

TOM HAS LYMPHOMA



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.

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For information about the sources used to put this publication together, or if you have any comments or queries about it, please contact us on 0300 300 0803 and ask to speak to the Young Lives vs Cancer Information Manager.

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TOM HAS LYMPHOMA



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Illustration by Tony Harris



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

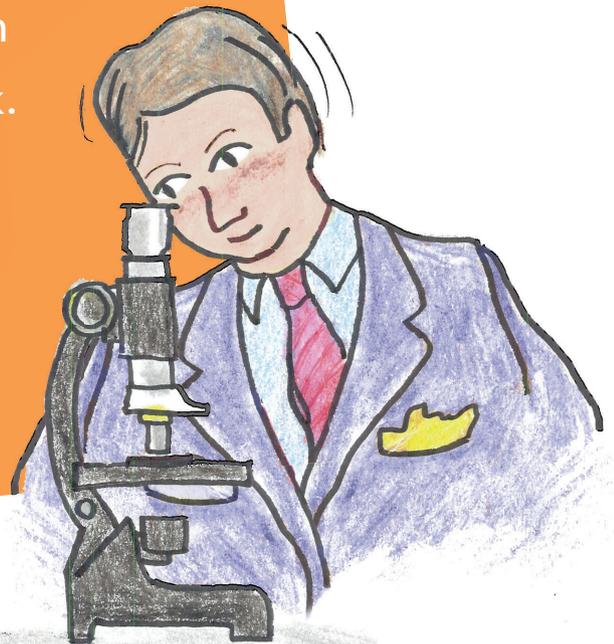
Tom had spent the day running around in the garden getting very muddy playing football. That night, in the bath, he noticed a lump on the side of his neck. He showed it to his mum. She wasn't sure whether it was just a *gland** in his neck. It looked much bigger than normal. Tom's mum decided to take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



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

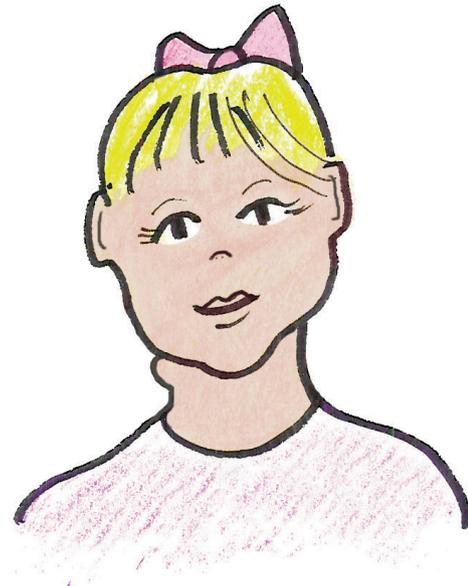
Tom was seen by a doctor who said he would need a small operation to take the lump out. A doctor called a pathologist would then look at the lump under a microscope. Pathologists can tell if there's something wrong with the *gland*.

"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 in 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.



But sometimes *lymph nodes* get bigger when there is no infection. That's because the *cells* inside them stop working properly. We call these 'abnormal' *cells* because they are not behaving normally. The abnormal *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* (lim-foh-muh).

Lymphoma is a cancer of the *lymph nodes*.

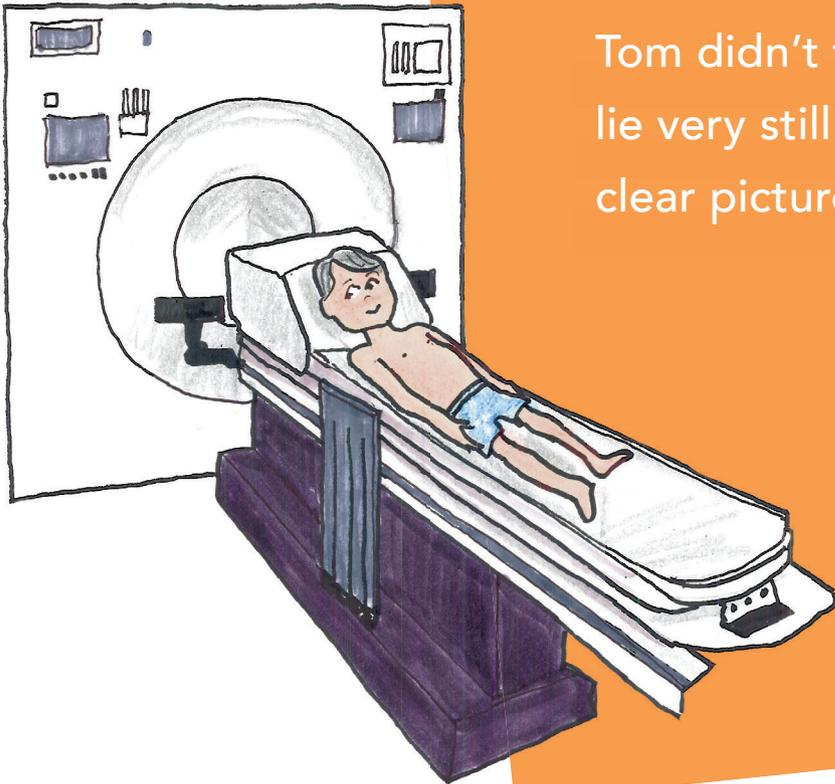


When Tom came back to hospital for his operation, he was given some medicine called a general *anaesthetic*. This made him have a sleep so that the surgeon, a doctor who does operations, could take out his big *lymph node* without Tom feeling anything. When Tom woke up, he saw his mum and was able to go home a little while later.

A few days later Tom went back to the hospital for some scans, so that the doctor could see if there were any big *lymph nodes* in other parts of his body. Sometimes people get them in their armpits, at the very top of their leg (which is called the groin), or in their tummy or in their chest.

There are lots of different types of scans, like *CT*, *MRI*, *PET* and *ultrasound*. Most of these need you to lie on a 'bed' that moves into a big machine that takes a picture of the inside of your body.

Tom didn't feel anything but he had to lie very still so the doctor could get a clear picture.



Tom felt a little bit scared. It was strange going to hospital to have the *lymph node* taken out and then coming back again to have the scans. But the doctors, nurses and play specialists explained everything that was going on. After the scans, Tom was able to go home and see his friends.



The following week Tom went back to the hospital with his mum and stepdad. The results came back from the pathologist saying that his lump was *lymphoma*. The doctor explained that there are lots of types of *lymphoma* that are all treated a bit differently. Tom's was called *Hodgkin lymphoma* (HL). Other types are called *non-Hodgkin lymphoma* (NHL).



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

Tom's stepdad asked the doctor how Tom got *cancer* as he was normally very healthy. The doctor explained that *cancer* is a scary word but there are lots of different types of *cancer*. She said that Tom hadn't done anything wrong and doctors and scientists still don't know exactly why some children get it.

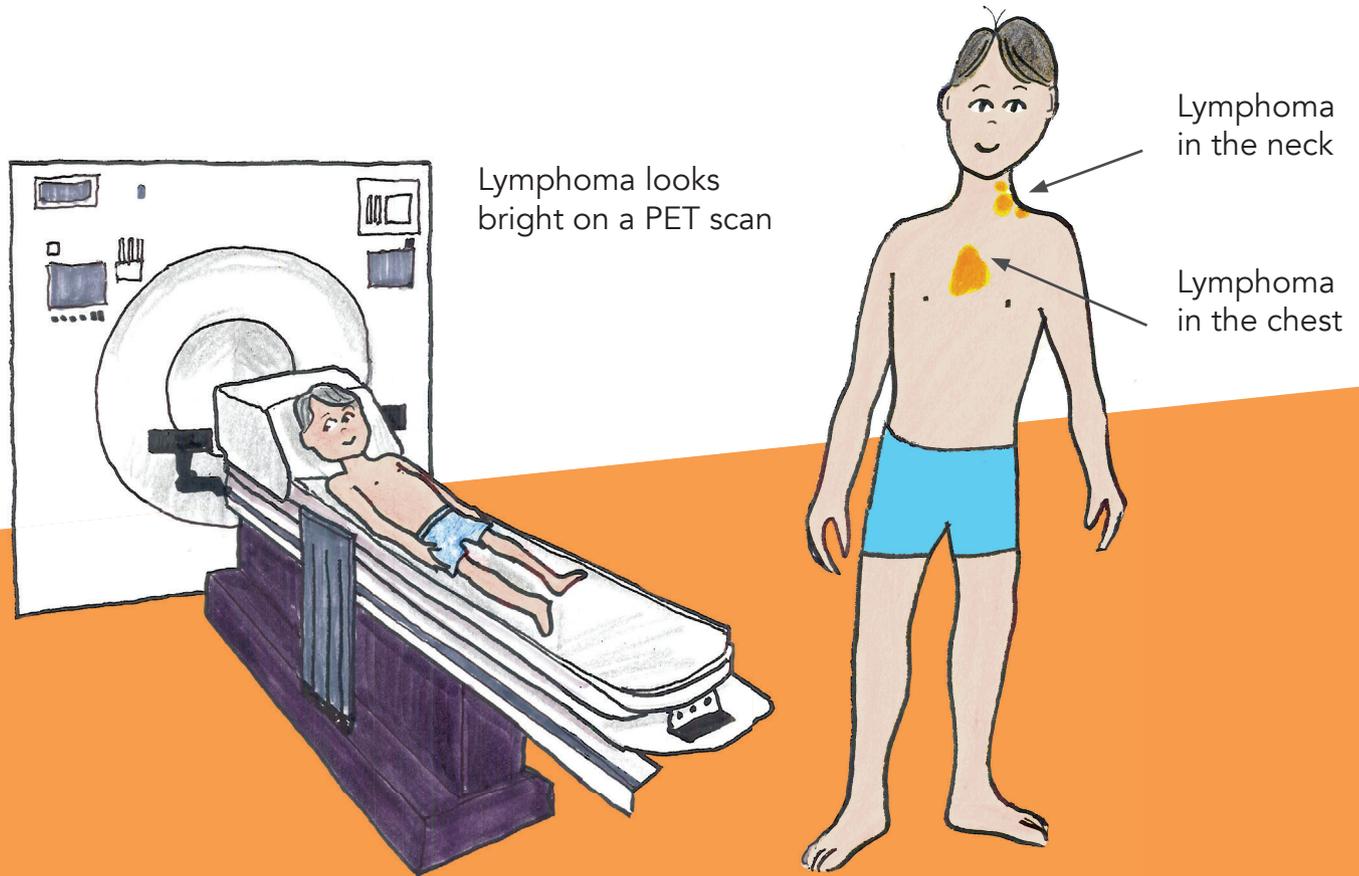
Some children with *lymphoma*, unlike Tom, are not so well and have lots of high temperatures (called fevers). They can sweat a lot, particularly at night. Sometimes they can sweat so much that their sheets have to be changed in the middle of the night. Some children lose weight and become much thinner, and some children get really itchy and scratch a lot.

The doctor told them what had to be done to make Tom's *lymphoma* go away – she called this 'your treatment'. She said that, although some of the *lymphoma* had been removed by the surgeon, the scans showed that there was also some inside his chest. The treatment would get rid of this bit, which would stop the *lymphoma* growing back.

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'll try to shrink the *lymphoma* and make it go away, which will make you better. Sometimes a *side effect* of the treatment is that your hair falls out but it will grow back when your treatment has finished."

The doctor said the amount and kind of treatment depended on what type of *lymphoma* you have, how much *lymphoma* there is in your body and how well it shrinks with the treatment. Tom wondered how they found this out. The doctor explained that they would use scans (like the scan he'd already had) to look at the amount of *lymphoma* in his body before and during treatment.

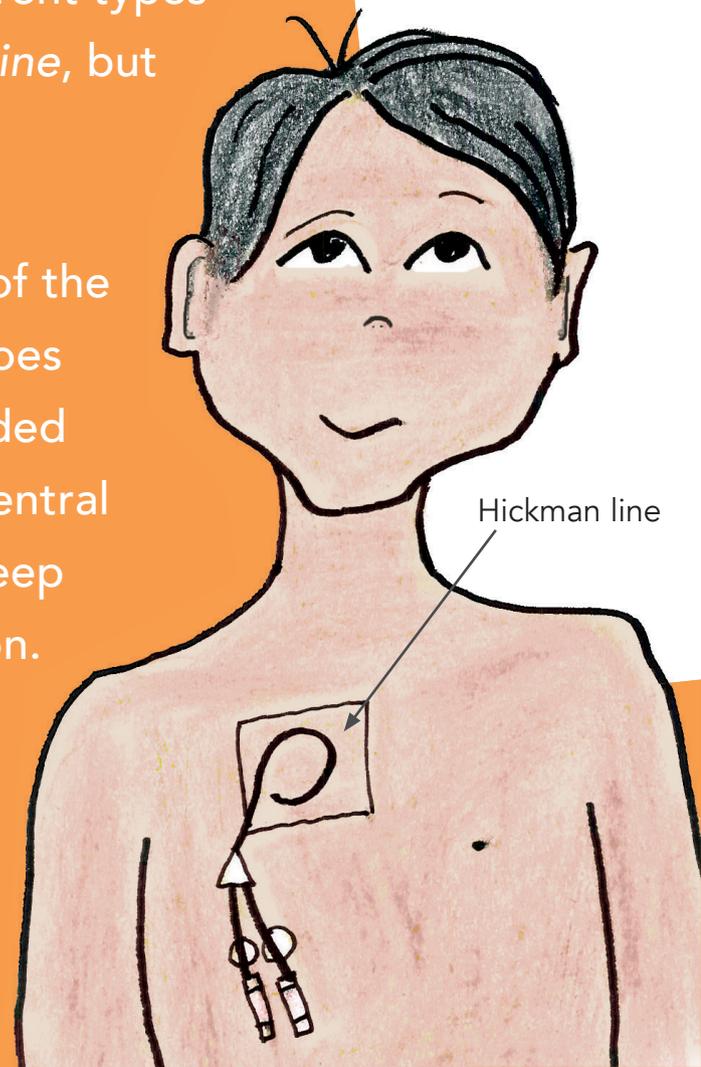
Tom had a *PET scan* to see which bits of the *lymphoma* were growing. Other children, like those with *non-Hodgkin lymphoma* (NHL), can have different types of scans. The growing *lymphoma* looks much brighter on the scan. Tom would have another scan after he'd had some of his treatment to see if all the bright *lymphoma cells* had gone away. Tom thought this sounded very clever.



Now that the doctors knew that Tom had *Hodgkin lymphoma*, and could see where else the *lymphoma* was in his body, he could start treatment to get rid of it.

As part of Tom's treatment he needed medicine, called *chemotherapy* (kee-moh-ther-uh-pee), to get rid of the *lymphoma*. He had a tube called a central line put into his chest to make it easier to give the medicine. 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 into Tom's body. Tom needed another small operation to put the central line in the right place, so he had a sleep again like he did for his first operation.



When he woke up the new line was safely in place. Tom heard some of the other children call their lines 'wiggles' because they look like wiggly worms, which he thought was funny.



Not all of the *chemotherapy* that Tom had went through the central line. Some of it came as tablets or as a runny syrup, like cough medicine. He preferred the tablets, but another boy on the ward couldn't swallow tablets so he 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 could go to school when he was well enough and wasn't in hospital.

Some of the other children having treatment stayed in the hospital a couple of nights each time, especially the ones who lived far away. One of Tom's friends had to stay in hospital to have all of her treatment, because it was stronger than Tom's treatment.

Over the next few weeks, Tom sometimes didn't feel very well and was quite tired.

There were lots of people around to help. Tom's social worker helped him feel okay about going back to school and seeing his friends when he felt well enough, and talked with his family about lots of different things. There was also a psychologist at the hospital, who was someone Tom could talk to about any worries he had.

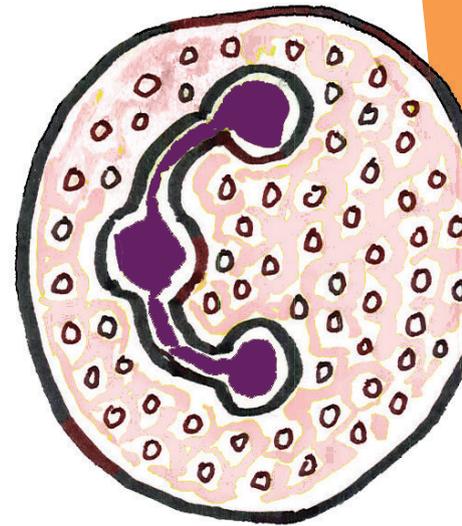
Gradually, Tom's hair did start to fall out so he decided to have it all cut off. He started to wear a beanie hat or a baseball cap if his head was cold. Some of the other children wore headscarves and one of his friends had a pirate bandana.



A few times, Tom had a fever 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 (nyoo-truh-fils), to fight infections. So the doctors and nurses gave him some antibiotics through his central line to make the fever go away and kill off any bugs causing the infection. Antibiotics are special medicines to treat infections.

Tom felt very poorly and he had to stay in the hospital for a few days. He missed his sister and stepbrother and his friends, because they were not allowed to visit in case they gave him another infection.

But he was allowed to play computer games and watch lots of TV until he was better.



This is what a neutrophil looks like under a microscope.

After a few more weeks, Tom had another *PET scan* to see if all the *lymphoma* had gone. If there were still bright bits on the scan, he would need to have *radiotherapy* to make sure all the abnormal cells were gone. Some children with *Hodgkin lymphoma* need to have *radiotherapy* after their *chemotherapy*. Children with *non-Hodgkin lymphoma* don't usually have *radiotherapy*.

If Tom needed to have *radiotherapy* for his *Hodgkin lymphoma*, he would meet the *radiotherapy* doctors who would plan the treatment. If he needed it, Tom would have *radiotherapy* at a *radiotherapy* centre a few weeks after he finished *chemotherapy*.

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

Even after Tom finished his treatment, he still had to go back to hospital sometimes to make sure that everything was fine. All his hair grew back and he was back playing football and having fun with his friends.



A year later, Tom was doing really well and only had to go back to the hospital occasionally for check-ups.



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 the *lymphatic system*, which helps fight against disease and infection. The *lymphatic system* is made up of *lymph nodes* that are linked together, like a chain. The *lymph nodes* get bigger when they fight disease and infection. They shrink back down when the disease or infection has gone.

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

The main type of HL is called classical HL, and is treated the way Tom's HL was treated. There's another type of HL that might be treated a bit differently.

All *lymphomas* that are not HL are called NHL. There are lots of different types of NHL. Their treatment depends on what type of NHL they are, but most people have *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 medicine that makes you 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 (this is called a full blood count or FBC).

Cancer

When the cells in your body become abnormal (don't work properly) and continue to grow on their own, out of control.

Cell

Everyone's body is made up of millions of tiny cells. They make up the different parts of the body like blood, muscle or bone.

Chemotherapy

A mixture of different medicines that treat cancer.

CT scan

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

Febrile neutropenia

When you are neutropenic and have a fever (a higher temperature than normal).

This is a sign of infection.

Gland

Another name for a lymph node.

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.

Lymphatic system

Part of your immune system. Cells that fight infection and disease travel around your body in the lymphatic system. These are the cells that go wrong in lymphoma.

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

A scan using strong magnets to take pictures of the inside of your body. It can be quite noisy. It doesn't hurt, but you might be given an anaesthetic or some medicine to help you relax and lie still.

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 serious infections.

Oncologist

A doctor who treats people with cancer, including lymphomas.

PET scan

Another scan which lets the doctors see what's going on in your body. Areas where there is lymphoma 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.

Radiotherapy

Special, powerful rays like X-rays are pointed at the lymphoma to kill any tiny bits left after chemotherapy.

Side effect

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

Ultrasound scan

A scan that uses sound waves to see inside your body. It doesn't hurt.

ABOUT YOUNG LIVES vs CANCER AND LYMPHOMA ACTION

Young Lives vs Cancer helps families find the strength to face everything cancer throws at them. We've been there before. We'll face it all, together.

Our website is your go-to place for everything you might need. You'll find honest answers to so many questions about cancer – and info on where to go if you want to know more.
younglivesvscancer.org.uk



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Lymphoma Action is the only UK charity dedicated to lymphoma. We provide emotional support and information for everyone affected by lymphoma, including parents and family. We are here for you, from diagnosis, through treatment, to life beyond cancer, because no family should face their lymphoma alone.

lymphoma-action.org.uk



Registered charity number (1068395) and registered in Scotland (SC045850).

DO YOU HAVE ANY QUESTIONS, OR NEED SOME HELP?

The Young Lives vs Cancer team are here, ready to support you. Message us online via Live Chat, call us on 0300 303 5220 (Monday–Friday 10am – 4pm) or drop us an email and we'll get back to you.

For full details of Lymphoma Action's services, including booklets, videos and support groups, visit lymphoma-action.org.uk or call the Helpline freephone on 0808 808 5555.

Please note that everyone's experience will be different and may not follow the order outlined here. Services will differ across the UK. Young Lives vs Cancer and Lymphoma Action do not accept any responsibility for information and services provided by third parties, including those referred to or signposted to in this publication.

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Tom has lymphoma is a storybook written especially for parents and carers to read with their children, to help them understand what lymphoma is and the treatment it involves.



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| ✓ | Evidence-based |
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