

Tom has lymphoma



***Tom has lymphoma* is a storybook written especially for parents to read with their children to help them understand what lymphoma 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, as well as a helpful explanation of Hodgkin lymphoma and non-Hodgkin lymphoma.



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



The Lymphoma Association is the only specialist charity providing information and emotional support to anyone affected by lymphoma, whether they are a patient, family member, friend or carer.

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Tom has lymphoma

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This book belongs to.....



Tom is 10 years old. He lives with his mum, his step-dad, his sister and his step-brother. And there's Mutley, his dog too! Tom likes having a big family.

Tom had spent the day running around in the garden getting very muddy playing football. That night, in the bath, he noticed a lump on the side of his neck. He showed it to his mum and she wasn't sure whether it was just a normal gland in his neck. But it looked much bigger than a normal gland. Tom's mum decided to take him to see their family doctor, who sent them to hospital.



Here Tom was seen by a doctor who said he would need a small operation to take the lump out. A doctor called a pathologist would then look at the lump under a microscope. Pathologists can tell if there's something wrong with the gland.



“What could be wrong with it?” asked Tom. The doctor explained that another name for a gland is a *lymph node**. You have them all over your body, not just your neck. Their job is to help the body fight off infections like sore throats or earache. They get bigger when they are doing this, which is normal.

* Words in italics are explained under ‘What these words mean’ at the back of this book

But sometimes *lymph nodes* get bigger when there is no infection. That's because the cells inside them stop working properly. These cells multiply and grow, making the *lymph node* get bigger too. When the *lymph node* is full of these abnormal cells we call this *lymphoma*.

Lymphoma is a cancer of the *lymph nodes*.



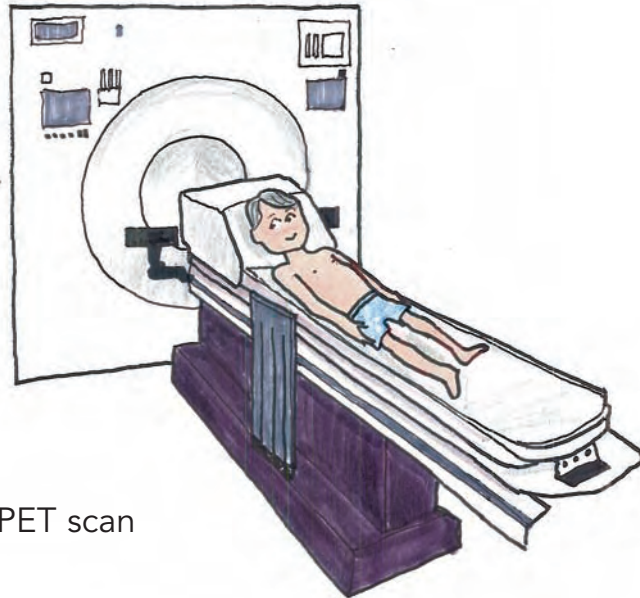
Tom was given some medicine, called a general *anaesthetic*. This made him have a special sleep so that the surgeon could take out his big *lymph node* while he was asleep and wouldn't feel any pain. A surgeon is a doctor who does operations. The *lymph node* was then sent to be tested by the pathologist. When Tom woke up he felt fine and was able to go home.

A few days later Tom went back to the hospital for some scans. Scans are ways of looking inside the body, a bit like X-rays but more complicated. Usually you have to lie on a table that moves into a big machine that takes a picture of the inside of your body.

Tom needed scans so the doctor could see if there were any other big *lymph nodes* in other parts of his body.

Sometimes people get them in their armpits, their groin (the bit at the very top of your leg), their tummy or chest.

There are lots of different types of scans which help the doctors to find them.



Tom having a PET scan

Tom did feel a little bit scared. It was strange going to hospital to have the *lymph node* out and then coming back again to have the scans. But the doctors, nurses and play specialists explained everything that was going on. He also had a social worker who talked to his family about what help they might need. After the scans Tom was still able to go home and see his friends.



The following week Tom went back to the hospital with his mum and step-dad. The results came back from the pathologist saying that his lump was *lymphoma* (a kind of cancer) and that his *lymphoma* was called *Hodgkin lymphoma*. This is named after Dr Hodgkin who first wrote about it nearly 200 years ago.



Tom thought his parents looked very worried when the doctor said the word '*cancer*'. And Tom remembered when his Auntie Julie had *cancer*. Everyone was really upset. She wasn't well for ages and her hair fell out.

Tom asked the doctor how he got *cancer* as he was normally very healthy. The doctor explained that there is nothing he did wrong and that, although there are lots of ideas about why children get *cancer*, medical people still don't know for sure why some children get it.

Tom asked the doctor if his hair would fall out, and how long it would take him to get better. The doctor told him, "We try to shrink the *lymphoma* and make it go away, which will make you feel better. Sometimes a *side-effect* of the treatment is that your hair falls out. Don't worry though, it will grow back."

The doctor told them what had to be done to make Tom's *lymphoma* go away – he called this 'your treatment'. He said that, although most of the *lymphoma* had been removed by the surgeon, the scans showed that there was some inside his chest. They had to get rid of this bit too, otherwise the *lymphoma* would grow back.

Some children with *Hodgkin lymphoma*, unlike Tom, are not so well and have lots of high temperatures, called fevers, and sweat a lot during the night. They can sweat so much that their sheets have to be changed in the middle of the night. Some children lose a lot of weight and become much thinner and some children also scratch a lot.

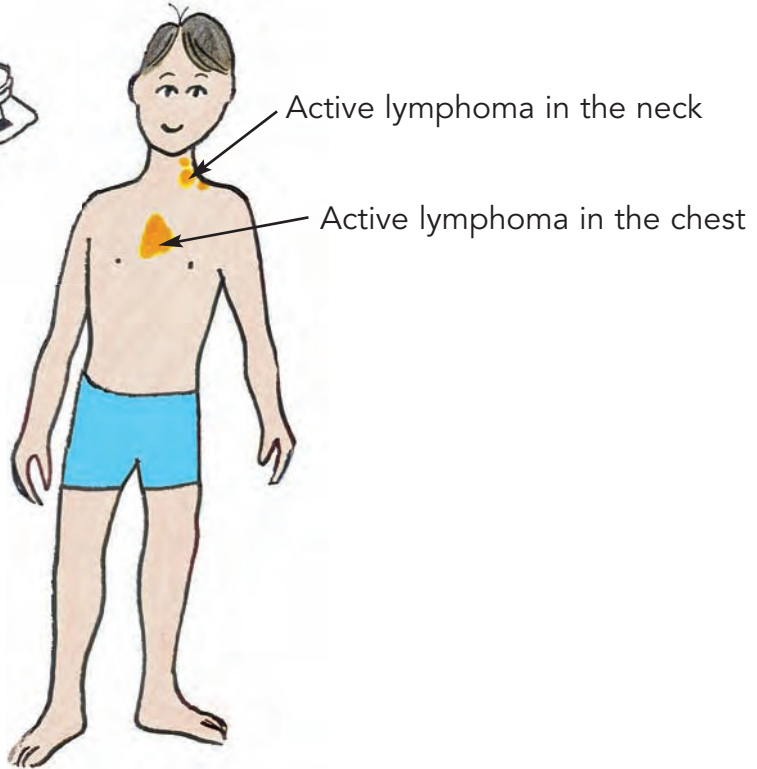
Now that the doctors knew that Tom had *lymphoma*, and could see where else the *lymphoma* was in his body, they said that treatment could start.

His doctor said the amount and kind of treatment depended on how much *lymphoma* there is in the body and how well it shrinks with the treatment.

Tom wondered how they found this out. The doctor explained that another scan (called a *PET scan*) shows which bits of the *lymphoma* are active and growing. The active bits appear much brighter on the scan. Another *PET scan* is done later on to see if all the active, bright *lymphoma* cells have gone away with the treatment. Tom thought this sounded very clever.



Tom having a PET scan

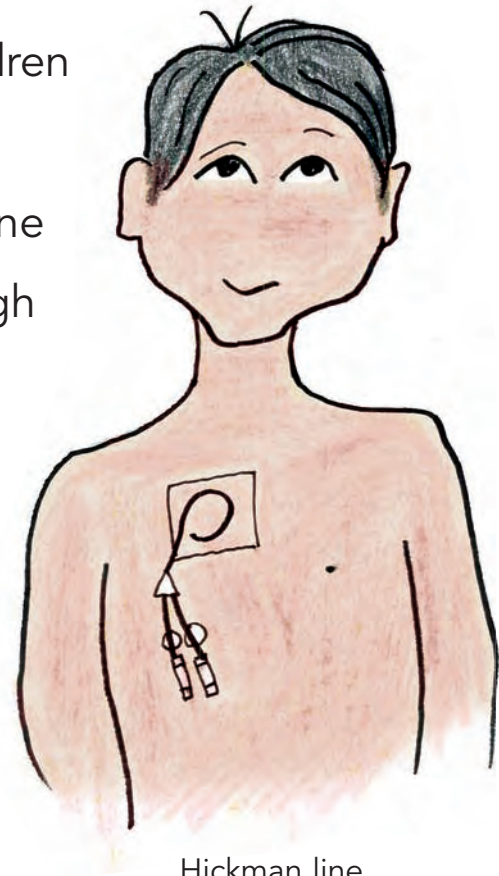


Active lymphoma in the neck

Active lymphoma in the chest

Active lymphoma shows up on a PET scan

As part of Tom's treatment he needed medicine, called *chemotherapy*, to get rid of the *lymphoma*. To help do this he had a tube called a central line put into his chest. There are different types of central lines – Tom had a *Hickman line*, but some children have a *portacath*. Blood for *blood tests* can come out of the central line and the *chemotherapy* goes through it. Tom needed another small operation to put the central line in the right place, so he had a special sleep again like he did for his first operation.



Hickman line

When he woke up the new line was safely in. Tom heard some of the younger children call their lines 'wigglies' which he thought was funny.

Tom stayed in hospital that night and they gave some of the *chemotherapy* through the central line. He went home the next day.





Not all of the *chemotherapy* that Tom had went through the central line. Some of it came as tablets or as a syrup, a runny medicine like cough medicine. He preferred the tablets, but another girl on the ward couldn't swallow tablets so she had syrup instead.



Tom had to keep coming back to the hospital for his treatment but he didn't have to stay long or spend the night there. He was home most evenings to watch his favourite programme on TV!

Some of the other children having treatment lived far away, so they stayed in the hospital a couple of nights each time.

Over the next few weeks, Tom sometimes didn't feel very well and was quite tired. But he did manage to see his friends and go to school. Tom's hair did start to fall out and so he decided to have it all cut off but he didn't mind. He started to wear a beanie hat or a baseball cap to school if his head was cold.



One time Tom had a high temperature and he had to go to hospital. A *blood test* showed that he didn't have enough of the right sort of white cells, called neutrophils, to fight infections. So the doctors and nurses gave him some antibiotics, which are special medicines to treat infections, through his central line to make the fever go away. He had to stay in the hospital for a few days, but that was OK because he got to play on the Playstation and watch lots of TV.



Neutrophil

After a few more weeks, Tom had another *PET scan* to see if all the active *lymphoma* had gone by checking there were no bright bits left in his body. If there were still bright bits he would need to have radiotherapy (X-ray treatment) at the end of all his *chemotherapy* to make sure all the abnormal cells were gone.

If Tom needed to have radiotherapy, he would meet the radiotherapy doctors who would plan where and when the X-ray treatment is given. Usually the X-ray treatment is given a couple of weeks after all the *chemotherapy* is finished and means going into a special room for the treatment each day for a couple of weeks.

Tom didn't have signs of any active, bright bits on his second *PET scan*. So once he'd finished his *chemotherapy* that would be the end of his treatment. Hooray!

Even though Tom had finished his treatment, he still had to go back to hospital for a scan or two to make sure that everything was fine. All his hair grew back and he was back at school, playing football and having fun with his friends. A year later, as he was doing so well, he only had to go back to the clinic once or twice a year.



What is Hodgkin lymphoma and non-Hodgkin lymphoma?

There are two main types of *lymphoma* – Hodgkin lymphoma (HL) and non-Hodgkin lymphoma (NHL). Both affect a part of the body which helps fight against disease and infection. This bit of the body is called the lymphatic system and is made up of *lymph nodes* which are linked together, like a chain. The *lymph nodes* are there to spot and fight disease and infection.

Although HL and NHL affect the same part of the body (the lymphatic system), they are different and are treated differently.

There are five kinds of HL and one of them is a bit different from the other four. The four main kinds are all treated in the same way – as described in Tom’s story.

NHL covers all the other different *lymphomas* which are not Hodgkin lymphoma. They are divided into many different sorts including the B-cell sort, which usually occurs in the neck, head and abdomen (tummy) and the T-cell sort, which most often occurs in the chest. Treatment depends on the type of NHL, but generally includes *chemotherapy* – the medicine described in this book.



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

A special sleep that you have during an operation, so you don't feel any pain.

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).

CANCER

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

CHEMOTHERAPY

A mixture of different medicines which treat cancer.

CT SCAN

A scan like an X-ray where the doctor can look inside your body.

What these words mean

HAEMATOLOGIST

A doctor who looks after people with blood or lymph node problems or diseases.

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.

LYMPHOMA

This is cancer of lymph nodes, or the lymphatic system.

LYMPH NODES

The cells which fight infections and disease live in the lymph nodes. They become bigger when they are fighting infection.

MRI SCAN

This allows the doctors to get a clear picture of what's going on in your body. It can be quite noisy and even though it doesn't hurt, you might be given an anaesthetic or some medicine to help you relax and lie still.

What these words mean

NEUTROPENIC

A person is neutropenic when they hardly have any neutrophils (the good white cells that fight infections). Being neutropenic means you are more at risk of getting infections.

ONCOLOGIST

A doctor who treats people with cancer.

PET SCAN

Another scan which lets the doctors see what's going on in your body. Areas where there is lymphoma will show up on the scan as bright spots.

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.

SIDE-EFFECT

A side-effect is something that may happen during your treatment, like feeling sick or your hair falling out.

Do you have any questions, or need some help?

CLIC Sargent is the UK's leading cancer charity for children and young people with cancer. We provide clinical, practical and emotional support for young cancer patients and their families, from diagnosis onwards. Talk to your CLIC Sargent Social Worker or Nurse, 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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The Lymphoma Association provides information and emotional support to anyone affected by lymphoma, whether they are a patient, family member or friend. If you would like to talk to us, please phone 0808 808 5555 (free of charge from a UK landline). Mon to Thurs 9am – 6pm, Friday 9am – 5pm.

You can also visit our website www.lymphomas.org.uk or email us at information@lymphomas.org.uk



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