ABBIE HAS OSTEOSARCOMA

A guide for children

BONE CANCER RESEARCH TRUST
UNTIL THERE'S A CURE

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Abbie Has Osteosarcoma is written for parents, carers and healthcare professionals to read with children to help them understand about their osteosarcoma and its treatment. This storybook has been produced especially for young patients.

At the back of this storybook, you will find a useful glossary of words you will come across during this storybook. Look out for these words in **bold**.

This storybook was written by Liam Marshall (Research and Information Officer at the Bone Cancer Research Trust) and Zoe Davison (Head of Research and Information 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.

Abbie Has Osteosarcoma was produced by the Bone Cancer Research Trust, a charity 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.

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About you

This book is designed to help you understand what **osteosarcoma** is. It includes information about diagnosis and the different treatments that will try to make you feel better.

This storybook has been written for young people aged 9 to 13 years. You may not want to do all the activities in the book, but they will help you to better understand osteosarcoma and the medicines that are given to treat it. For younger children, it is suggested that this book is to be read with an adult.

My name is:

……………………………………………………

……………………………………………………

……………………………………………………

I am ……………. years old.

My hospital/ward is called:

……………………………………………………

……………………………………………………

Use this space to draw a picture of yourself:

Meet Abbie

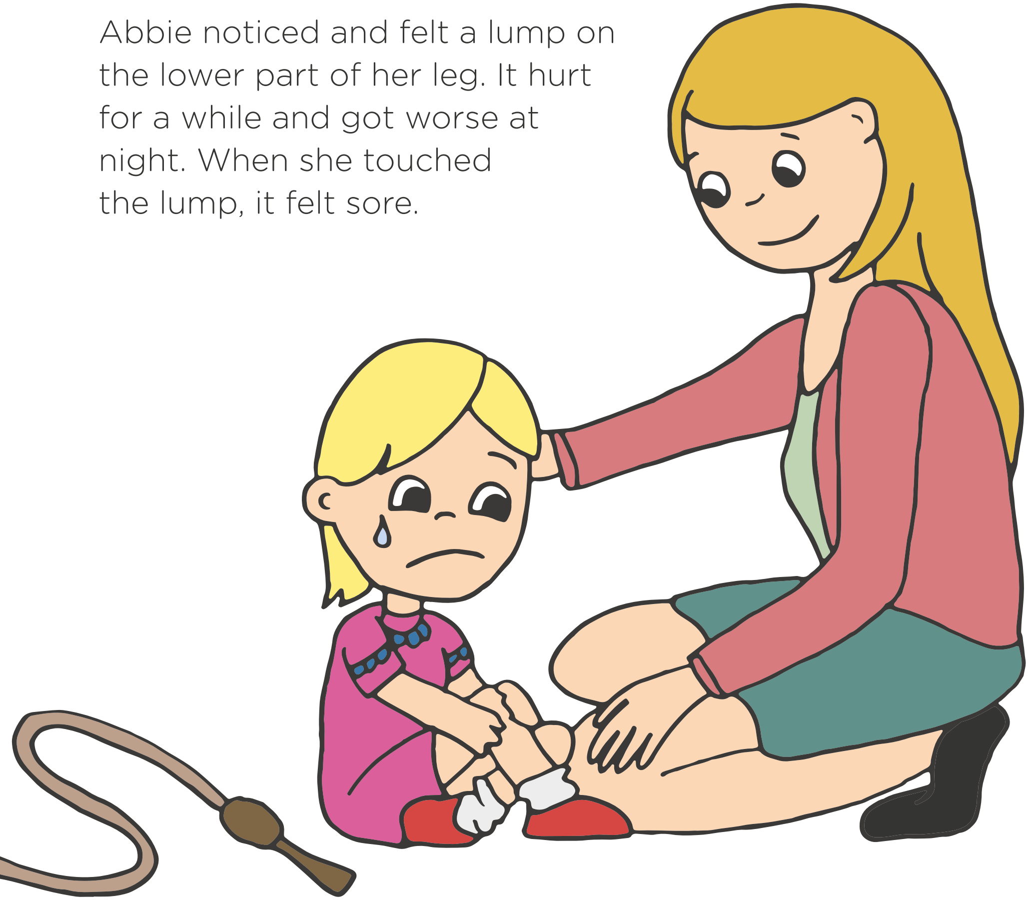
Abbie is nine and three quarters and she lives with her Mum, big brother Tom and baby brother Adam. She loves to skip and play outside with friends when it's sunny and go swimming when it is raining.

Abbie loves pretending to be different superheroes, Mrs Incredible is her favourite. She is very creative and loves using her imagination.

Write down or draw some things that you like to do:

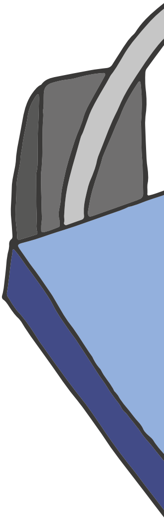
Abbie's leg hurt

Abbie noticed and felt a lump on the lower part of her leg. It hurt for a while and got worse at night. When she touched the lump, it felt sore.



When she tried to skip, she couldn't move her leg as well as before. Both her Mum and her teacher at school were worried about the lump on Abbie's leg.

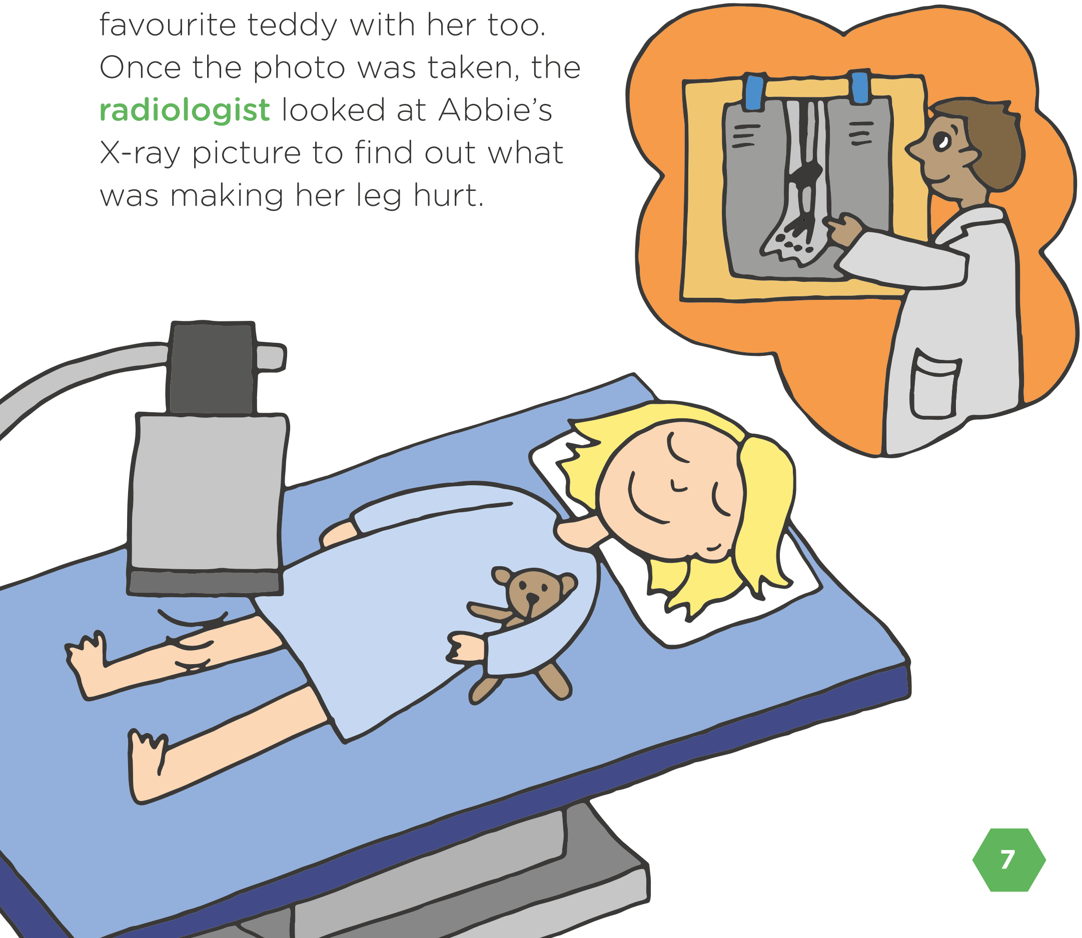
Abbie went to the doctors a few times with her Mum. They were then told to go to a special hospital for some tests.



Abbie had some tests

There are lots of different tests that help doctors find out what is making a person poorly. When Abbie arrived at the hospital with her Mum, the doctor told Abbie she needed to have a scan. This scan was called an **X-ray** which was done on the part of her leg that was hurting.

The X-ray was very simple. It only took a few minutes and did not hurt. When the X-ray machine was placed over her lump, Abbie had to lie very still whilst the photo was being taken. Abbie's Mum was able to come with her whilst she had her X-ray. She also took her favourite teddy with her too. Once the photo was taken, the **radiologist** looked at Abbie's X-ray picture to find out what was making her leg hurt.

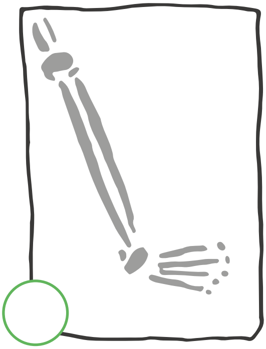


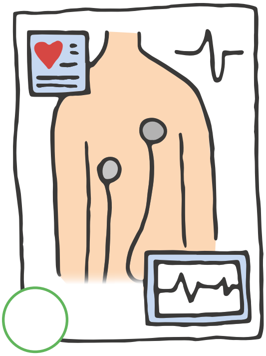
Abbie had to have other types of scans and tests to find out what was wrong with her leg and how to make it better. Abbie also had to have a **CT scan** on her chest. This was so that the doctors could get a picture of her lungs. The doctors explained to her that this scan did not hurt.

For this scan, she had to lie down on a bed and place her arms above her head. The bed then moved her in to position so that a machine called a scanner could take a picture of her lungs. When the scanner was ready to take the picture, Abbie had to hold her breath for a little bit. It was a little tricky, but the doctor said she did a great job.

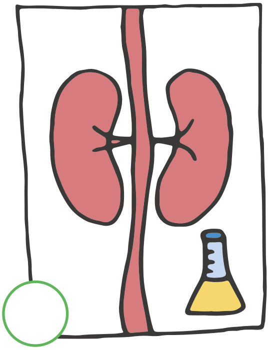
You may also need to have other scans and tests, just like Abbie. These can include:

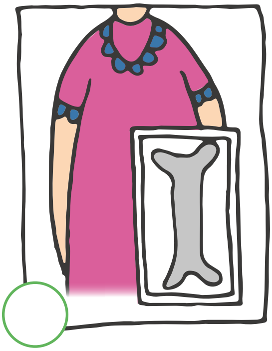
- Blood tests
- An X-ray scan
- An MRI scan
- A hearing test
- A bone scan
- Heart scan
- Kidney test

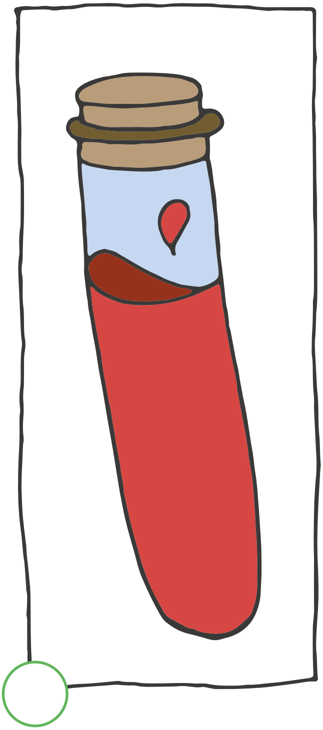


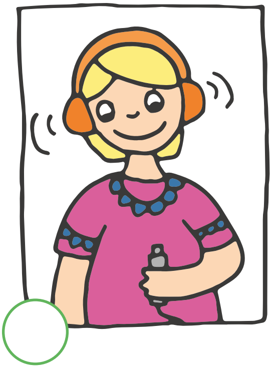


Match the picture to the test...









1: Blood test
2: X-ray Scan
3: MRI Scan
4: Hearing test
5: Bone Scan
6: Heart Scan
7: Kidney test

Abbie then had another test called a biopsy.

For this test, Abbie had to be put into a special sleep. This is because the doctor wanted to take a tiny piece of the lump and look at it through a special tool called a **microscope**. To go into the sleep, she had to take a medicine called an **anaesthetic**. Abbie did not feel anything in her deep sleep.

Abbie woke up with a small bandage on her leg where a bit of her lump was taken out, she was very brave.

A doctor, called a **pathologist**, used the microscope to zoom in on the cells within the tiny piece of the lump that was taken from Abbie's leg. This was to understand what was causing the pain and to figure out what kind of lump it was. This helped her doctors to decide what medicines she needed for her treatment.

What’s wrong with Abbie?

Abbie and her family met a doctor called a **paediatric oncologist**. After looking at her tests and scans, the oncologist told Abbie and her family that she had osteosarcoma.

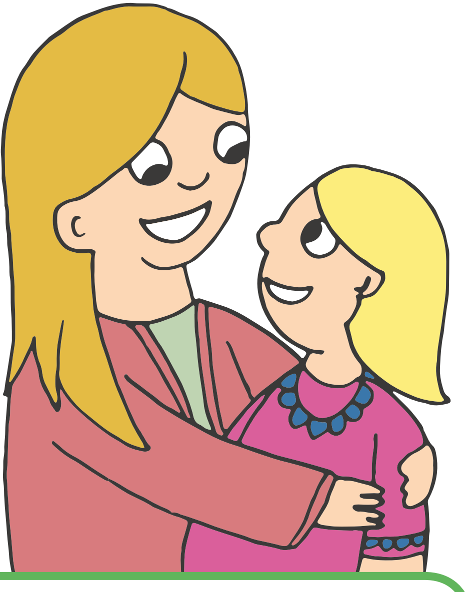
Osteosarcoma is a type of cancer that starts in the bone. You may hear this being called **primary bone cancer**, bone sarcoma or bone tumour. These mean the same. It most commonly occurs in the long bones, such as the bones in the legs and arms, but it can happen in almost any bone in the body. It normally forms where the bone is growing quickest.

The oncologist explained that Abbie’s osteosarcoma was found below her knee, in a lower leg bone called the **tibia**. She was confused and very upset by this news as she didn’t understand why children like her could get osteosarcoma. Her oncologist explained that osteosarcoma starts when something goes wrong with the cells in the bone which causes them to grow too quickly and go out of control. If this happens, a lump can form. Abbie’s nurses and doctors explained that the lump was no one’s fault, and she did not do anything to cause it.

Sometimes, osteosarcoma cells get into the blood stream and travel to other parts of the body where they settle and start to grow. This is called **metastasis**. Osteosarcoma can sometimes spread to other bones in the body, or to the lungs which are in the chest. This is why Abbie had a chest scan.

The oncologist said that there was a big team in the hospital that were going to look after her. Abbie's nurse and family told her that it was completely natural to feel upset and confused. They told her that she should talk to her doctor or nurse if anything was worrying or upsetting her.

If you have any questions or are upset about something, don't be scared to ask. There is no such thing as a silly question!



Write any questions you or your family may have here:

Feelings

Everyone feels differently about receiving a diagnosis of osteosarcoma. It is a very long journey which includes having different scans and tests, meeting a lot of new people, taking chemotherapy and having **surgery**. Throughout this journey, it is completely normal to feel many different feelings, sometimes many at the same time. You can feel nervous, excited, worried, sad, scared, angry…or all those things at once.

It helps to talk to someone else about how you are feeling, don't keep it all bottled up inside! Abbie sometimes spoke to a clinical psychologist about her feelings and this helped her to feel better. Try telling your family or doctors about how you are feeling.

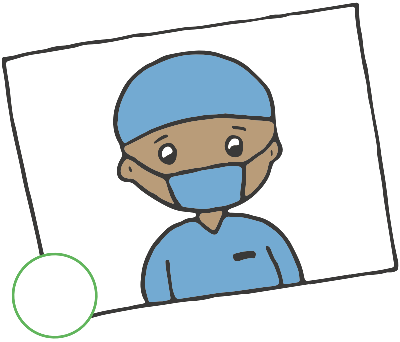
If you are not sure how, try drawing circles around your feelings on this page first so that you can show them to your family, friends or nurse whenever you feel ready.

Or you could draw your own picture here:

Abbie's hospital team

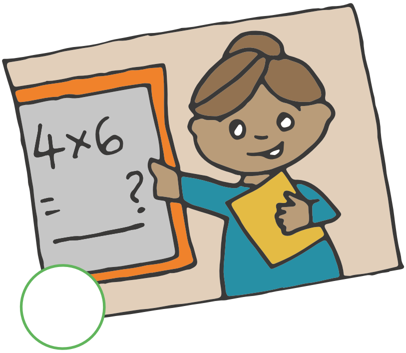
Abbie and her family met lots of new people at the hospital. This included a special team to help Abbie through her treatment called a **multi-disciplinary team**. This might be called an MDT for short and means the team is made up of lots of different types of doctors, nurses and other people who all work together to help their patients. They were also joined by other team members

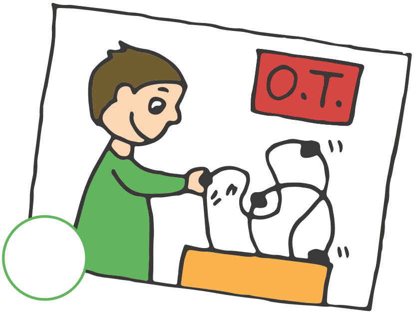
Match the person to the job description



② Physiotherapist

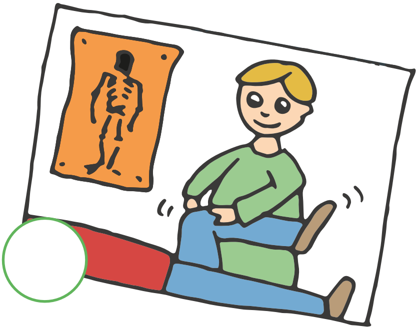
① Radiologist

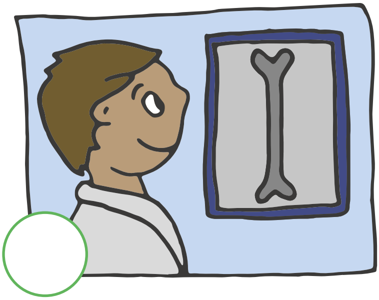




③ Clinical nurse specialist

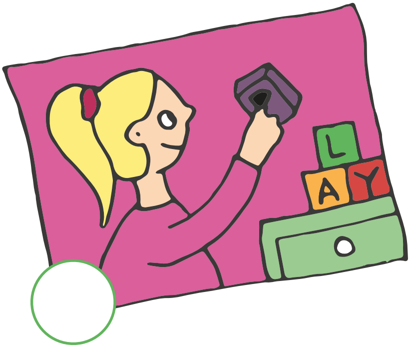
④: Teacher





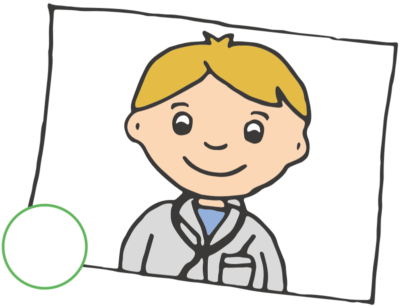
⑤: Surgeon

⑥: Play Specialist



⑦: Occupational therapist

⑧: Paediatric oncologist



Your hospital team

Abbie met lots of new people while she 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 nurses are:

....

My play specialist is:

....

My physiotherapist is:

....

My social worker 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.

....

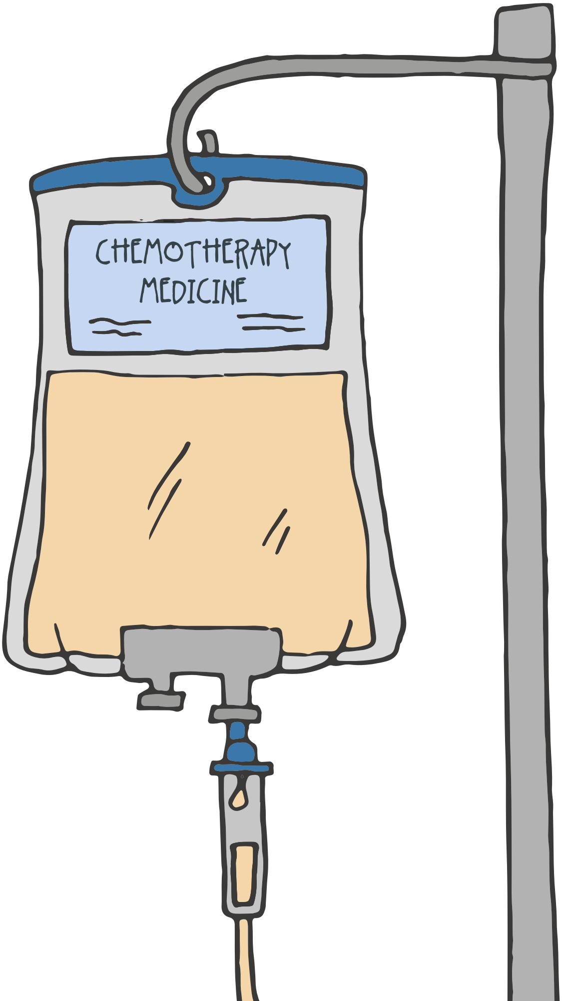
....

....

Abbie's treatment

Once Abbie had been told that she had osteosarcoma, her team got together to talk about how they were going to treat her and worked out a treatment plan. This plan included taking some medicine called **chemotherapy**.

You will hear people calling this 'chemo' for short. After the chemo, Abbie needed an operation to remove the lump. Abbie would then have more chemotherapy after her operation.



What to expect when taking chemotherapy - side effects

Before Abbie started taking her chemotherapy medicine, her clinical nurse specialist told her that she might notice a few changes about how she looked and felt whilst taking the chemo. These changes are called side effects and happen to many people who have chemo like Abbie.

The nurse told her that she may lose her hair which is a side effect of chemo. Out of all the side effects explained to Abbie, this was what she found most upsetting.

The nurse made Abbie feel better by suggesting that she could wear colourful head scarfs which she could decorate herself. The nurse also told her that on the days she did not want to wear a head scarf, she would help her choose a wig to wear. Abbie said she would like to wear a long, curly wig.


WIGS AND HEADSCARVES

Chemotherapy

The first step in Abbie's treatment plan was for her to start chemotherapy. She was given a mixture of 3 different chemotherapy medicines which her doctors sometimes called MAP chemotherapy.

The three different chemo medicines that were given to Abbie were called Methotrexate, Doxorubicin and Cisplatin. These different chemo medicines work in slightly different ways but work better when they are given together. Abbie was given the chemo medicines to make the osteosarcoma smaller. This would help the surgeon remove the lump. As well as making the lump smaller, the chemo kills any other osteosarcoma cells which may have managed to travel around Abbie's body.

To prepare Abbie to have chemotherapy, a special tube called a **PICC line** was put into a **vein** in her arm. This was so the nurses could give the chemotherapy safely. It also meant that Abbie didn't need to have any more needles for blood tests which she was happy about.

Other patients that have chemotherapy may be given their chemo through a **Hickman line** or **ports**.

Abbie had to take the chemotherapy medicines for a certain number of days, and then had a break for a while to let her rest, before taking them again. This is called a cycle. Abbie had to have two cycles of this chemo before her operation.

While Abbie was having her chemotherapy, her Mum kept her company and packed one of her favourite superhero costumes for her to wear in the hospital as it made her feel brave.

What did you bring in to the hospital? How did it make you feel?

Abbie had difficult days when taking the chemotherapy. Sometimes she felt tired, at other times she found it hard to go to the toilet.

When Abbie felt tired, she slept and rested, which no one minded. When she felt sick or had trouble going to the toilet, Abbie's nurses gave her medicines to help her feel better.

Abbie also got upset when her chemotherapy made it hard for her to eat. Her taste changed slightly and she got a sore mouth from the chemo, so she lost her appetite sometimes. When this was the case, Abbie ate small meals and soft foods like mashed potatoes or ice cream, which were easy to eat and tasty. If her mouth hurt too much for her to eat, her doctors gave her some painkillers to help.

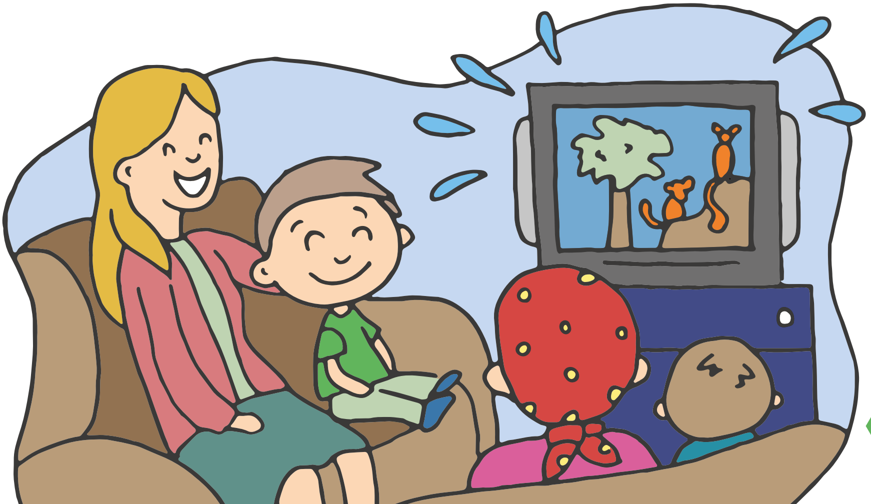
Are there any side effects that really upset you?

Abbie's nurse told her that all these side effects were normal. The nurse told her that most people who were given chemotherapy got a lot of these side effects all the time, and sometimes had others which she did not have.

However, Abbie also had days where she felt a bit better and wanted to do things like play with her friends and visit her classmates. Other days, she tried to do a bit of school work with a teacher that visited the ward. Between cycles of her chemotherapy, she went home to rest and then went back to the hospital when she had to take her chemo again.

One weekend when Abbie was at home, her Mum and brothers planned a day out with her at the zoo. Abbie was so excited and was looking forward to seeing the different animals, especially the meerkats. However, when she woke up, she felt unwell and tired and didn't feel like going. She was upset, but no one was cross with her. Abbie's family all gave her a hug. They stayed in and watched a film together instead.

Sometimes, even when she was not taking her chemo, Abbie felt too unwell to go home. If this happened, she just stayed in hospital so that her nurses and doctors could look after her. She made lots of friends in the hospital who were also having chemotherapy like her. She was never alone and told her family and nurses everything that was upsetting or worrying her.



Surgery

Abbie had to go to a special hospital for her operation. An operation can sometimes be called surgery. Before the operation, Abbie had to have some more tests and scans. This included a CT scan on her chest, and an MRI scan of her lump.

There are different types of surgery that people with osteosarcoma may have. The most common type of surgery is called **limb sparing surgery**, which is sometimes called limb salvage surgery. Occasionally, some patients may need to have different types of surgery such as **rotationplasty** or **amputation**. Your doctor will explain what type of surgery you may need and why.

Abbie and her Mum met with her team to discuss the surgery. Her doctors and nurses said that her osteosarcoma had responded well to the chemotherapy and that the lump had shrunk. Her doctors explained that this was good news and meant that Abbie could have limb sparing surgery.

Abbie was nervous about the surgery, but she was glad the surgeons were going to get rid of the lump.

Abbie had lots of questions. Her family and team always listened to what she was worried about. They knew that this was difficult for her and gave her as much support as possible. Abbie, her family and the nurses thought of some questions to ask the surgeon about the operation and wrote them down.

Do you have any questions about your surgery?

Abbie met her surgeon

The surgeon helped Abbie to fully understand what would happen in the operation and listened to all her worries. The clinical nurse specialist arranged for Abbie and her family to speak to a boy who also had a bone sarcoma. This friend was called Alex. He was 12 years old and had already had an operation.

Alex reassured her that she would still be able to play with her friends again after her surgery. This made her feel less scared. Abbie also met a boy called Harry who was 10 and had just been diagnosed with a bone sarcoma, he was upset so Abbie played games with him.

You can read more about Harry in 'Harry has an Operation'.

To request a copy of our children's book 'Harry has an operation' visit www.bcrt.org.uk

More medicine

Once Abbie's leg had healed after her surgery, the doctors wanted to try to make sure that all the osteosarcoma cells had been killed and that no cells were remaining. Abbie therefore had to have more chemotherapy.

Having more chemotherapy meant that Abbie had to spend a lot more time in hospital. This was upsetting for her as she did not want to have to take the chemotherapy again, but she knew what to expect and knew that her team would take care of her. Her Mum and brothers could also visit with fun things to do. Abbie liked watching films on her big brother's computer.

Sometimes, a medicine called Mifamurtide can also be given after surgery, along with the chemotherapy. Not everyone who has osteosarcoma will have Mifamurtide, so it is best for your family to talk about this with your doctors.

Abbie was feeling better

Once Abbie had recovered from her operation, she was able to go home and back to school which made her very happy. All of her friends were so excited to see her and loved that she was back with them. Sometimes, Abbie had to go back and stay in the hospital to have more chemo. She knew what to expect from the side effects, but this still made her upset because sometimes some of the side effects were painful. Abbie knew she could talk to her nurses and family whenever she was in pain.

Some of the children at school had lots of questions for Abbie so she took a booklet to school that her nurse had given her when she first went into hospital. Her teacher helped her explain to her school friends what had happened to her when she was in hospital. She felt tired when she went at first, but she gradually got used to it.

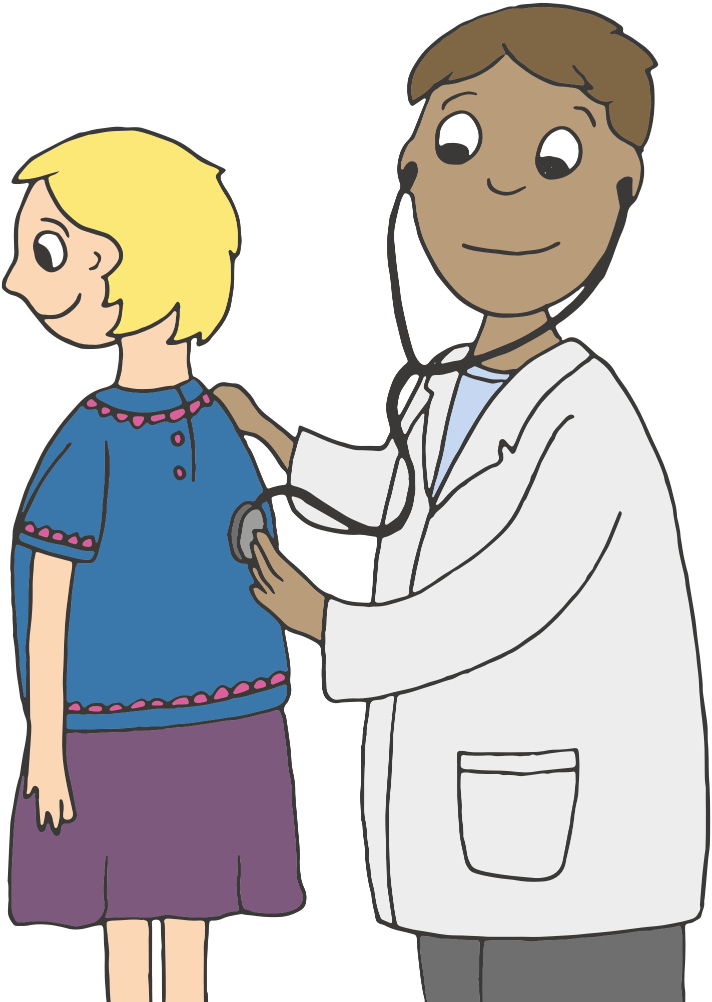
Abbie could not quite do all the things she used to do before she had osteosarcoma, but she was still seeing her physiotherapist and was determined to try new activities.

She still saw her oncologist regularly for check-ups. She did not mind this as she liked to see her team that had helped her so much.

Long term side effects

Once Abbie had finished her treatment, she and her family were told that it was important that she went back for check-ups to make sure everything was okay with her. This is because sometimes, the chemo can make you poorly a long time after treatment has finished.

The doctors said that Abbie might not get poorly at all, but it was better to just keep checking up on her regularly.



We hope that Abbie's story has helped you learn more about having osteosarcoma, about chemotherapy and other details concerning treatment.

Your story may not be exactly the same as Abbie's as you may have different medicines and operations, so if there is anything else you want to know, ask your nurse or doctor at the hospital.

You can use this page to write any notes or other questions you may have:

Glossary:

Amputation: The surgical procedure of taking away part of or the whole of a limb.

Anaesthetic: A medicine that helps someone go to sleep for an operation.

Biopsy: A procedure in which a small round piece of tissue is removed to check for signs of disease.

Chemotherapy: A cancer medicine used to treat people with cancer.

Clinical Nurse Specialist: A nurse that can provide expert advice for patients throughout their illness.

CT scan: A scan which uses X-rays and a computer to create detailed images of the inside of the body.

Hickman Line: A long, flexible plastic tube that is put in the chest wall skin and into a large vein.

Limb sparing surgery: A type of operation where the tumour in the limb is removed without removing the limb.

Metastasis: When cells from the first tumour break off and start growing in another location.

Microscope: A piece of equipment used for viewing very small objects such as cells.

MRI scan: A type of scan that uses strong magnets to produce detailed images of the inside of the body.

Multi-disciplinary Team: A group of healthcare professionals where each member of the team provides a different and specific service to the patient. The team bring together their areas of expertise to form a care plan for the patient.

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

Osteosarcoma: A cancerous tumour that starts in the bone.

Paediatric Oncologist: A doctor who has special training in diagnosing and treating children with cancer.

Pathologist: a doctor who uses a microscope to look at cells to see what is wrong with someone.

Physiotherapist: A person who helps people through movement and exercise.

PICC Line: A long, thin, hollow tube that is inserted into a vein in the arm. In the chest it is called a Hickman line.

Play Specialist: Someone who uses play as a way to help the patient understand their illness and treatment.

Port: A long, flexible plastic tube which connects to small disc made of plastic or metal that sits under the skin, that delivers chemo into the veins.

Primary Bone Cancer: Cancer that originates from the cells of the bone.

Psychologist: A person who talks to people about their feelings.

Radiologist: A doctor that has special training in diagnosing patients by looking at medical pictures from different types of scans, such as X-Ray and MRI images.

Rotationplasty: An operation where a portion of a limb is removed, whilst the remaining limb below it is rotated and reattached.

Side effects: An unwanted and unpleasant effect caused by medicine.

Surgeon: A doctor who performs operations on the patient, such as removing cancerous lumps.

Surgery: Another term for operation.

Tibia: Also called the shin. It is the inner and larger of the two bones of the lower leg. The bone next to it is called the fibula.

Vein: A type of blood vessel.

X-ray: A type of scan which creates a picture of the inside of the body.

A Parent's Guide:

The page is for patients 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 those 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 everything will be fine straight after a procedure.

- 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.bcrt.org.uk**

The 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 ‘Abbie Has Osteosarcoma’, or require further information, please contact us using the details below.

Abbie Has Osteosarcoma was produced by the Bone Cancer Research Trust, 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 Bone Cancer Research Trust would like to thank the following professionals and patients for reviewing Abbie Has Osteosarcoma:

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