

ALEX AND THE BRAVEST DAD IN THE WORLD



A storybook developed to help adults explain multiple myeloma to children.

This book was inspired by people with multiple myeloma, who have young families and struggled to find resources to explain their disease to their children.

Thank you to everyone who has been involved in the development of this book. The insights shared by patient advocacy groups, healthcare professionals, people with multiple myeloma and their families were vital in creating a book that families find useful, realistic and informative.

My name is Alex, and I have
the best Dad in the whole world!
This is the story of my Dad, and how
he got sick, and then got better again.



For as long as I can remember,
Dad and I would spend hours
doing cool stuff together.





Building...



Telling stories...



Having big adventures...



And racing in the park. Dad's fast, but I'm faster! I always win.

But then, a while ago,
something strange happened...



Each time I'd ask Dad to play,
Dad would say "no".

Dad said "no"
to playing with blocks,
because his back hurt.



Dad said "no" to
telling stories, because he
couldn't concentrate.



Dad said "no"
to having adventures,
because his joints ached.



Dad said "no" to racing
in the park, because he
was out of breath.

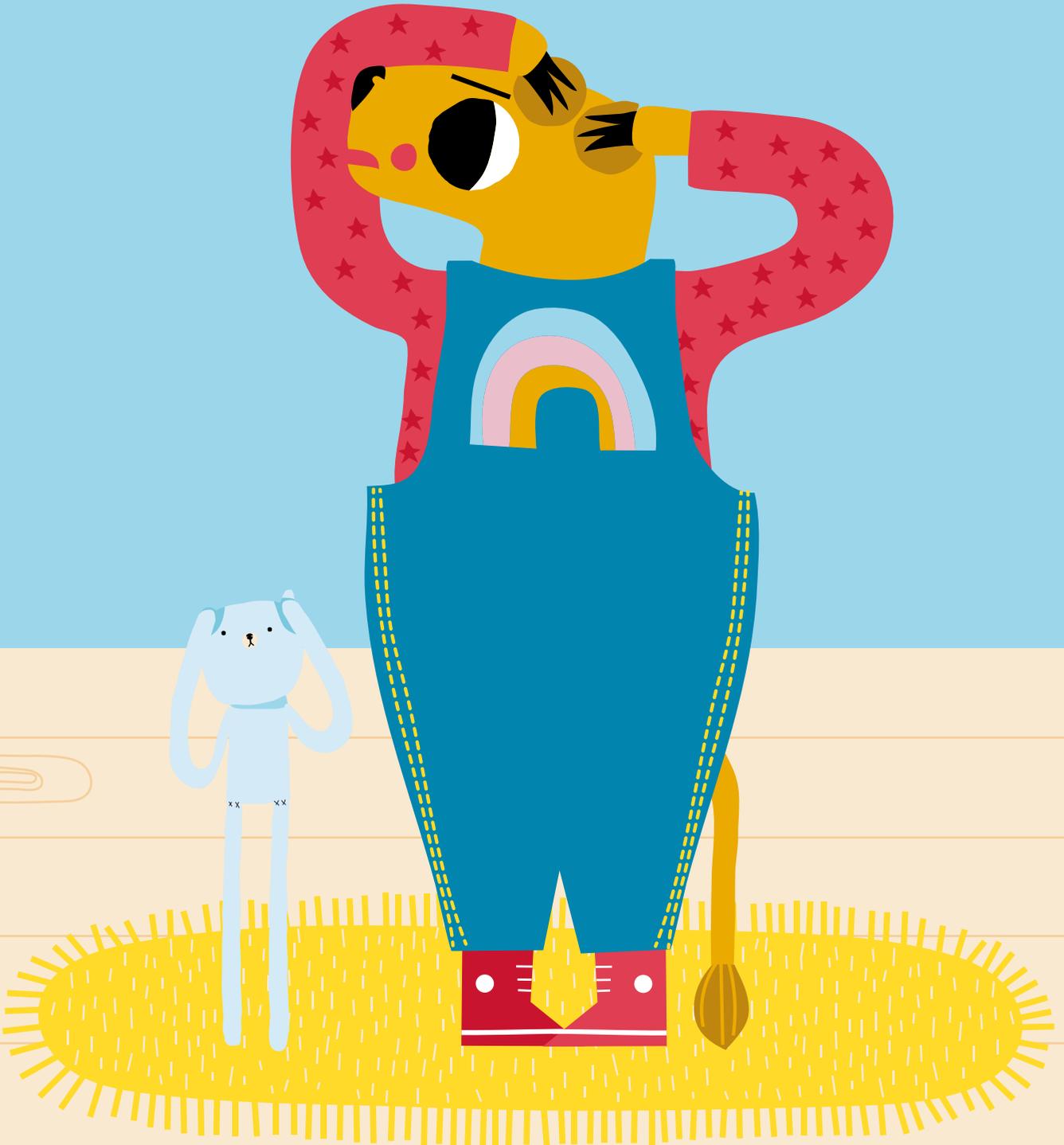


No

no

no

no





Dad just didn't want to play with me anymore.
And that made me feel really sad.
I asked Dad what I had done wrong, and Dad said "nothing".

I even asked Teddy what I had done wrong, but Teddy didn't know...



I just couldn't understand it.
Why didn't Dad want to play anymore?

Then one day I came home from school and Dad said he wanted to talk to me. He looked very serious. Like the way he looked when I didn't do my homework...

But I hadn't done anything naughty for ages!

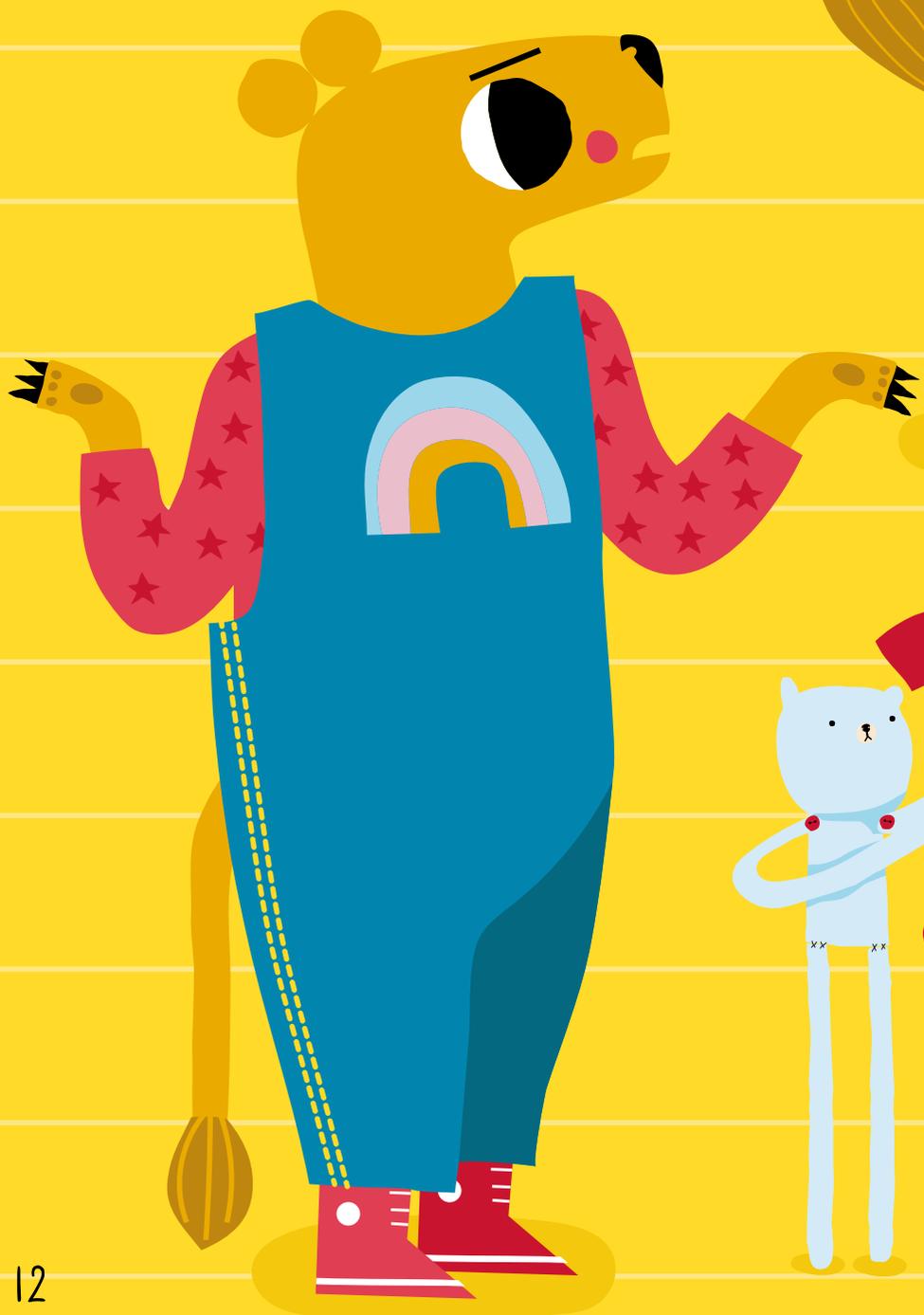


Dad told me he'd been feeling sad, because he had been too unwell to play with me. So he had gone to the doctor. And the doctor did some tests and told Dad that he has multiple myeloma.



Dad explained. "Multiple myeloma is the reason I've been feeling tired, and achy, and out of breath. When you have multiple myeloma some of your body's blood cells, called plasma, don't grow normally and stop being able to fight germs, so you get sick."

"But how does multiple
myeloma make you get sick?"
I asked.



"In the body, there are
these special blood cells
called plasma cells."

I was confused. "What's a cell?"

"Cells are the small blocks that every living thing is made of. They're like the blocks we build with, except cells make people, and trees, and animals, and everything else.

In the body, all the different cells have different jobs, and the job of plasma cells is to fight infection and once they are outnumbered by cancerous cells it is harder for them to fight germs."



"Like tiny little Superheroes?"
I asked.





BOOM

“Exactly!” said Dad.

“When you have multiple myeloma, your body starts making many lazy and bad plasma cells. You get ill because these cells crowd out the good cells and make it harder for them to do their job. These bad plasma cells also don’t want to do their own job so they don’t fight germs. And that’s the reason I haven’t felt well enough to play with you.”

“Why do you have multiple myeloma?” I asked.
I thought about the time I was really unwell and had to
stay home from school. “Did you catch it from me?”



“No” said Dad. “You can’t catch multiple myeloma from other people.
Multiple myeloma is a type of cancer, which is what it is called when the
bad cells in the body crowd out the other cells.”

I was worried that multiple myeloma meant that Dad was going to die.

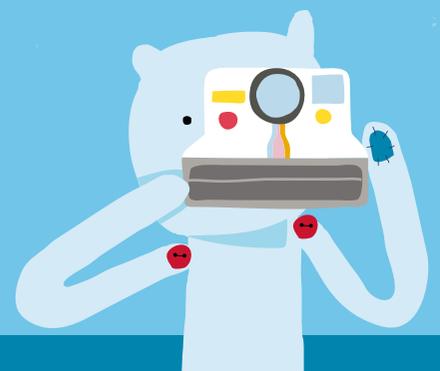
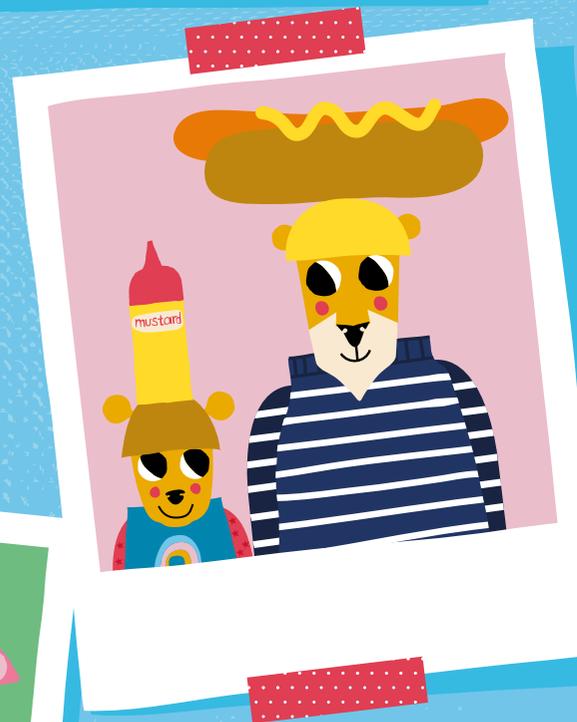


But Dad said I shouldn't worry. The doctors would give Dad medicine to fight the bad plasma cells. Dad would have to go to the hospital regularly for a special medicine called an infusion, and take pills at home every day.

After a few visits to the hospital, Dad's hair started to fall out. I didn't understand why - it was scary!

But Dad said that sometimes the multiple myeloma medicine can make that happen. He said that some people take medicine that makes their fingers feel funny or makes them more tired, or can sometimes give them an infection or an upset tummy. It just depends on the medicine.

We decided Dad should wear lots of silly hats until his hair grew back. Sometimes I would choose a hat for Dad to wear. It was fun!





Every time Dad came home from the hospital he would be very tired. He'd spend the next few days in bed sleeping and I would play very quietly so I didn't wake him up.





I didn't mind though, I knew Dad wanted to play with me and it wouldn't be long until we could play together in the park.



One lovely sunny day, Dad was well enough to go for a short bike race!

It was amazing!!!

I won!

Everything started getting better at home, and soon Dad and I were spending lots of time doing cool stuff together.



Until, some time later, when I came home from school and Dad said he had something important to tell me. He looked sad.



Dad said "My multiple myeloma has come back. I've started feeling unwell again, and the doctor says I have to go back to the hospital to get more medicine."

"But I thought you were all better?" I said.

Dad explained that when you have multiple myeloma you can go for ages and ages and ages feeling great, but after a while, your bad and lazy plasma cells can start to come back.



Dad said that it was called a relapse, and that it can happen more than once. He said it would be okay though, because he would just go back to the doctor for more medicine to help fight the bad plasma cells.

It was a lot to think about! But Dad told me
not to worry about that now.

I knew Dad would go back to feeling tired all the time,
and I wouldn't have my Dad to play with for a while.
And that made me feel sad.





But I also knew the medicine would help, and after some time, it did!

It's been a really long time since
Dad's had a relapse.





His plasma cells have been hard at work,
helping Dad to fight germs.



Now, when I ask Dad to play with blocks he says "yes!".



And he says "yes!" to telling stories.



"Yes!" to having adventures.

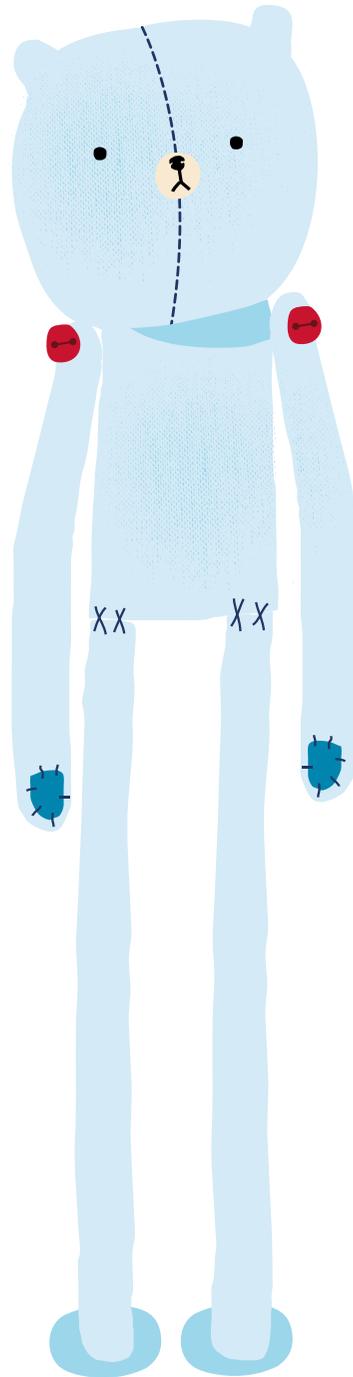


And "yes!" to racing in the park.

I know that sometimes my Dad will get ill,
but he will always make time for me if he can.
And that's why my Dad is the best and
bravest Dad in the whole world!



This is Alex's Teddy. Teddy goes everywhere with Alex!



Can you spot Teddy in every picture?

Alex's glossary

Cancer

what it is called when some cells in the body change, quickly multiply and crowd out normal cells, making it hard for them to do their job. People with cancer will feel unwell but there are lots of different medicines that can be given to them to help fight the cancer/bad cells.

Cell

the building blocks that every living thing in the world, including people, are made of.

Infusion

a way of giving medicine so it goes straight into the blood. People with multiple myeloma can be given an infusion to help fight bad/cancer cells that cause illness.

Multiple myeloma

a type of illness which affects plasma cells in the bone marrow. Multiple myeloma can't be caught from other people. People with multiple myeloma can get better if they take medicine.

Plasma cell

cells that make substances called antibodies that fight the germs that can make you ill.

Relapse

when someone gets ill again after being well for a while.

This storybook was developed in consultation with healthcare professionals, people with multiple myeloma and their families.

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