

# Tom has Lymphoma



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# Tom has Lymphoma

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Tom is ten 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 soccer. 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. They weren't sure so they went to see their family doctor, who sent them to hospital.



At the hospital Tom was seen by a doctor who said he would need a small operation to take the lump out. Then, a doctor called a pathologist would 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. They get bigger when they are doing this, which is normal.

But sometimes lymph nodes get bigger when there is no infection. That's because the cells inside them stop working normally. They 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.

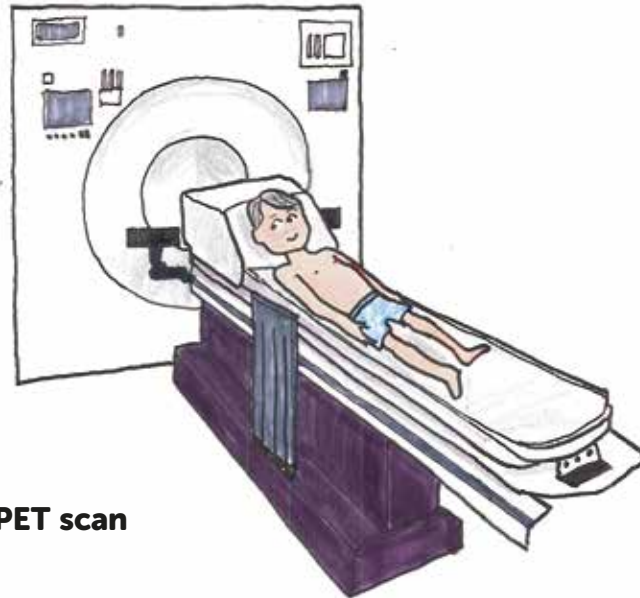


Tom was given some medicine to make him go to sleep so the surgeon (the doctor who does operations) could take out his big lymph node without it hurting. Then the lymph node was sent to be tested by the pathologist. When Tom woke up he felt fine and went home.

A few days later he 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 armpit, groin (the bit at the very top of your leg), 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 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. Tom was still able to go home and have fun with 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 if his hair would fall out, and if he would get better quickly. The doctor told him, "We hope to shrink the lymphoma and make it all go away, which will make you feel better. Sometimes a side effect is that your hair falls out. Don't worry though, it will grow back."

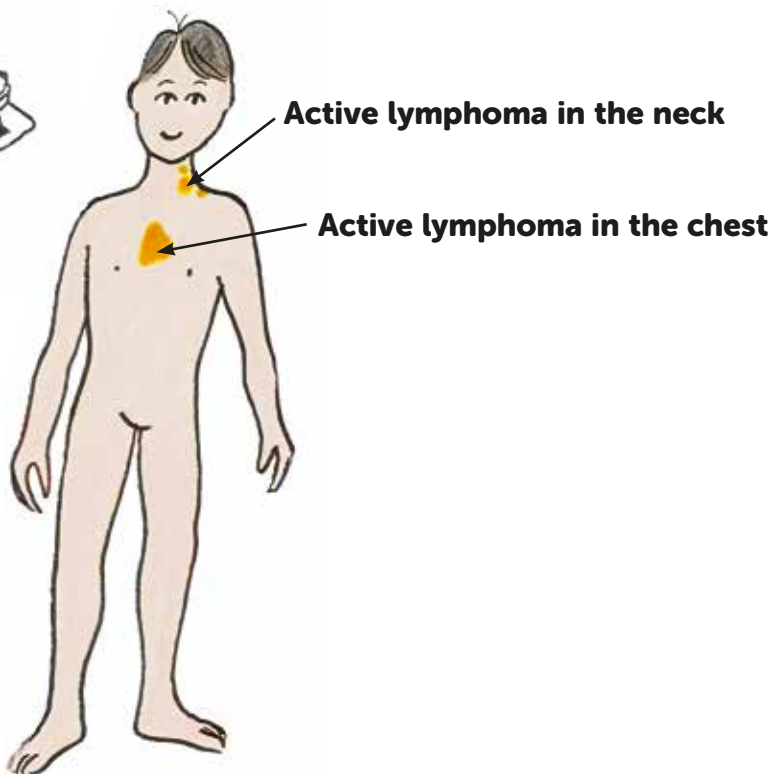
The doctor told them what had to be done to make Tom's lymphoma go away – he called this 'your treatment'. He said that, although most of the lymphoma had been removed by the surgeon, the scans showed that there was some inside his chest. They had to get rid of this bit too, otherwise the lymphoma would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

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

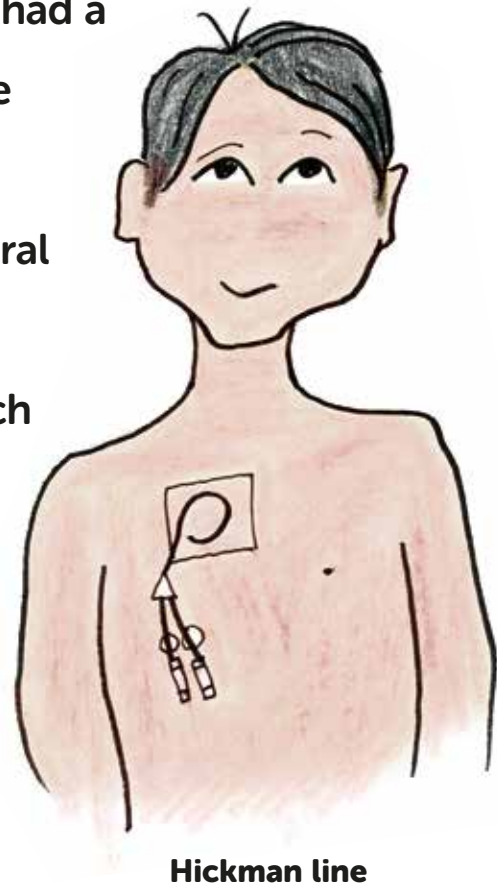


**Active lymphoma in the neck**

**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 or a PICC line. Blood for blood tests can come out of the central line and the chemotherapy can go in through it – which makes things much easier. Tom needed another small operation to put the central line in the right place, so the doctors gave him some more medicine to make him go to sleep, just like his first operation.



**Hickman line**



When he woke up the new line was safely in! He 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 the syrup instead.

Tom had to keep coming back to the hospital for his treatment but he didn't have to stay long or overnight. 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 or nearby for 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, which looked really cool. He wore a beanie hat or a bandanna to school if his head was cold!



One time Tom had a high temperature and he had to go to hospital as the doctors and nurses said he had to come in if he got a temperature. A blood test showed that he didn't have enough of the right sort of white cells (neutrophils) to fight infections so the doctors and nurses gave him some antibiotics (medicines to treat infections) through his central line to make the fever go away. He had to stay in 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 then 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 disease on his 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 regularly to hospital for scans to make sure that everything was still fine. All his hair grew back and he was back at school, having fun with his friends. A year later as he was doing so well, he only had to come back two or three times a year to clinic.



## **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 part 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 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 the others. The four main kinds are all treated in the same way – as described in this book.

NHL covers all the different lymphomas which are not classed as Hodgkin lymphoma. They are divided into many different sorts including the B-cell sort which usually occur in the neck, head and abdomen (tummy) and the T-cell 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 are some of the main ones and what they mean. If you're unsure about any others, just ask your doctor or nurse.

## **ANAESTHETIC**

When the doctors give you some medicine that makes you go to sleep 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.

## **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.

# What these words mean

## **CT SCAN**

An x-ray where the doctor can look inside your body at all your organs.  
You need to lie very still.

## **HAEMATOLOGIST**

A doctor that looks after people with blood or lymph node diseases  
or problems with their blood or lymph nodes.

## **HICKMAN LINE**

One or two lines are inserted under anaesthetic, the end comes out through a  
small hole in the skin on your chest.

## **LYMPHOMA**

Cancer of the lymphatic system.

## **LYMPH NODES**

Where the cells which fight infections and disease live.  
Lymph nodes become bigger when they are fighting infection  
and disease as they are making more cells.

## **MRI SCAN**

A scan that 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.

# What these words mean

## **NEUTROPENIC**

When you hardly have any neutrophils (the 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.

## **PICC LINE**

One or two lines are inserted under anaesthetic the end comes out of a small hole in your skin on your arm

## **PORTACATH**

A device is inserted under the skin under anaesthetic near the armpit, then runs under the skin to the main vein in the neck. If treatment is given or blood taken, 'magic cream' is put on the skin covering the portacath one hour beforehand – to make it go numb so it will not hurt so much when the needle goes in.

## **SIDE EFFECT**

Something that may happen through having treatment, for example, feeling sick or your hair falling out.



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**Leukaemia & Blood Cancer New Zealand is a national organisation in New Zealand dedicated to supporting patients and their families living with leukaemia, lymphoma, myeloma and related blood conditions.**

**Every family's experience is different;  
living with a blood cancer or condition is not easy,  
but you don't have to do it alone.**

**0800 15 10 15**

**[www.leukaemia.org.nz](http://www.leukaemia.org.nz)**



Adapted from the "Tom has Lymphoma", a publication jointly produced by CLIC Sargent, the UK's leading cancer charity for children and young people and their families, and the Lymphoma Association, a charity specialising in providing easy to understand information and appropriate support to anyone affected by lymphatic cancer.

[www.clicsargent.org.uk](http://www.clicsargent.org.uk)

[www.lymphomas.org.uk](http://www.lymphomas.org.uk)

CLIC Sargent and the Lymphoma Association accept no responsibility for the accuracy of this adaptation.





**If you have any questions  
or if you are unsure about anything,  
please ask a member of your treatment team  
or contact Leukaemia & Blood Cancer New Zealand.**

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