Zarah to wear while she was having ***radiotherapy*** - this kept her head in the right position. Mum and the ***play specialist*** made up a game where Zarah and Mum had a special song they both sang to themselves. When the song was finished it would be time for the treatment to stop.

Did you know?

Radiotherapy can make your hair fall out, but only on the part of your head where you're having the treatment. It will usually grow back, but sometimes it doesn't. Your doctor or nurse can help you know what to expect.

When the ***radiotherapy*** started, Zarah had to lie on a narrow table with a big machine above her that gave her the treatment. She had to be in the room by herself while the machine was working, but it was only for a minute or two and it didn't hurt at all. Mum or Dad watched her on a screen in the next room and they could always talk through an intercom.

The ***radiotherapy*** sessions lasted for six weeks and the worst thing about it was that Zarah got sore ears, just like sunburn. Towards the end of the treatment Zarah felt very tired. The doctor had said this might happen and Zarah got lots of rest.

What happens next?

After some months, Zarah felt much better. Her hair was growing back and she was able to play with Ali and Ruby and help look after Buzz the rabbit. Dr Rees told her that she had finished all the treatment. In a while the wiggly line would be taken out.

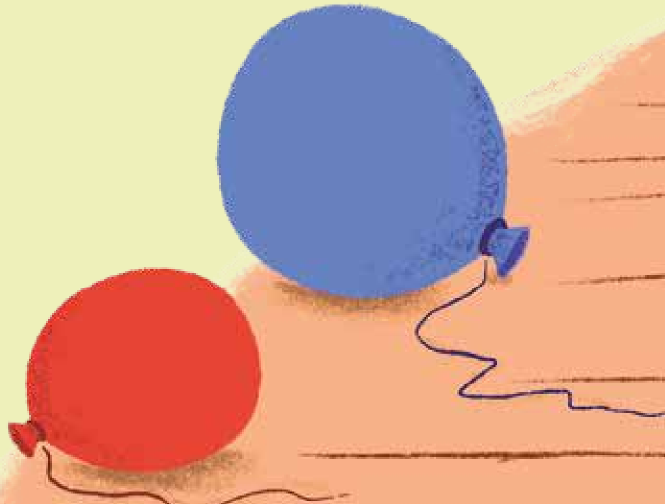
She'd still need to come to the hospital for checkups, tests and scans to make sure she was growing properly and staying well, but she wouldn't have to be there nearly as much as she was during treatment.

Zarah was really happy to have finished her treatment. Mum and Dad were very proud of her because she'd been so brave.

Ali helped Mum and Dad to arrange a surprise party for when Zarah finished her treatment. All her friends came and although she was not quite well enough to run around as much as them, Zarah had a wonderful time.

The biggest surprise was a little kitten all of her own!

What do you think she called him? Wiggly!



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 so you can sleep right through it without feeling anything. Afterwards the doctors will wake you up.

Anaesthetist

This is a doctor who gives you anaesthetic and looks after you while you're asleep during an operation.

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.

Cancer

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

Central line/Broviac® line/Hickman® line/PICC 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 (or in your arm for a PICC line). This is inserted under general anaesthetic. Sometimes these are called Broviac® or Hickman® lines. Some people call them wigglies!

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.

Neurosurgeon

A doctor who specialises in operations on the brain.

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.

Physiotherapist

A physiotherapist helps people to get moving again after they've had an operation or hurt themselves. They teach people exercises to help them get stronger and improve how they move.

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.

Radiotherapy

Where special rays are pointed at the tumour. The job of the rays is to try to get rid of even the tiniest scrap of tumour that might be left after the operation and chemotherapy.

Scan

This can be a CT scan, which is fairly quick, or an MRI scan which takes a longer time. It’s like an X-ray. The machine is very noisy but it gives a very clear picture of the inside of your body.

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!

Speech and language therapist

Speech and language therapists help people with speaking, communicating, eating and drinking.

Theatre/operating room

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

Tumour

When damaged cells in the body stick together to form a lump. Not all tumours are cancer – tumours that are not cancer are called benign.

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.

We endeavour to ensure that the information provided is accurate and up to date at time of printing. Young Lives vs Cancer cannot accept liability for any loss or damage resulting from any inaccuracy or omission in this publication. Information in this publication should not be relied on in place of appropriate professional advice specific to your circumstances.

Zarah Has a Brain Tumour is a story for children who have a brain tumour to read with their families.

We hope it will help you understand what a brain tumour is 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 **younglivesvscancer.org.uk/ storybook-survey**

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