# Mary has a brain tumour

CLIC Sargent for children with cancer

***Mary has a brain tumour* is a storybook written especially for parents and carers to read with children, to help them understand what cancer is and the treatment it involves.**

At the back of the book you will find a useful glossary of words you may come across during your child's treatment.

CLIC Sargent is the UK's leading cancer charity for children and young people, and their families. We provide clinical, practical and emotional support to help them cope with cancer and get the most out of life.

# Mary has a brain tumour

By Victoria Barton

Medical reviewer for this edition: Professor Richard Grundy,
Children's Brain Tumour Research Centre, University of Nottingham

Illustration by
Tony Harris

This book belongs to...........................................................................

This is Mary. She is five years old and lives with her mum, dad, brother Lewis and baby sister, Patsy. Mary has a dog called Pickles, and a rabbit called Flora.

She enjoys lots of things like running, skipping and doing cartwheels, but most of all Mary likes to play with her friend Susie who has two kittens, Jack and Jill.

For a few weeks Mary had been unwell. 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 Mary to the doctor – he looked in Mary's eyes and checked her thoroughly and then he said that she needed to go to hospital straight away.

The hospital doctor examined Mary again and said that she would need to have some tests, one of them was called a *scan*[*].

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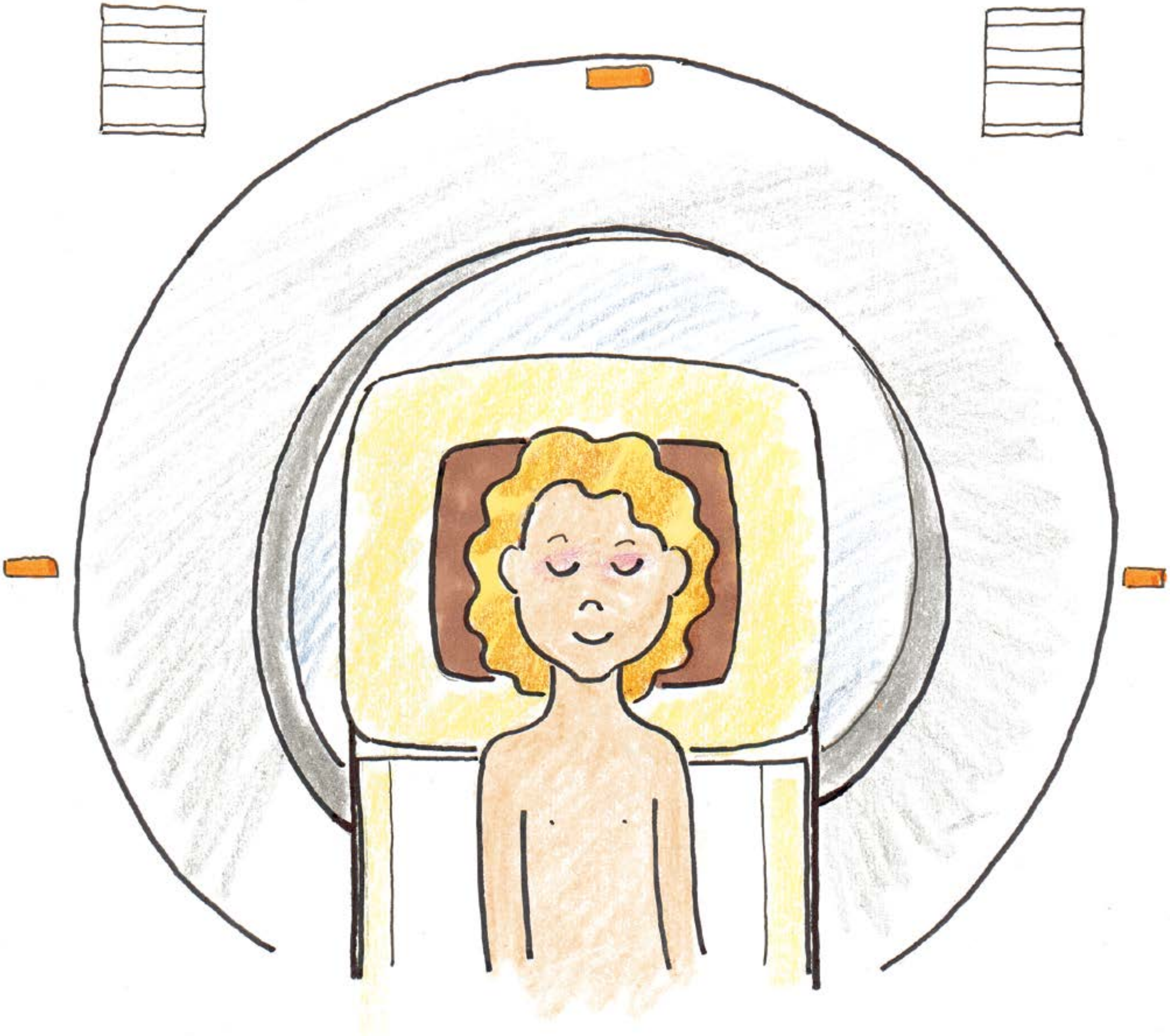
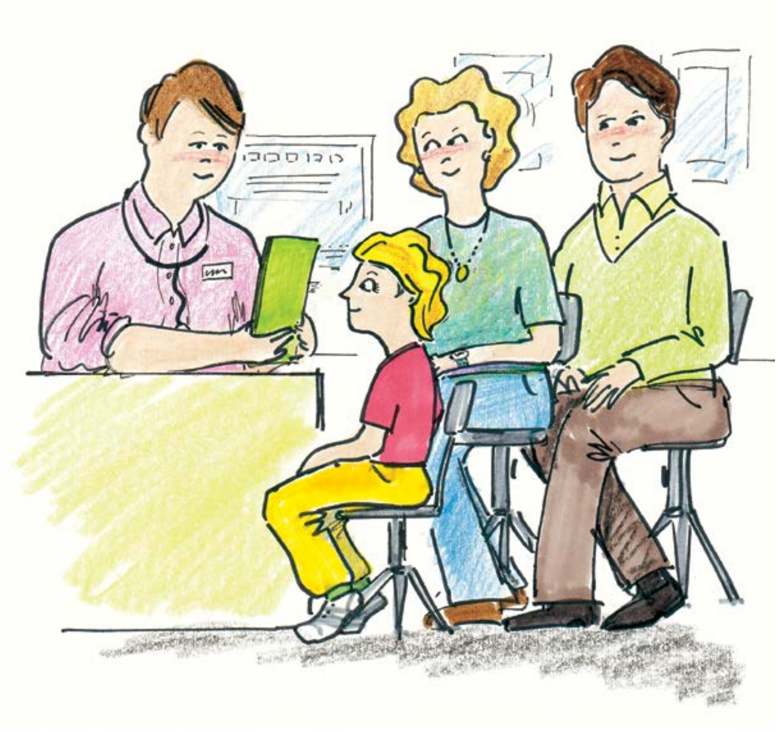
[*] Words in italics are explained under 'What these words mean' at the back of this book.

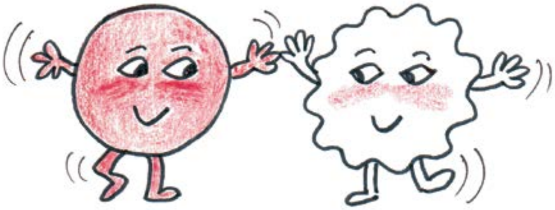


The *scan* would take pictures of the inside of Mary's head. Mary would need to lie very still inside the big tube that took the pictures, but it would not hurt at all. The *scan* would be quite noisy but she could listen to some music or a story.

Soon after the *scan*, the doctor saw Mary, and Mum and Dad. He told them that Mary 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*.



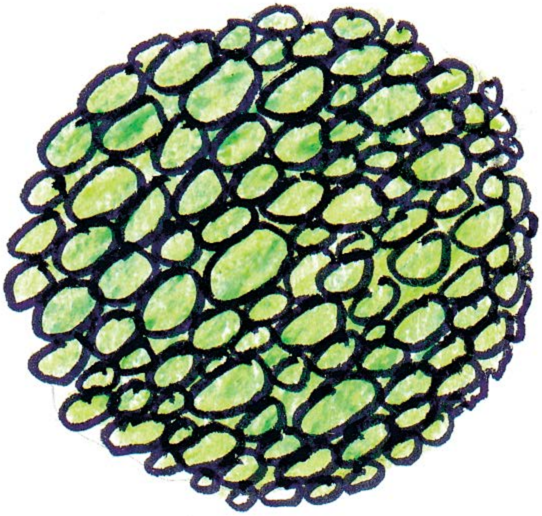
"What is *cancer*?" Mary asked. The doctor explained that "Everyone's body is made up of millions of tiny cells, so tiny that you cannot see them without a microscope. These cells make up different things our bodies need - like blood, muscle or bone.


Healthy cells

Sometimes the cells start to divide up to make new cells too quickly and do not 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."


Damaged cells

“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.

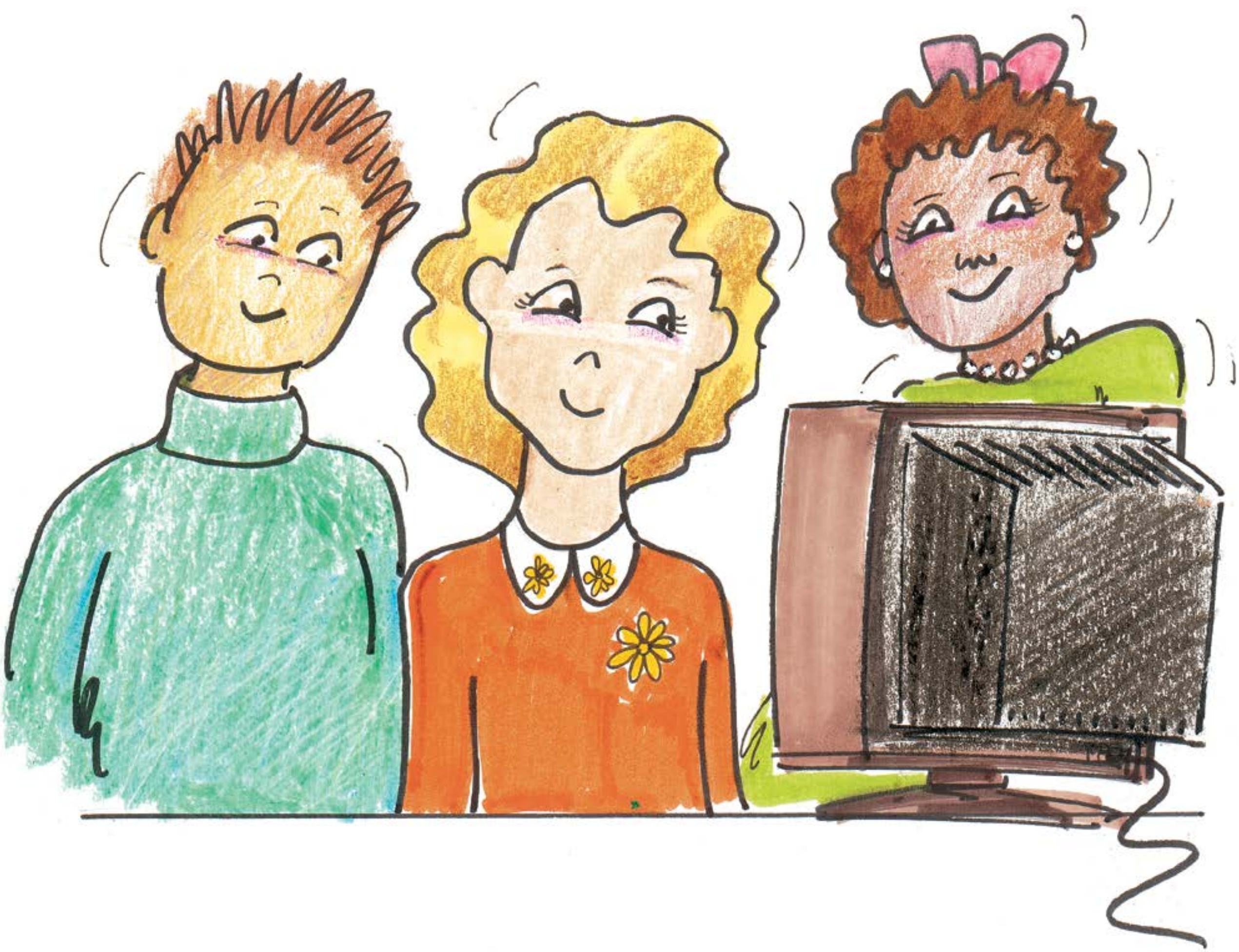


There are different types of brain tumour. Some are treated with surgery only, and others need to be treated with *chemotherapy* and *radiotherapy* as well.”

The doctor said that Mary would need to have an *operation* to take the tumour out and she would need to stay in hospital. He explained that sometimes children find it difficult to talk or walk for a little while after an *operation*. If this happened to Mary there would be specialists to help her.

The doctor would find out what kind of tumour Mary had and he would then tell her what treatment she would need to make sure the tumour stayed away.

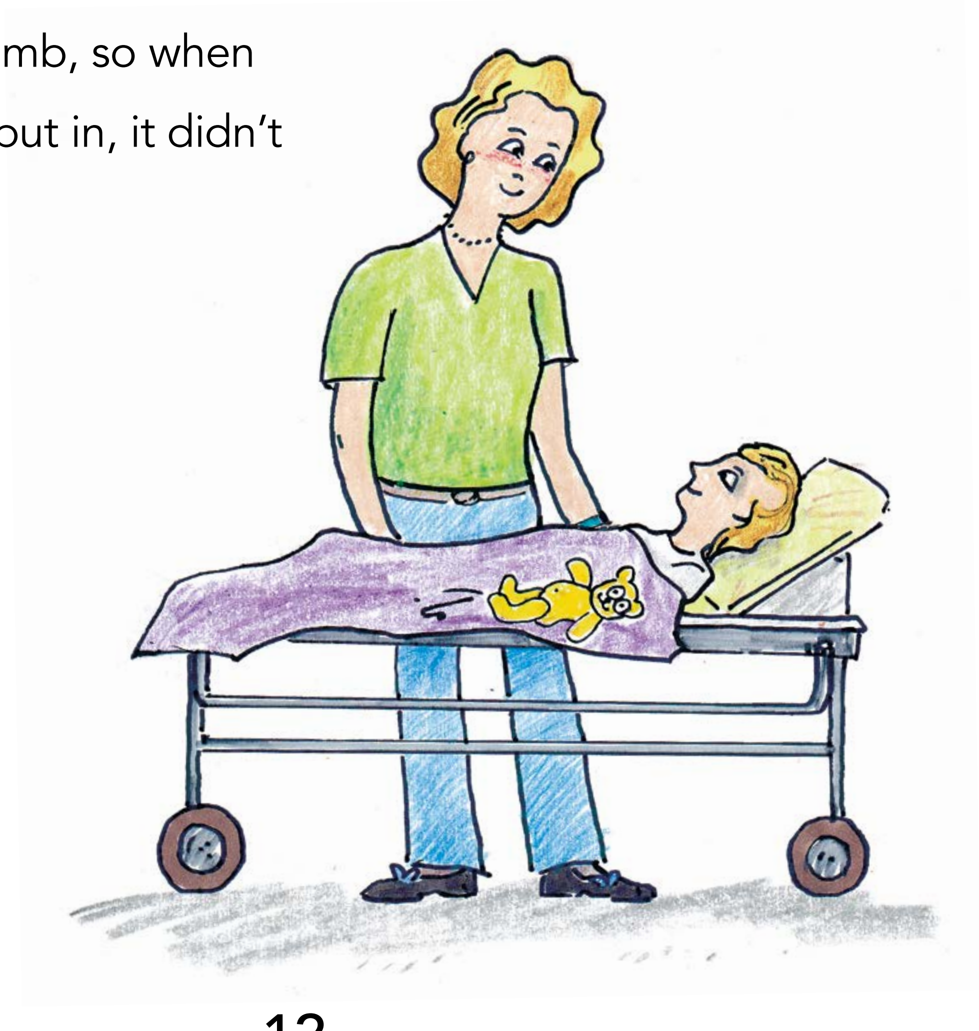
Mary was unhappy about staying in hospital, but there were other children to play with on the ward and Mum and Dad took it in turns to stay with her and look after Lewis and Patsy, Pickles and Flora.



The next morning Mary was not allowed to have anything to eat because she was going to have her *operation*. First of all another doctor came to see her. She was called an *anaesthetist* and her job was to look after Mary 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, he was called a *neurosurgeon* and he was going to do her *operation*. Mary wanted to know what would happen. The *neurosurgeon* explained that he would have to shave a little hair off Mary's head when she was asleep so he could see her head properly. Mary would have a big bandage on when she woke up and she might feel a bit tired and sore. He told her that she would wake up in another ward called Intensive Care.

When the nurses came to take Mary for her *operation* she had to put on a special gown with an opening at the back. She also had some magic 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.



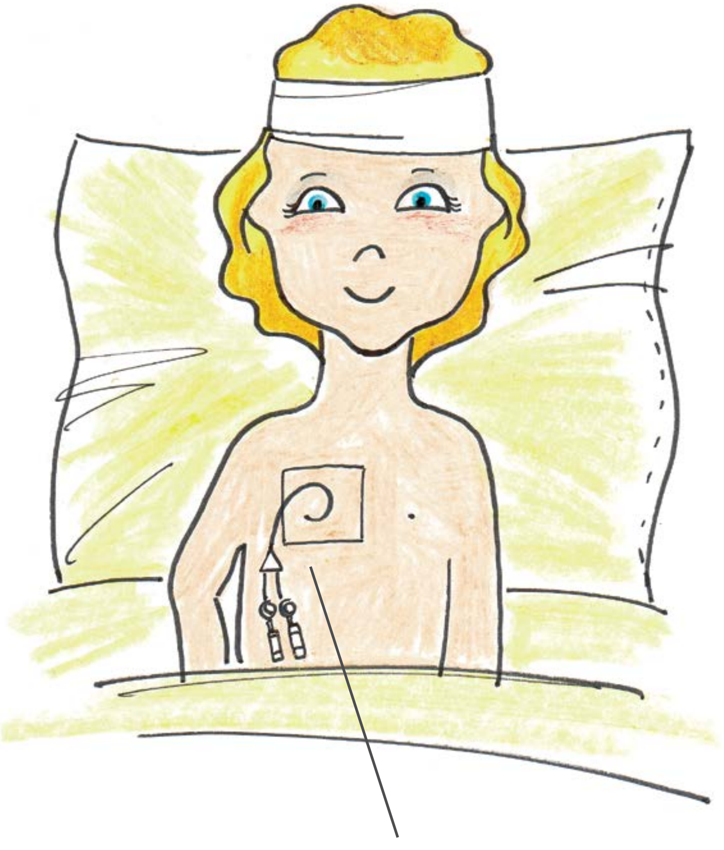
The tube was used to give Mary the medicine she needed to make her sleep through the *operation*. Mary's mum was with her and she held her hand until the medicine made her go to sleep.

The next thing Mary knew was that 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 Mary was feeling better and she was able to sit up and have something to eat. Mum and Dad were very proud of her. The nurse came and said it was time to go back to her ward so Mum, Dad and the nurse pushed Mary, in her bed, along the corridor.

A week later the doctor came to see Mary, Mum and Dad, and told Mary that she would need to have *chemotherapy* and she might need *radiotherapy* as well. With the *chemotherapy* some would be tablets and some would be medicine which would go through a central line. There are different types of central line - a *portacath* and a *Hickman line*.

Often the line is called a wiggly! The line is very useful because, as well as giving medicines, it is used for taking *blood tests*. The doctor said that Mary would not be in hospital all the time but she would need another small *operation* to put the central line in. First she could go home for a while to get a little bit stronger.



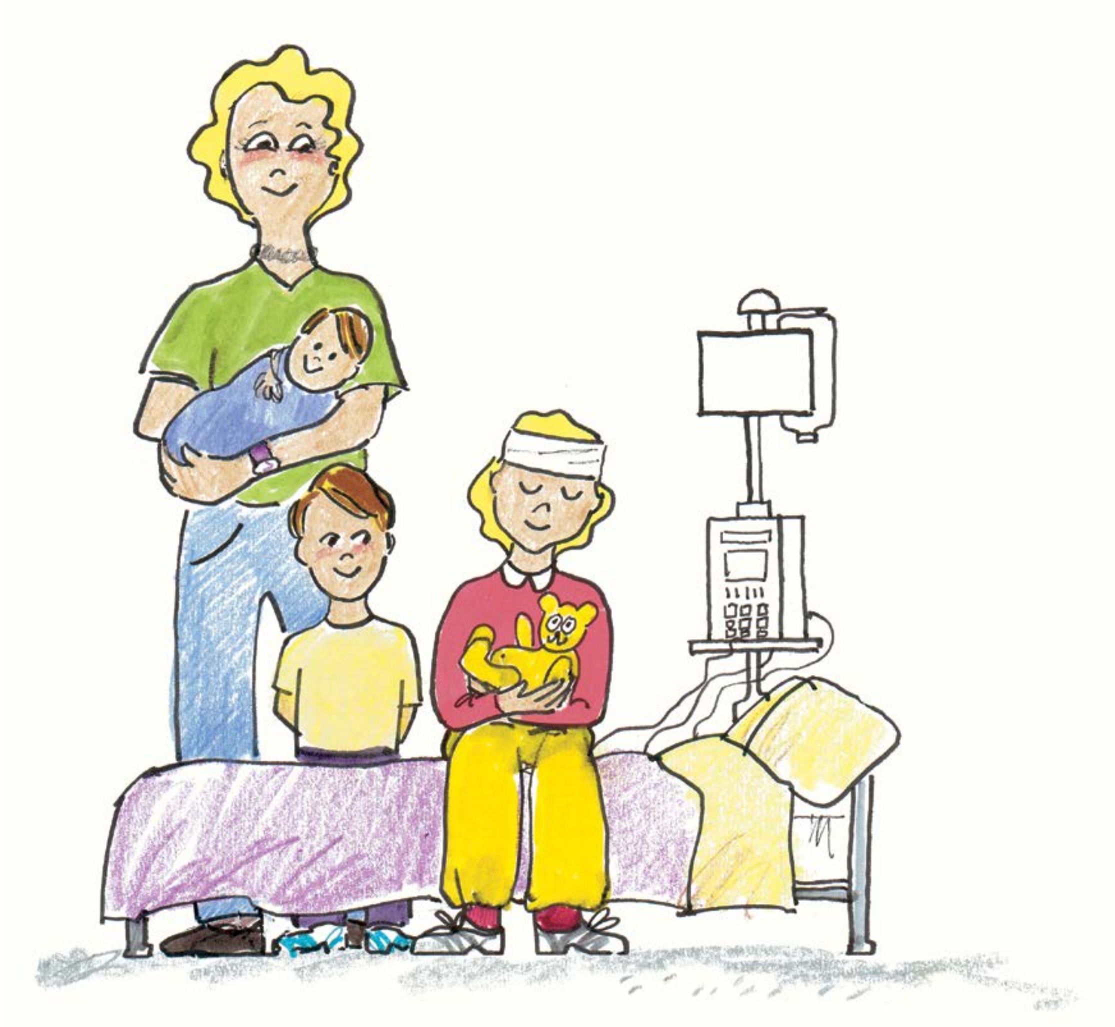
When Mary went home everybody made a fuss of her and bought her presents. Her brother Lewis was really pleased to see her, but he felt a bit left out. Luckily Mum and Dad soon realised this and he and Patsy were always included.

Once the central line was in, Mary started her *chemotherapy*. She was usually weighed and measured when she came to the hospital for treatment and a *blood test* was always taken too. The doctor could then decide if Mary should have her treatment that day or if she needed a *blood transfusion*. The transfusion helped Mary to have more energy and made her feel better.

When Mary had *chemotherapy* it was given through a drip attached to the wiggly line.

It did not hurt but sometimes it made her feel a bit strange.

When the *chemotherapy* had finished the machine bleeped!



The *chemotherapy* took a few days each time and she had to stay in hospital. Mum and Dad took it in turns to be with her, and sometimes Lewis and baby Patsy visited too. Every so often Mary had to stay in hospital a little longer if she had a temperature, and Lewis and Patsy went to stay with Granny.

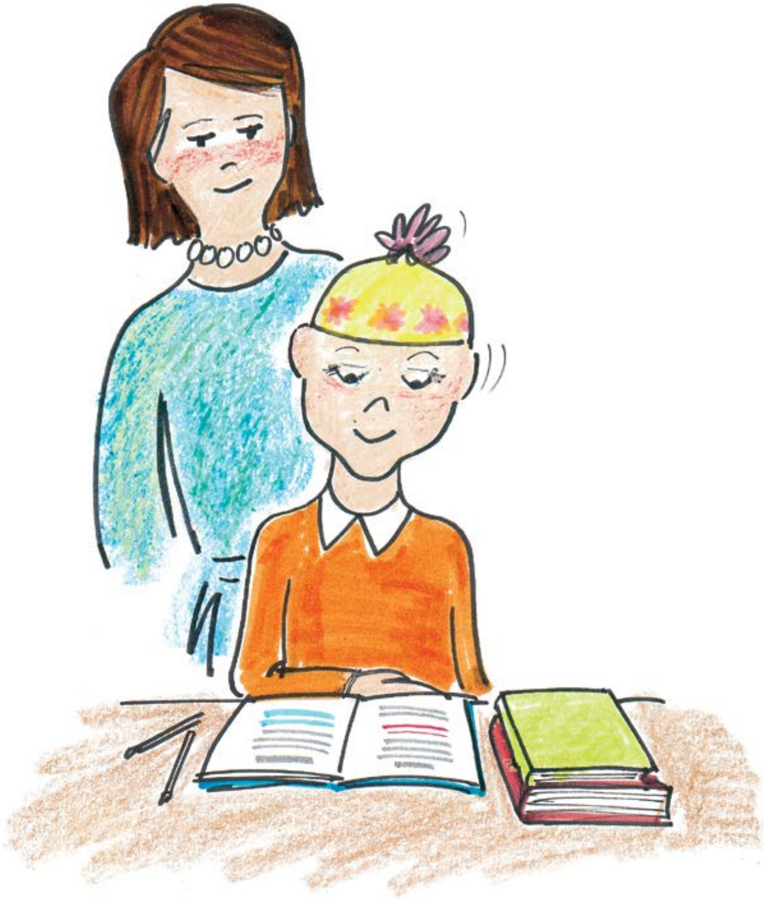
Mary did not mind being on the ward as she made friends with the other children. If she felt well enough the teachers and play specialists always had things she could do or make.

At home Mary was given her medicine by Mum and Dad and the community nurse came to take blood.

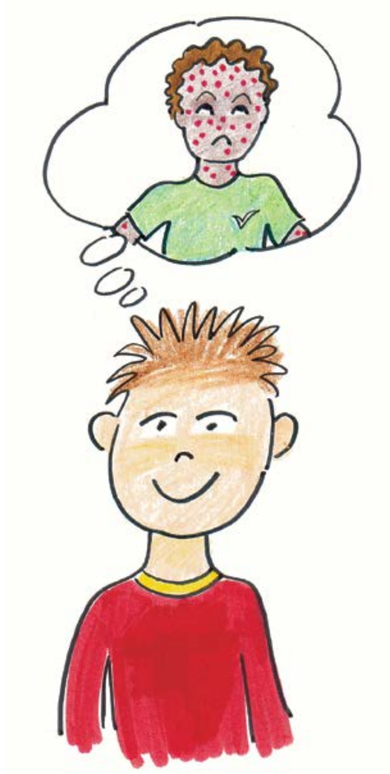
After a few weeks of starting the *chemotherapy*, Mary's hair started to fall out. The doctor had told her this would happen and that it would grow back once the treatment had stopped. He also told her that it wouldn't hurt and, although Mary had not believed him, he was right.

Mary saw other boys and girls in hospital without hair – some had wigs and some wore caps or scarves. Mary wore a hat. Mary and the other children often talked and played together.

Sometimes Mary felt well enough to go to school for a little while and see her friends. When she was not well enough for school Mrs Brown, a teacher, sometimes came and gave her lessons at home. Mary really enjoyed that. Mum said the lessons would help her to keep up with the work her friends were doing in school.



One day Mary saw a boy called Joe come to the ward who was not allowed to play with anyone. She was told that he had come for some medicine to help stop him catching chickenpox from his friend at school who had woken up one morning with spots all over his body. People who are having *chemotherapy* can be very unwell if they catch chickenpox, or other bugs. Mary thought it strange that you could catch chickenpox but that you could not catch *cancer*.



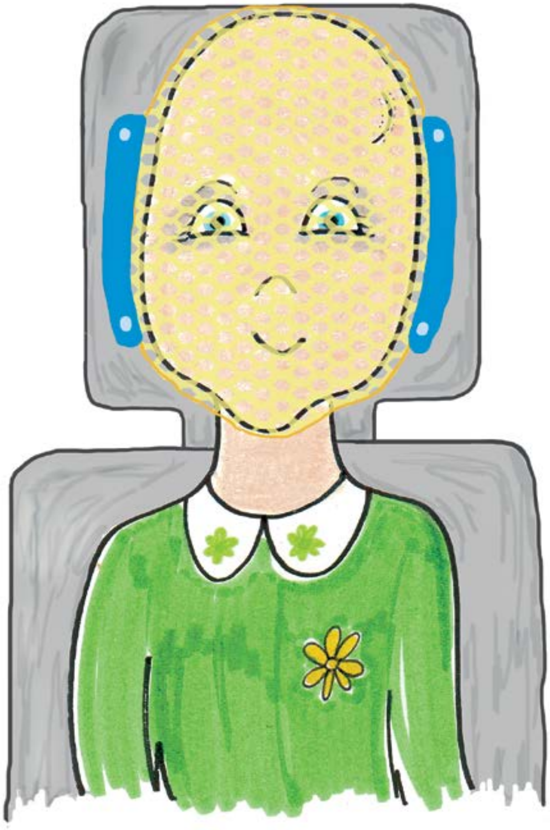
People having *chemotherapy* can also become unwell if they get infections in their bloodstream, which is why Mary's mum took her temperature quite often.

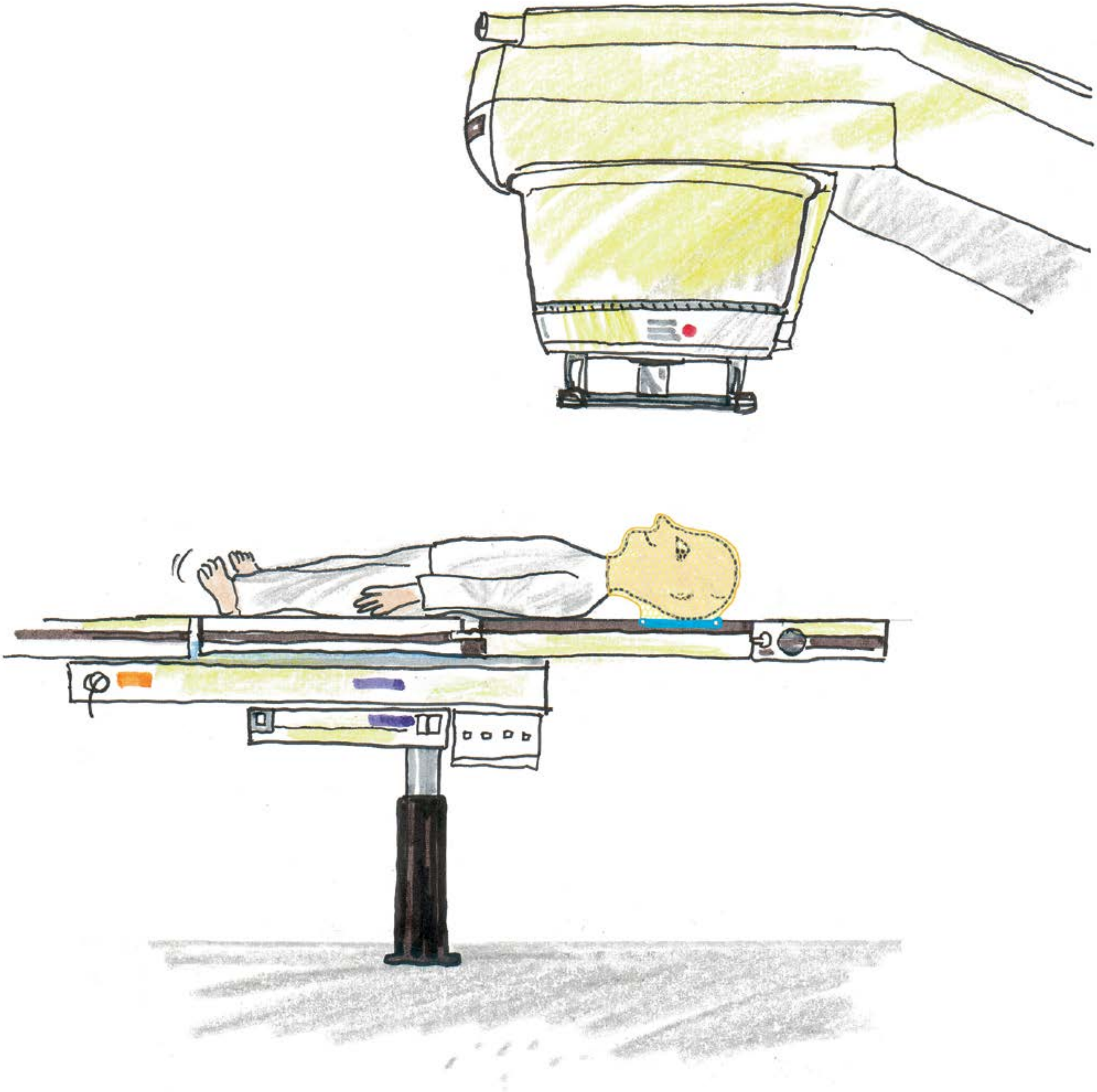
It took a long time to finish all the *chemotherapy* treatment, but at last it was finished. Mary had another *scan* and then the doctor said she would need to have *radiotherapy*.

The doctor explained that *radiotherapy* was like having an X-ray or another *scan*. It would not hurt but Mary might feel tired or a bit sick so the doctor would give her medicine to help with this. Sometimes *radiotherapy* can make hair fall out too, but only on the part of the head where the *radiotherapy* has been given. Like when she had the *scan*, Mary would need to lie very still for a few minutes.

A mask, a bit like a space helmet, would be made especially for Mary to wear while she was lying still.

Mum and the play specialist made up a game where Mary 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.





When the *radiotherapy* started, Mary had to lie on a narrow table with a big machine above her that gave 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 did not hurt at all. Mum watched her on television and they could always talk through an intercom.

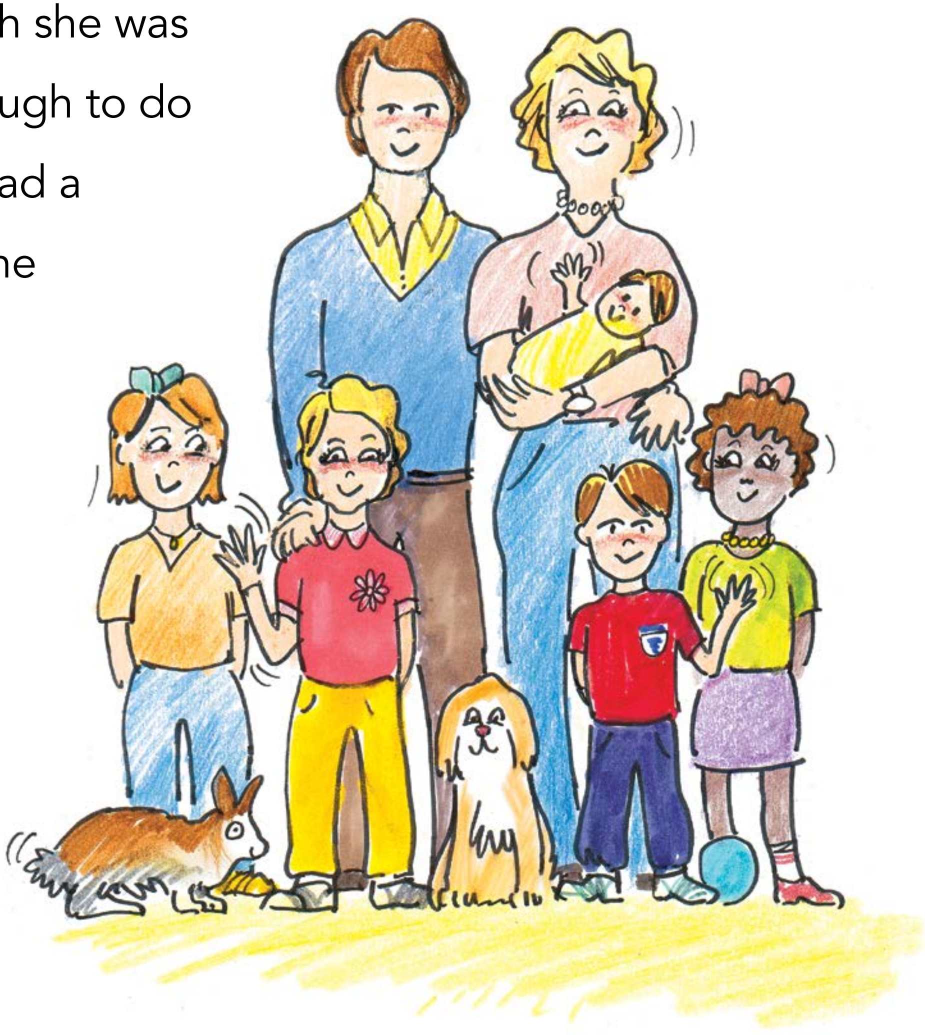
The *radiotherapy* sessions lasted for six weeks and the worst thing about it was that Mary got sore ears, just like sunburn.

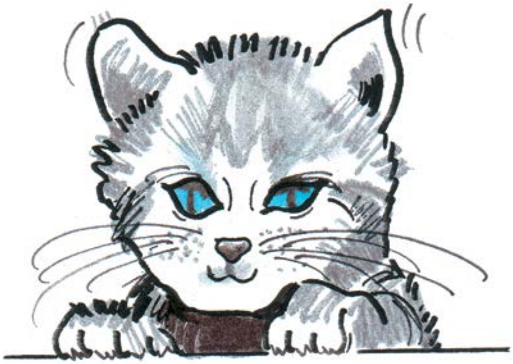
Towards the end of the treatment Mary felt very tired. The doctor had said this might happen and Mary got lots of rest.

After some months Mary felt really well and the doctor told her that she had finished all the treatment. In a while the line would be taken out.

The doctor said that Mary would need to continue to come to the hospital for checkups, tests and *scans* to make sure she was growing properly and keeping well.

Lewis helped Mum and Dad to arrange a surprise party for when Mary finished her treatment. All her friends came and although she was not quite well enough to do cartwheels Mary 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.

### ANAESTHETIST

This is a doctor who gives you a medicine 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 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.

## What these words mean

CHEMOTHERAPY

A mixture of different medicines which treat cancer.

HICKMAN 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. This is inserted under general anaesthetic.

NEUROSURGEON

A doctor who specialises in operations on the brain.

OPERATION

Where you have some medicine called anaesthetic to make you go to sleep for a while, then the doctors can have a look at your body without hurting you.

PORTACATH

A device, or bobble, is inserted under the skin near the armpit under general anaesthetic and a very thin tube (the line) then runs under the skin to the main vein in the 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.

## What these words mean

### RADIOTHERAPY

Is where very 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 a 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 inside your body.

### 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.

# Do you have any questions, or need some help?

CLIC Sargent is the UK's leading cancer charity for children and young people, and their families. We provide clinical, practical and emotional support to help them cope with cancer and get the most out of life. Talk to your CLIC Sargent care professional, or call us on 0300 330 0803 and we'll put you in touch with someone who can help.

You can also visit our website at
**www.clicsargent.org.uk**
or email us at **info@clicsargent.org.uk**

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