

HARRY HAS AN OPERATION

A guide for children with bone sarcoma



Harry has an Operation is written for parents, carers and healthcare professionals to read with children in order to help them understand their sarcoma and its treatment.

This storybook has been produced especially for young patients who require limb-sparing surgery or amputation.

At the back of this storybook, you will find a useful glossary of words. Look out for these words throughout 'Harry has an Operation' in **bold**.

This storybook was written by Dr Heather Borrill (Consultant Clinical Psychologist, Royal Victoria Infirmary, Newcastle) and Hannah Birkett (Research and Information Officer at the Bone Cancer Research Trust). It was illustrated by Debra Liggins at Bearded Squirrel. A full list of reviewers can be found at the back of this resource.

Harry has an Operation was produced by the **Bone Cancer Research Trust**, who are committed to providing reliable, accurate and up-to-date information. Information provided in this storybook should be used in conjunction with advice provided by healthcare professionals with knowledge of your circumstances.

The review and development process of this storybook was carried out by the **Bone Cancer Research Trust** and the **Children's Cancer and Leukaemia Group**.

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About you

This booklet is yours to help you understand more about your treatment and what it is like to have an operation.

My name is:

.....

I am years old. My hospital is called:

.....

Use this space to write about what you like doing, or you could draw a picture of yourself:

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Meet Harry

Harry is ten years old and he lives with his Mum, Dad, little brother Joe, little sister Poppy and their dog called Scamp. Harry loves riding his bike and going to the park with Scamp!



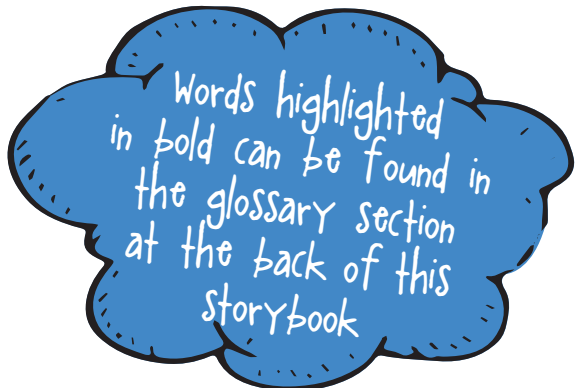
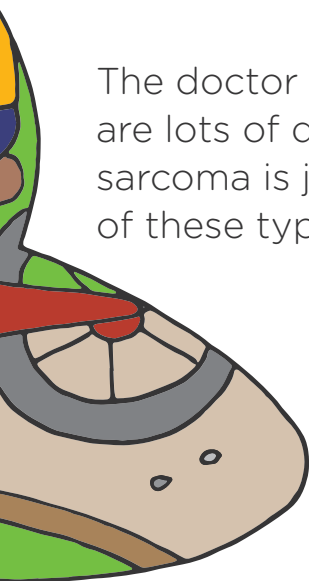
Harry had a lump on his leg called a **sarcoma** (a type of **cancer**) and he is going to tell you all about an operation he had to make his leg better.

What is cancer?

Your body is made up of millions of tiny **cells**, which all have a special job to do to keep your body healthy. New cells are always being made to replace any cells which get damaged or stop working.

Sometimes, new cells are made too quickly and become damaged, meaning they can't do their job properly. These damaged cells can stick together to form a lump, and this lump is called cancer.

The doctor told Harry and his family that there are lots of different types of cancer and sarcoma is just one of these types.



Harry had some tests

When Harry first went to the hospital, he had to have some tests to find out what was the matter with his poorly leg. You may need to have the same tests as Harry before your operation, so he has listed some of the tests he had.



Harry had:

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



Biopsy

Harry had another test called a **biopsy**, which is a small operation.

He was given medicine called an **anaesthetic** to help him go for a special sleep during his biopsy so that he couldn't feel, hear or see anything. He woke up very quickly afterwards and felt fine – he just had a little bandage on his leg.

During the biopsy, a doctor took away a little piece of the lump in his leg. This little piece was tested to find out exactly what type of lump Harry had.

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



After his biopsy, Harry met a doctor who told him that the lump in his leg was called a **sarcoma**. This doctor was called a **paediatric oncologist**. A paediatric oncologist is a doctor who knows how to look after children with cancer like Harry.

The oncologist spoke with Harry and his family and told them that the hospital team would look after him to make him feel better.



Your Hospital Team

Harry met lots of new people while he was in 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 specialist nurse is:

My play specialist is:

My physiotherapist is:

My occupational therapist is:

My social worker is:

My teacher is:

Here is some extra space for you to write down the name of anyone else you meet on the ward, or the names of any new friends you make in hospital.

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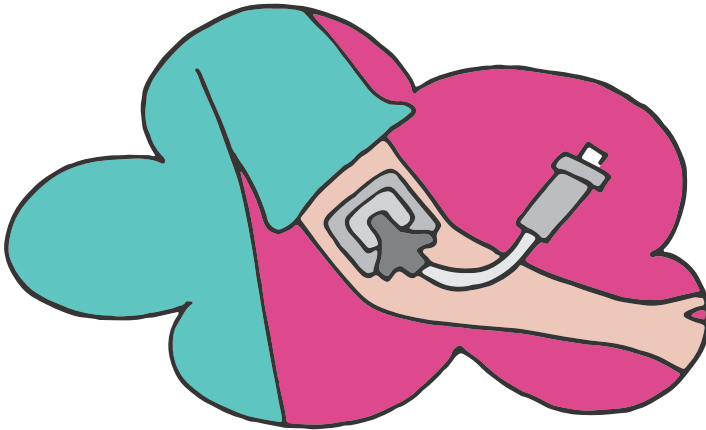
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Harry's Treatment

Before his operation on his leg, Harry had some medicine known as **chemotherapy**.

Chemotherapy goes around the whole body to fight cancer cells that may have escaped from Harry's leg. It also helps the surgeon by making the lump in Harry's leg smaller.

Before having chemotherapy, Harry had to have a special tube put in his arm called a **PICC line**. This helps the doctors and nurses give Harry his medicines safely...and means no more needles!



Some children on Harry's ward had their chemotherapy through a different tube called a **Central line** or a **Hickmann line** instead. You may have heard this being called a 'wiggly'!

Harry went to the hospital for a few days at a time to have his chemotherapy. Sometimes Harry had to stay in hospital a little longer, but his Mum or Dad always stayed with him.

Harry didn't mind staying in hospital. He made lots of new friends, watched DVDs and did fun things with his nurses, teacher and play specialist to keep himself active.

**Try writing down a list of things
you enjoy doing for fun.**

.....

.....

.....

.....

.....

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

After having some chemotherapy, Harry was ready for an operation to take away the rest of the lump in his leg.

Harry and his Mum met a **surgeon** who told them all about what was going to happen in the operation.

Before this, Harry and his family spoke with a nurse to think about any questions they wanted to ask the surgeon about Harry's operation.

They wrote down a list together which they took to the meeting.



At the meeting, the surgeon told Harry that he was going to take away the lump in his leg and the poorly part of his bone too.

He said he was going to put in a new metal bone where the poorly bone had been taken out.

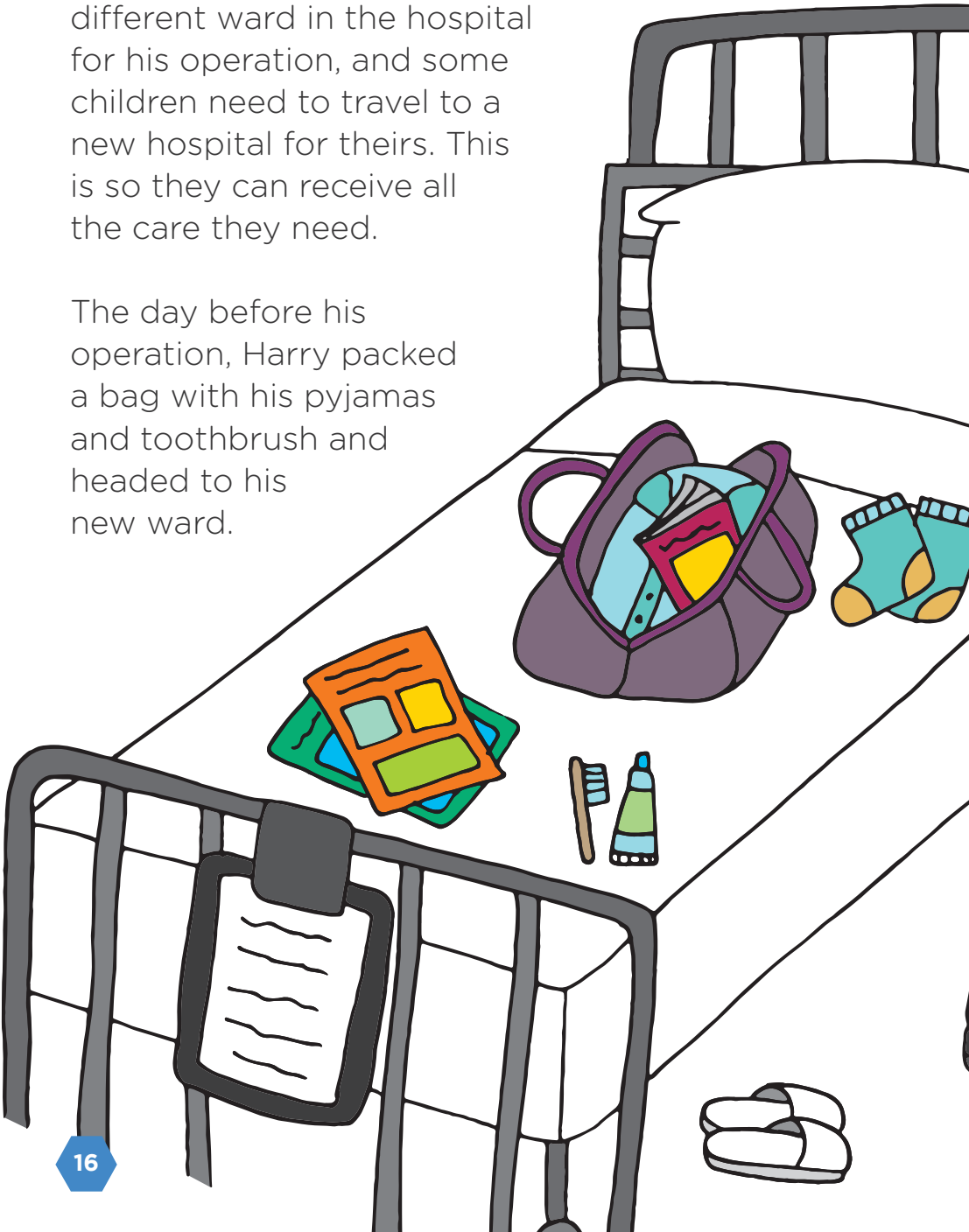
Harry and his family asked the surgeon all the questions they had prepared so they were ready for Harry's operation.



[illegible]

Harry needed to go to a different ward in the hospital for his operation, and some children need to travel to a new hospital for theirs. This is so they can receive all the care they need.

The day before his operation, Harry packed a bag with his pyjamas and toothbrush and headed to his new ward.



He made sure he had his toys, DVDs and comics with him so he had lots of things to keep him busy after his operation!

When they got to the new ward Harry's Dad had a big surprise for him. It was a new teddy that looked just like Scamp the dog!



When Harry got to the new ward, a nurse weighed him on the scales and checked his temperature. The nurse also gave Harry a name band to wear on his wrist so that everybody would know who he was.



Harry liked being on the new ward. The nurses were very friendly and he made a new friend called Abbie, who had sarcoma just like him.

Operation Day

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

Harry wasn't allowed to have any food in his tummy before his operation, but he did have a drink of water and his play specialist stayed with him while he was waiting to keep his mind off being hungry.

When it was time to go Harry put on his special gown and headed to the **operating room**. Harry's Mum went with him and stayed with him and held his hand while his anaesthetic helped him to fall asleep.



When Harry woke up from his operation, his Mum and Dad were by his bed. He felt very tired and a little sore but after a 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 didn't remember anything from his operation, as he was asleep dreaming happy dreams, but when he woke up he had a bandage round his leg. The nurse told Harry that this was to keep his poorly leg still while it was getting better.

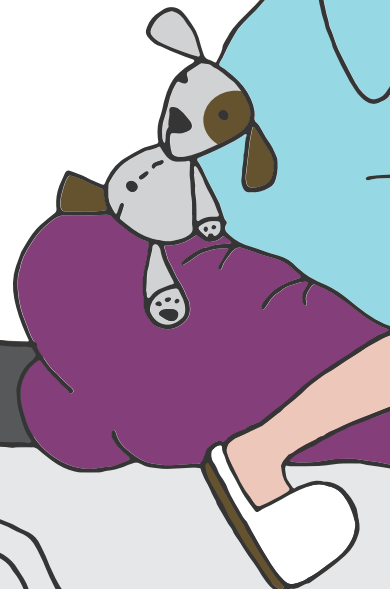
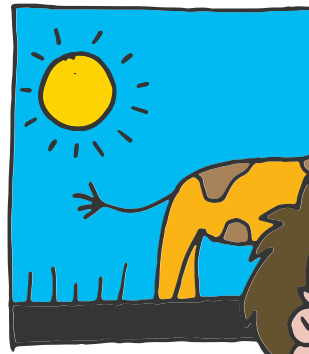


When Harry felt less tired, his surgeon came to check he was ok and tell him all about the operation he had had.

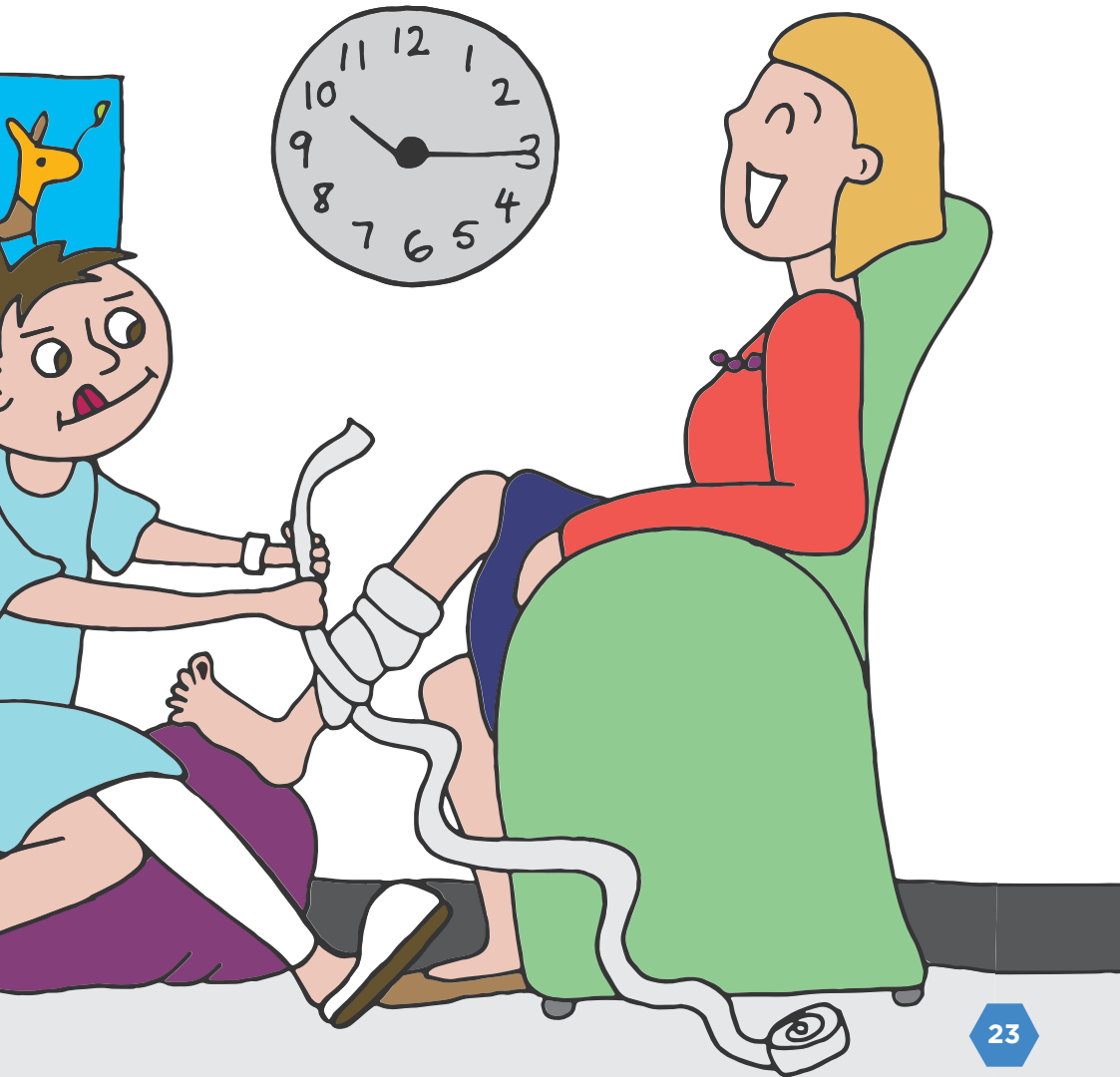
He told Harry that the doctors fitted a little tube in Harry's back to help with any pain he might have. This is called an **epidural**. Harry told his Mum that this gave him a tingly leg, but it didn't hurt.

The surgeon also told Harry about another tube called a **catheter**. Harry had this fitted during his operation so that afterwards he didn't need to get out of bed to have a wee and could rest his leg.

The nurse took Harry's epidural and catheter out after a couple of days when he could move around more easily.



Harry needed to have his bandages checked every couple of days to make sure that 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 had to stay in hospital for a little while after his operation. He didn't mind as he got to watch his favourite DVDs, read his book and play some games with his family and friends.

Harry needed to have some lazy days in bed whilst his leg got better from the operation.



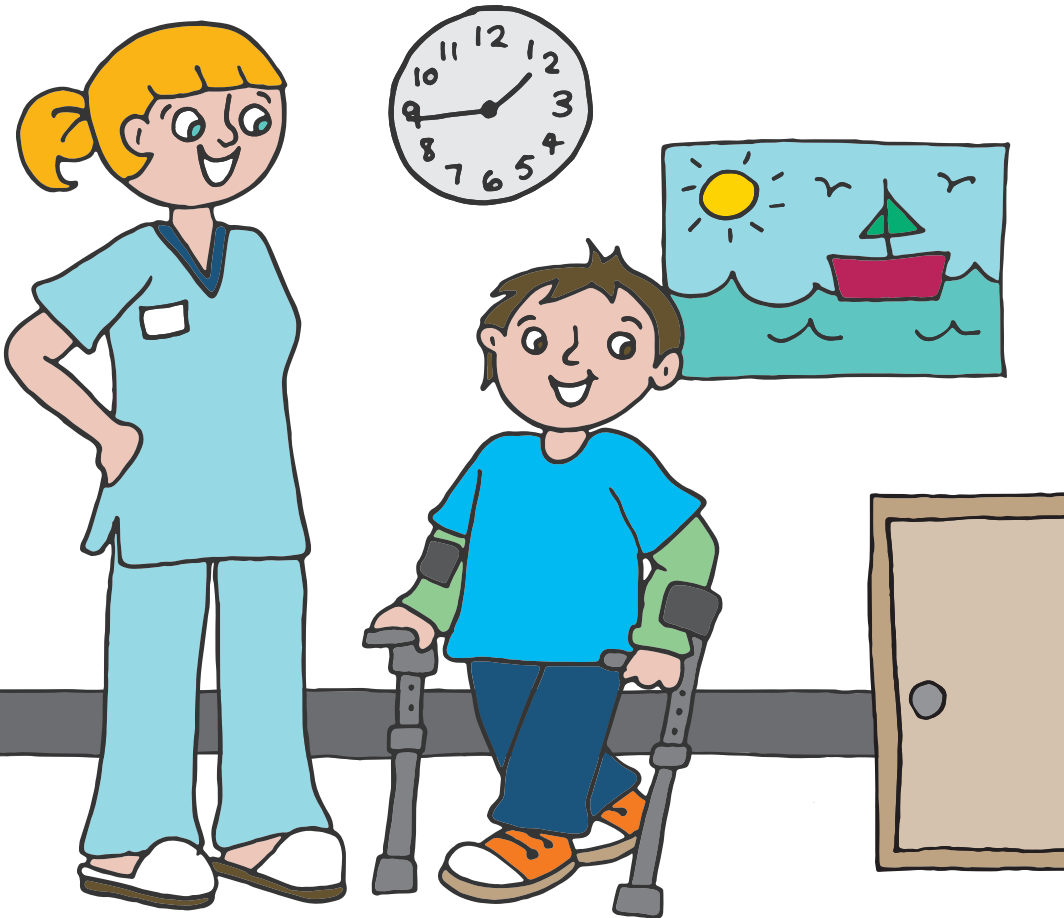
For a while, Harry used a wheelchair or crutches to help him get around while he learnt how to use his leg again. Harry was quite excited about having a wheelchair to zoom about on!

When Harry felt up to it, he visited the hospital gym to have physiotherapy. In **physiotherapy** Harry learnt how to move around again and was given exercises to do every day to help him get stronger.



Harry's family also met an occupational therapist in hospital.

The **occupational therapist** spoke with Harry's Mum and Dad about how Harry would manage at home following his operation. They wanted to make sure he could get around and be comfortable.



Over the next few weeks, Harry learnt how to get in and out of his bed and his wheelchair. Then he practised moving around on his crutches and walking on his own. When Harry felt ready, he practised going up and down the stairs.

As Harry got stronger and stronger, he planned with his **physiotherapist** and **occupational therapist** about how he would manage to do all the things he liked doing and go back to school to see his friends. He worked very hard doing his exercises to make his leg work better.



While he was in hospital, Harry met a friend called Abbie. Abbie had a sarcoma in her leg as well. The surgeon had to take away Abbie's poorly leg from below her knee to make her better. This is called an **amputation**.



Abbie told Harry that it didn't hurt when the surgeon took away the poorly part of her leg because she was asleep during her operation.

At first Abbie felt sad and scared, but she talked to her Mum about it and even got to meet another girl who had had an amputation. This made Abbie feel much better.



Harry asked Abbie what happened after her operation. Abbie said that when she woke up, she couldn't see her leg as it was in a big bandage and she had an epidural just like Harry so that her leg didn't hurt.

Abbie knew the lower part of her leg wasn't there anymore, but sometimes it felt like it was still there. The doctor said that this feeling was normal after an operation like Abbie's.

Once Abbie has fully recovered from her operation she will learn to walk and run around again on a new metal leg that attaches to her knee.

Feelings

Everyone feels differently about having an operation. You can feel nervous, excited, worried, sad, scared, angry... or all of those things at once!

It helps to talk to someone else about how you are feeling, don't keep it all bottled up inside! Harry spoke to a **clinical psychologist** about his feelings and this helped him to feel better. Try telling somebody how you are feeling about your operation.

If you're not sure how, try drawing circles around your feelings on this page first so that you can show them to your Mum, Dad, friend or nurse whenever you feel ready.



Or you could even draw your own picture here:

Harry is feeling better

After some time, Harry was told he could go home! He felt much better and was really looking forward to seeing his little brother and sister and all his friends at school.

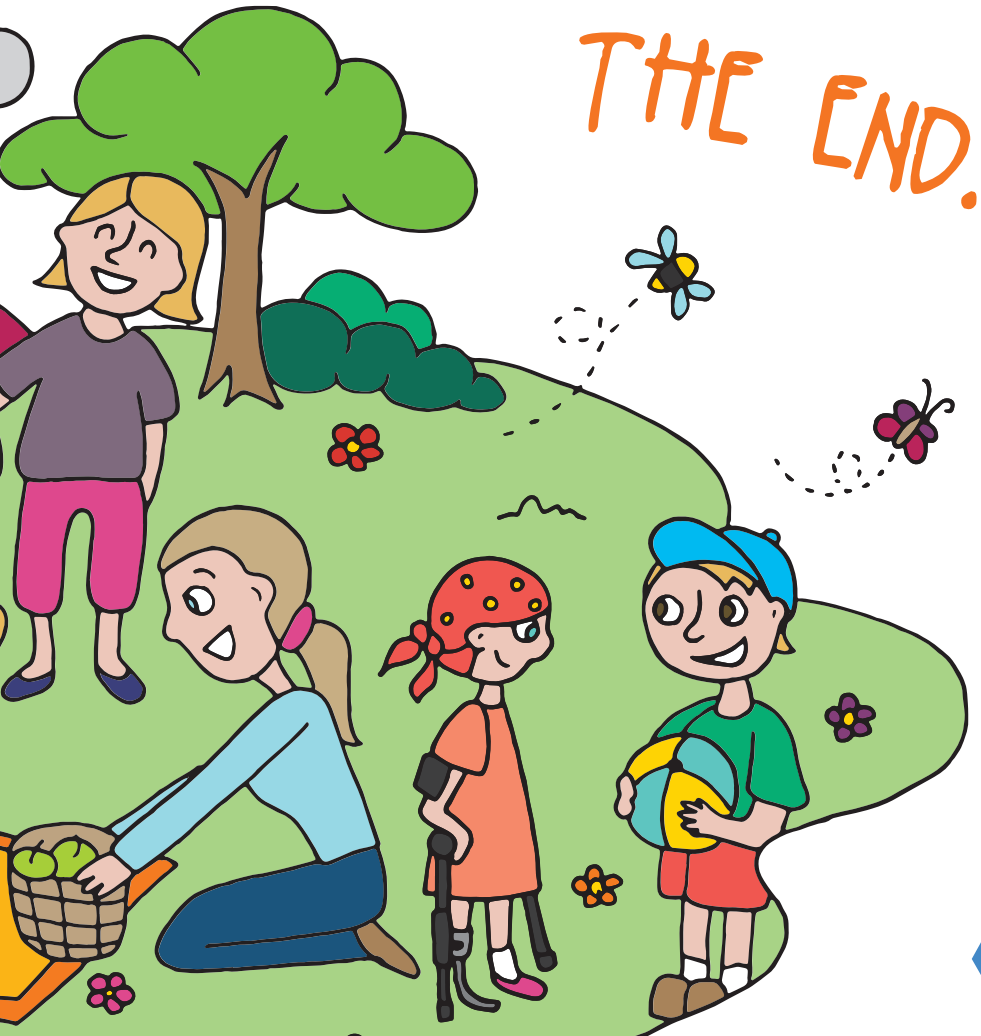
He knew he had to go back to the hospital to start his chemotherapy treatment, but he didn't mind because he enjoyed seeing all his friends at the hospital too.

Even though all his treatment has finished now, Harry still visits his oncologist for check-ups and has his physiotherapy at home to help him become stronger. Harry can't wait to start riding his bike again soon!



Harry is very happy that he can go on walks with Scamp again, sometimes Abbie and her Mum come along too!

We hope that Harry's story has helped you learn more about having an operation. Your story may not be exactly the same as Harry's, so if there is anything else you want to know, ask your doctor or nurse at the hospital.



What does this mean?

Here is a list of words you may have seen in this book or heard people talk about. If there are any other words you don't understand, try asking your family or a nurse for help.

Amputation: Taking away part of an arm or leg that isn't working properly any more

Anaesthetic: Medicine which makes you sleep during an operation so that you don't feel any pain

Biopsy: When a little piece of a lump is taken out and looked at under a microscope

Cancer: When your cells multiply lots of times to make lumps in your body that shouldn't be there

Catheter: A tube that goes inside your body to help you wee after an operation

Cells: Everyone's body is made up of millions of cells, which all have specific jobs to keep your body healthy.

Central line: A long, thin, tube that is inserted into your chest to give you medicine without you needing to have lots of injections.

Chemotherapy: Medicines used to treat cancer

Clinical Psychologist: Someone who talks to people about their feelings

Epidural: A little tube that goes into your back to give medicine to stop things hurting after an operation

Hickman line: A long, thin, tube that is inserted into one of the big veins (blood vessels) in your body, usually your neck, to give you medicine without you needing to have lots of injections

Occupational Therapist: Someone who helps children with an activity that is important to them, for example moving around or playing games

Operating Room: A place where surgeons do operations

Paediatric Oncologist: A doctor who looks after children with cancer

PICC Line: A long, thin, tube that is inserted into your arm to give you medicine without you needing to have lots of injections.

Physiotherapy: Exercises that help you move around again and become stronger after your operation

Physiotherapist: Someone who helps people with movement and walking

Sarcoma: A type of cancer

Social Worker: Someone who helps families when a child has cancer

Surgeon: The doctor who does operations

A Parent's Guide

This page is for parents and carers of a child undergoing surgery for the treatment of sarcoma. The following advice has been suggested to the Bone Cancer Research Trust by healthcare professionals and parents affected by sarcoma. We hope these points help you support your child.

- **Encourage** your child to ask questions and take them seriously. If you don't know the answer, be honest with them. Your doctor can give you more guidance on answering your child's questions if you are unsure.
- **Write down** any questions or concerns you or your child have so that you can ask the nurse or doctor when you see them. If you don't understand what you have been told, let medical staff know so they can explain it to you again.
- **Be honest** about surgery. It is important that your child knows what's going on, what surgery they will need and has the opportunity to ask the surgeon their own questions.
- It is a natural instinct to want to protect your child from things that will cause distress, however, don't promise that things won't be uncomfortable following a procedure. **Create a level of trust** by explaining that it may be uncomfortable afterwards, but that things will get better.
- Often, things that **provide distraction** can help calm down a distressed child, including visitors and a new book, game or toy. Consider taking something to the hospital that your child can look forward to after their procedure.
- Children pick up on adult anxieties, so in addition to your words consider using **non-verbal cues** such as body language or tone of voice to reassure your child.
- It's ok to **talk about your feelings**. Nurses and social workers are there to talk to and to provide you with help and support. It is important to take care of your own needs and not feel guilty for doing so.

For more information on bone sarcoma and details on ways in which to gain support, please visit www.bcrct.org.uk

Bone Cancer Research Trust is the leading charity dedicated to fighting primary bone cancer. Our mission is to save lives and improve outcomes for people affected by primary bone cancer through research, information, awareness and support.

If you have any comments or questions about 'Harry has an Operation', or require further information, please contact us using the details below.

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This storybook was reviewed by Dr Rachael Windsor, Dr Bernadette Brennan, Hannah Baldwin, Cathy Cook, Anita Pabla, Richard Moody, Abu Sidhane, Claire Shinfield, Helen Boyer, Penelope Hart-Spencer, Helen Hutchison, Callum Young, Malcolm Matthews, Val Matthews, Jane Wingrove and Daisy Wingrove.

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