

# Harry has an operation

A story for children with bone sarcoma



This book tells the story of Harry. Harry tells us about getting bone cancer and an operation he has to help him get better.

When you read about bone cancer and operations, there may be words you have not heard before or don't understand. We explain some of these words in the 'Tricky words' section on page 29.

### **Guidance for parents, carers and healthcare professionals**

We hope this story will help younger children understand their bone cancer diagnosis, its treatments and types of surgery, including limb-sparing surgery.

We encourage parents, carers and healthcare professionals to read the book with the child. The book is aimed at children aged 5 to 9 years old. However, it may be suitable for some younger or older children too. It can be used as a tool for talking to children about what they are going through, answering questions they may have and checking their understanding.

There are sections in the book where children can write and draw.

There are also some tips for parents and carers on page 32 to help you support a child as they go through treatment.

# About you

This book is yours to read and write in. It will help you find out more about something called an operation. You can ask your family, friends, doctor or nurse too.

**My name is:** .....

**I'm** ..... **years old.**

**I live in:** .....

**Write about what you like doing, or  
draw a picture of yourself here.**

What do  
you like to do  
for fun?





# Meet Harry

Harry is 9 years old. He lives with his mum, dad, little brother Joe, little sister Poppy and their dog Scamp.

Harry loves riding his bike and going to the park with Scamp!

One day, Harry and his mum found a lump on Harry's leg. So, they went to see a doctor. The doctor said Harry needed to go to the hospital to have it checked out.

Harry went to the hospital with his mum and dad. The hospital doctor wanted to find out what was the matter with his leg. He said Harry needed some tests.



# These are the tests that Harry had:

- An X-ray
- A PET scan
- A CT scan of his chest
- An MRI scan
- A bone scan
- A heart scan
- Blood tests
- A hearing test

You may need to have the same tests as Harry. Ask your doctor if you want to know more about these tests.



The X-ray and scans took pictures of the inside of his body. These tests didn't hurt. Harry liked looking at his X-ray because he could see the bones in his leg! The doctors also checked that Harry's blood was okay and that he could hear okay.

Harry needed one more test called a biopsy. This is a small operation.

Before his biopsy, he was given medicine that made him fall asleep. It meant he could not feel, hear, or see anything. He woke up very quickly after the small operation. He felt a little bit sick but soon felt better. He just had a bandage on his leg.

During the biopsy, a doctor took a tiny bit of the lump from his leg. It was tested to find out what was wrong with Harry.

Harry's nurse told him that a biopsy was a very important test. It made sure that Harry was given the right treatment.



After his biopsy, Harry and his family met a doctor who told him that the lump in his leg was cancer. The doctor said there are lots of different types of cancer and Harry had a type called bone cancer. Doctors sometimes call it sarcoma.

The doctor said he needed to have some treatments to make his leg better. He needed a treatment called chemotherapy and an operation.

The doctor told Harry and his family that he would be well looked after while he was in hospital.



Harry was not sure what bone cancer or chemotherapy were. But he remembered what an operation was because he had already had one for his biopsy. Well remembered Harry!

Because Harry was feeling a bit confused, he asked his doctor to explain what bone cancer is. The doctor said that sometimes your bones can go wrong. This is called bone cancer. The cancer can stop your body working as well, so doctors may try to take it out by doing an operation.



**Remember:**  
*Tricky words can be found  
on page 29 of this  
storybook.*

Harry met lots of new people when he was at the hospital.

You may want to write down the names of the people you meet and find out what they do to help you remember them.

**My doctor is** .....

**My surgeon is** .....

**My special nurse is** .....

**My play specialist is** .....

**My physiotherapist (physio) is** .....

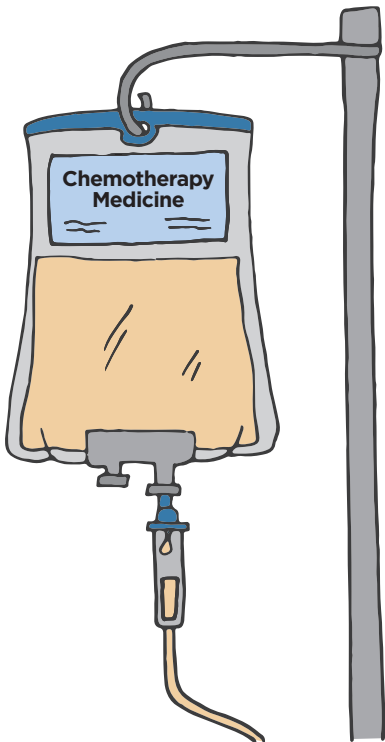
**My social worker is** .....

Write down the name of anyone else you meet or new friends you make at the hospital below.

Before the operation on his leg, Harry was given some medicine called chemotherapy. He sometimes heard his nurse call it chemo.

The medicine went around Harry's whole body. It helped make the lump in Harry's leg smaller before his operation.

Harry had a special tube called a line put in his skin. The chemo medicines dripped from a bag, into the tube and into his body. This meant Harry could be given his medicines without having injections. He didn't like the feeling of needles going into his skin, so was happy about this!



Harry went to the hospital every few days to have his chemo. Sometimes he had to stay in hospital a little longer because the chemo made him poorly. His mum or dad always stayed with him. Harry didn't mind staying in hospital. He made new friends, watched films and did fun things with his nurses and play specialist.

Harry did miss his friends at school though.

## **Have a go at writing or drawing things you enjoy.**

When your play specialist comes to see you, show them your list or pictures, so you can plan lots of fun things to do together.



After his chemo, Harry was ready for an operation. He was told that he would meet a surgeon who would explain what was going to happen in the operation.

So, Harry and his family spoke with a nurse and wrote down questions they wanted to ask the surgeon.



You might want a grown up to help you write down questions for your surgeon. There are some tips about things you could ask on page 31 of this book.

**Are there any questions you would like to ask?  
Remember, no question is a silly question!**

The surgeon told Harry he would take away the lump in his leg and the poorly part of his bone.

He said he was going to put in a new metal bone where the poorly bone had been taken out. His surgeon called it limb sparing surgery.

Harry and his family asked the surgeon all their questions, so they were ready for Harry's operation.



The day before his operation, Harry packed a bag with his pyjamas and toothbrush. He made sure he had his toys and books with him, so he had lots of things to keep him busy!

Harry needed to go to a different part of the hospital for his operation. When they got there, Harry's dad had a big surprise for him. It was a new teddy that looked just like Scamp the dog!



Once Harry was settled in, a nurse weighed him on the scales and checked his temperature. The nurse gave him a name band to wear on his wrist, so everybody would know who he was.



On the day of his operation, Harry was a little nervous. His nurse came to see him and talked about his worries.

Harry was not allowed to eat anything before his operation, but he did have a drink of water. His play specialist stayed with him while he was waiting, so he forgot he was hungry!

When it was time to go, Harry put on a special gown and headed to the operating room. Harry's mum went with him and held his hand while the medicine helped him fall asleep.



When Harry woke up from his operation, his mum and dad were by his bed. He felt very tired, a bit sore and there was a bandage around his leg. The nurse told Harry the bandage would help keep his poorly leg still while it was getting better.



After a little while, some medicine made him feel better and he was able to have something to eat. Harry and his mum and dad ordered pizza!

Harry's surgeon came to check he was ok and told him all about the operation.

He told Harry that while he was asleep, he had put a little tube in his back to stop his leg from feeling funny after the operation.

The surgeon also told Harry he put in another tube so that he could wee straight into a bag and didn't need to get out of bed to go to the toilet.

After a couple of days, the nurse took the tubes out so he could move around more easily.

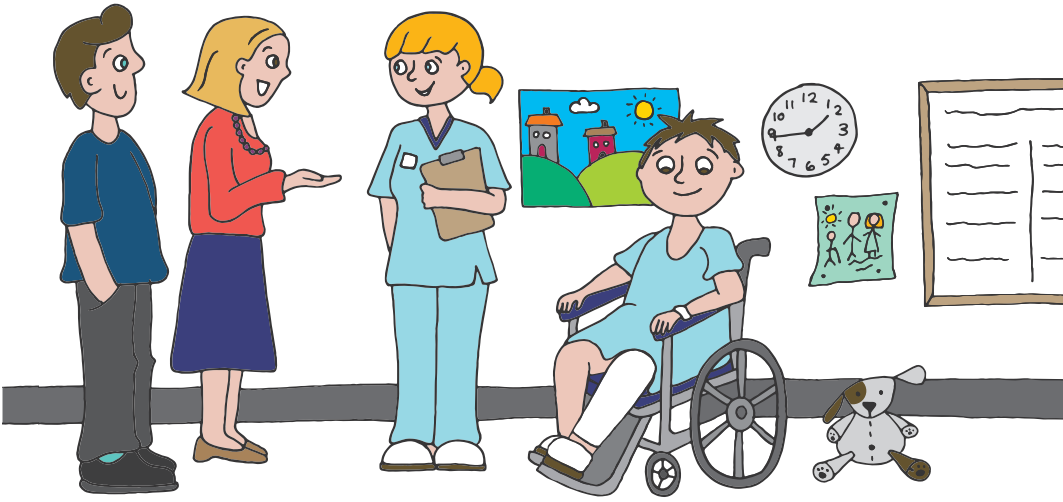
Harry also had his bandages checked every few days to make sure his leg was getting better.

To get used to his bandages, Harry practised wrapping a big bandage round his mum's leg. You could try this too!



Harry stayed in hospital for a while after his operation. He didn't mind. He got to watch his favourite films and read his books. Sometimes he played games with his family and the friends he had made in hospital.

Harry had some lazy days in bed while his leg got better.



Harry used a wheelchair or crutches to help him get around while he learnt how to use his leg again. He was quite excited about having a wheelchair to zoom about on!





When Harry felt ready, he went to the hospital gym to have physiotherapy. Harry learnt how to move around again. He was given exercises to do every day to help him get stronger.

His physio wanted to make sure he could move around and do things at home.

Over the next few weeks, Harry practised how to get in and out of bed and his wheelchair. He practised moving around on crutches and walking on his own.

When he felt ready, Harry practised going up and down the stairs.

As Harry got stronger, his physio helped him plan how to do all the things he liked. He also went back to school to see his friends.

He worked very hard doing his exercises to make his leg work better.



While in hospital, Harry made some friends called Charlie and Abbie. Charlie had an operation called an amputation. The surgeon took away the bottom of Charlie's leg to make her better.

Charlie said she felt scared about her operation. So, she talked to her mum about it and chatted to another girl who had an amputation.



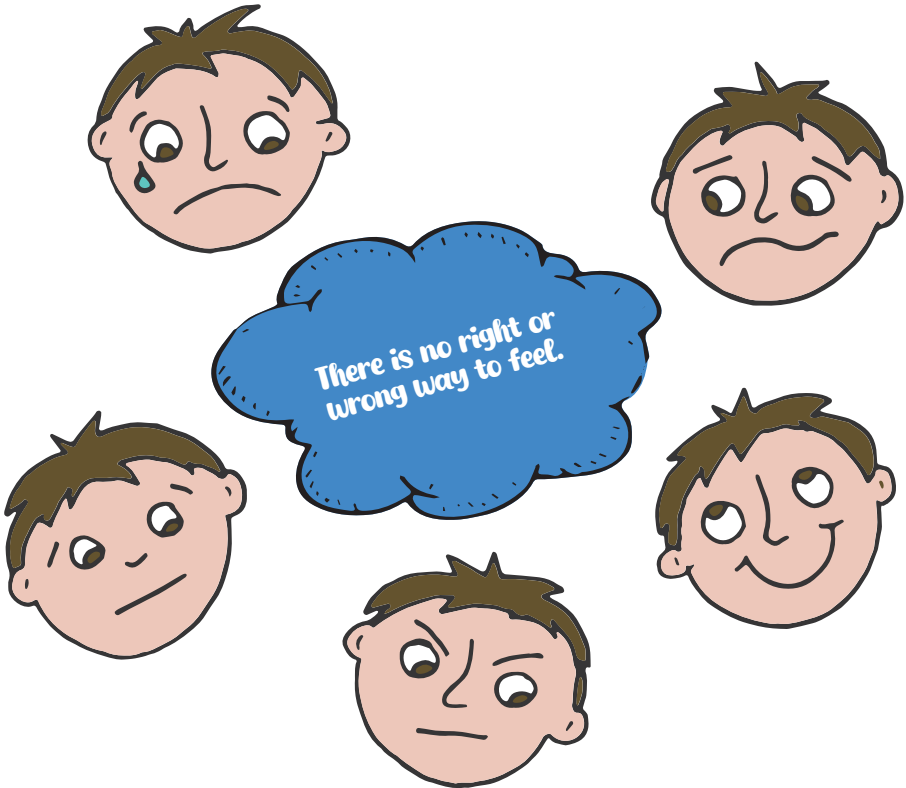
This made her feel better. Charlie said she is learning to walk and run again on a new metal leg. It was made to fit her just below the knee.

Harry's other friend Abbie had a type of bone cancer called osteosarcoma. Abbie had an operation like Harry, called limb sparing surgery. You can read more about Abbie in the storybook **Abbie has osteosarcoma**.



Everyone can feel different things about having an operation. You might feel worried, sad, scared, angry, or all those things at once. Harry spoke to a doctor called a psychologist about his feelings. This made him feel better. Try telling somebody how you feel about your operation.

You can draw circles around the pictures below or write down how you're feeling in the space on the next page, and show someone when you're ready.



**Write your feelings down in  
this box.**

After some time in hospital, Harry was told he could go home. He felt much better and was really looking forward to seeing Scamp, his brother, sister and all his friends.

He knew he would go back to the hospital to have more chemo. He didn't mind because he liked seeing his friends at the hospital too.

Harry still sees his doctor for check-ups. His physio helps him get his leg even stronger. He's not yet able to ride his bike but he loves playing wheelchair tennis with his dad.



Harry is very happy that he can go on walks with Scamp again.

We hope that Harry's story has helped you learn more about having an operation. Your story may be different to Harry's. Talk to your family, doctor or nurse if you are worried or have any questions. They are there to help you.

## The end.



# Be a detective

This is your chance to pretend to be a detective! There are some questions below for you and the person you read this book with to answer. You might remember the answers or want to find them using the clues.

## 1. In this story, Harry finds a lump on his leg. What is it?

Clue: Harry explains this on page 8.

## 2. Harry has chemo. What is it for?

Clue: Take a look at page 11.

## 3. What did Harry's surgeon do?

Clue: You can find this out on page 14

## 4. What did Harry do after his operation to get better?

Clue: Take a look at page 21.

## 5. Everyone has different feelings about having an operation. What feelings might people have?.

Clue: Have a look on page 24 for some ideas.

1. Bone cancer  
2. It helped make the lump in Harry's leg smaller before his operation  
3. Took away the lump in Harry's leg and the poorly part of his bone and put in a new metal bone  
4. Went to the hospital gym to have physiotherapy, practised how to get in and out of bed and his wheelchair;  
practised moving around on crutches and walking on his own  
5. Worried, sad, scared, happy, mad and lots of other things.

Answers:



# Tricky words

Here is a list of tricky words you may have seen in this book or heard people talk about. If there are any other words you don't understand, ask the person who looks after you, or a nurse to explain them.

**Amputation:** An operation where part or all of a leg or an arm is taken away.

**Anaesthetic:** A medicine given before an operation to make you fall asleep. It means you won't feel any pain while the operation happens.

**Biopsy:** When a small bit is taken out of a lump. Doctors will look at it under a microscope to find out what it is.

**Bone cancer:** When your bone goes wrong and makes a lump which should not be there.

**Chemotherapy (chemo):** Medicine used to treat cancer.

**CT scan:** A scan that uses X-rays and a computer to take a picture of the inside of the body.

**Hickman line:** A special tube called a line. The line goes into your chest. Doctors give you medicines through it.

**Hospital:** A place where poorly people go to get better. Doctors and nurses look after people in hospital.

**Limb:** An arm or leg.

**Limb sparing surgery:** An operation where cancer is removed from an arm or a leg.

**MRI scan:** A type of scan that uses strong magnets to take a picture of the inside of the body.

**Oncologist:** A doctor who looks after children with cancer.

**Operation:** When doctors remove or fix something inside the body. It is sometimes called surgery. People are usually asleep during an operation, so it does not hurt.

**Operating room:** A place where doctors do operations.

**PET scan:** A type of scan where a picture is taken of inside your body.

**Physio:** A medical person who helps you move around and walk after an operation. They will give you exercises to do.

**PICC line:** A special tube called a line. The line goes into your arm. Doctors can give you medicines through it.

**Play specialist:** Someone who will play with you while in hospital. You can tell them what your favourite toys and games are.

**Portacath:** A special tube called a line. The line goes into your chest. Doctors can give you medicines through it.

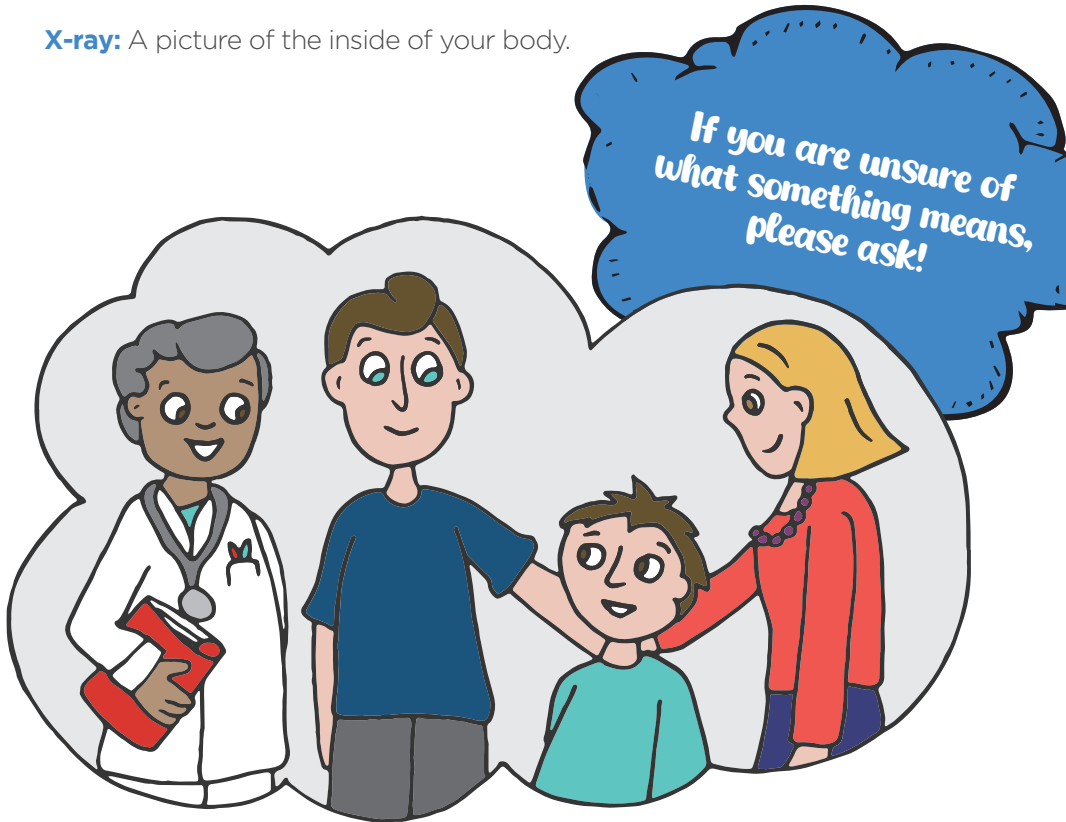
**Psychologist:** Someone who may talk to you about what you are thinking and feeling.

**Sarcoma:** A cancer which starts in the bones or soft tissue.

**Social worker:** Someone who helps families when children have cancer.

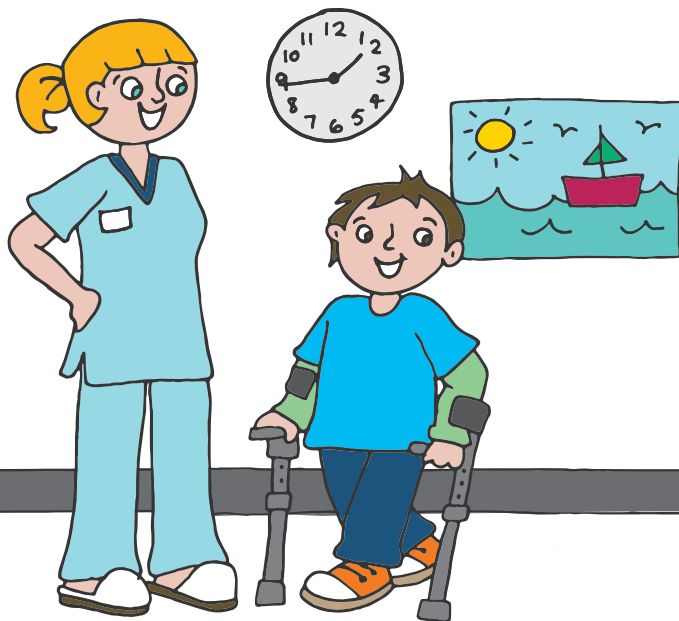
**Surgeon:** A doctor who does operations.

**X-ray:** A picture of the inside of your body.



# Questions for children to ask their hospital team

- How big is the lump?
- How will the chemo make me feel?
- Will the operation hurt?
- How long will I be asleep in the operation?
- Can my mum or dad stay with me while I have the operation?
- How long will I have to stay in hospital?
- How will I feel after the operation?
- Can my friends come and visit me in hospital?
- When can I go back to school?
- Will I be able to play with my friends?



# Tips for parents and carers

Healthcare professionals and parents of children with bone cancer have suggested some tips and advice below. We hope they help you support the child you care for as they go through treatment.

- Encourage the child and any siblings to ask questions and take these seriously. If you do not know the answer, be honest with them. Your doctor can give you more guidance on answering questions if you are unsure.
- Write down any questions or worries you or the child you care for has. Then ask the nurse or doctor those questions when you see them. If you do not understand what they tell you, let them know, so they can explain it in a different way.
- Be honest about surgery. It is important the child you care for knows what is going on and what surgery they will have. Give them time to ask the doctor their own questions.
- It is natural to want to protect the child you care for from things that will upset them. However, do not promise they will feel fine after treatments, like an operation. Create a level of trust by explaining it may be uncomfortable after surgery, but things will get better.

- Things that provide distraction can often help calm an upset child. This might be a visitor, a new book, game, or toy. Consider taking something to the hospital that the child you care for can look forward to after their operation.
- Children pick up on adult anxieties. Think about how you can reassure the child you care for by using positive body language, or a calm tone of voice, as well as the words that you use.
- It is ok to talk about your feelings. Nurses and social workers are there for you to talk to and provide help and support. It is important to take care of yourself without feeling guilty.
- We also have a suggested list of questions on our website, which you might want to ask the doctor. Look for 'Questions to ask your medical team' on [bcrct.org.uk/aboutpbc](https://www.bcrct.org.uk/aboutpbc)

# About us

The Bone Cancer Research Trust (BCRT) is a charity devoted to fighting primary bone cancer (PBC). Our mission is to save lives and improve outcomes for people affected by PBC. We do this through research, information, awareness and support.

Our ambition is for a future where PBC is cured. For those affected by it right now, our high-quality information and supportive network means no one should have to feel alone.

## Our support and information service

We are here for anyone who needs support with, or information about primary bone cancer.

If you would like more support, information or have any questions, please contact our Support and Information Team:

**Call: 0800 111 4855**

**Email: [support@bcrt.org.uk](mailto:support@bcrt.org.uk)**

**Visit: [bcrt.org.uk](http://bcrt.org.uk)**

# Thank you

We would like to say thank you to everyone who has contributed to this latest version of the booklet.

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# Your feedback

We are always trying to improve our health information. If you would like to share any thoughts about this booklet, please get in touch. We would love to hear from you.

Your feedback helps with the development of new resources and helps us to make sure our current resources meet your needs.

Visit: [bcrct.org.uk/ourhealthinformation](https://www.bcrct.org.uk/ourhealthinformation) to find out how we produce our information resources.

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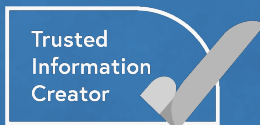
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Patient Information Forum

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