

A present for my sister



The Cure & Action for Tay-Sachs (CATS) Foundation

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For our sibling squad - you're all amazing

This is Rose.

Rose loves singing, dancing,
eating chips and giving
people presents.





This is Rose's mum.

She loves reading and having five minutes peace.

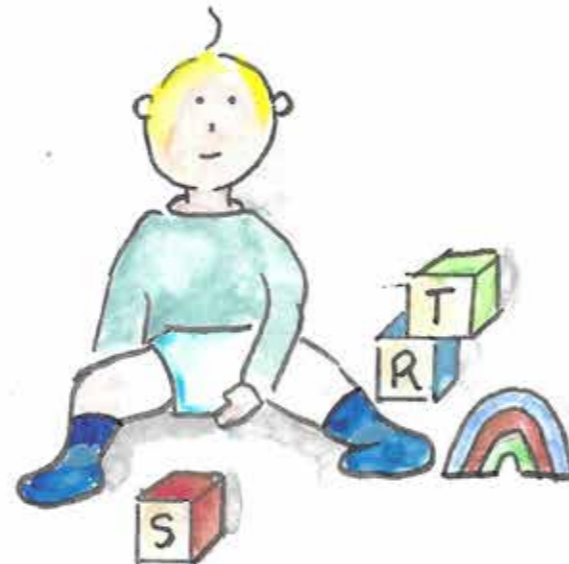


This is Rose's dad.
He loves gardening.



This is Tom, Rose's baby brother.

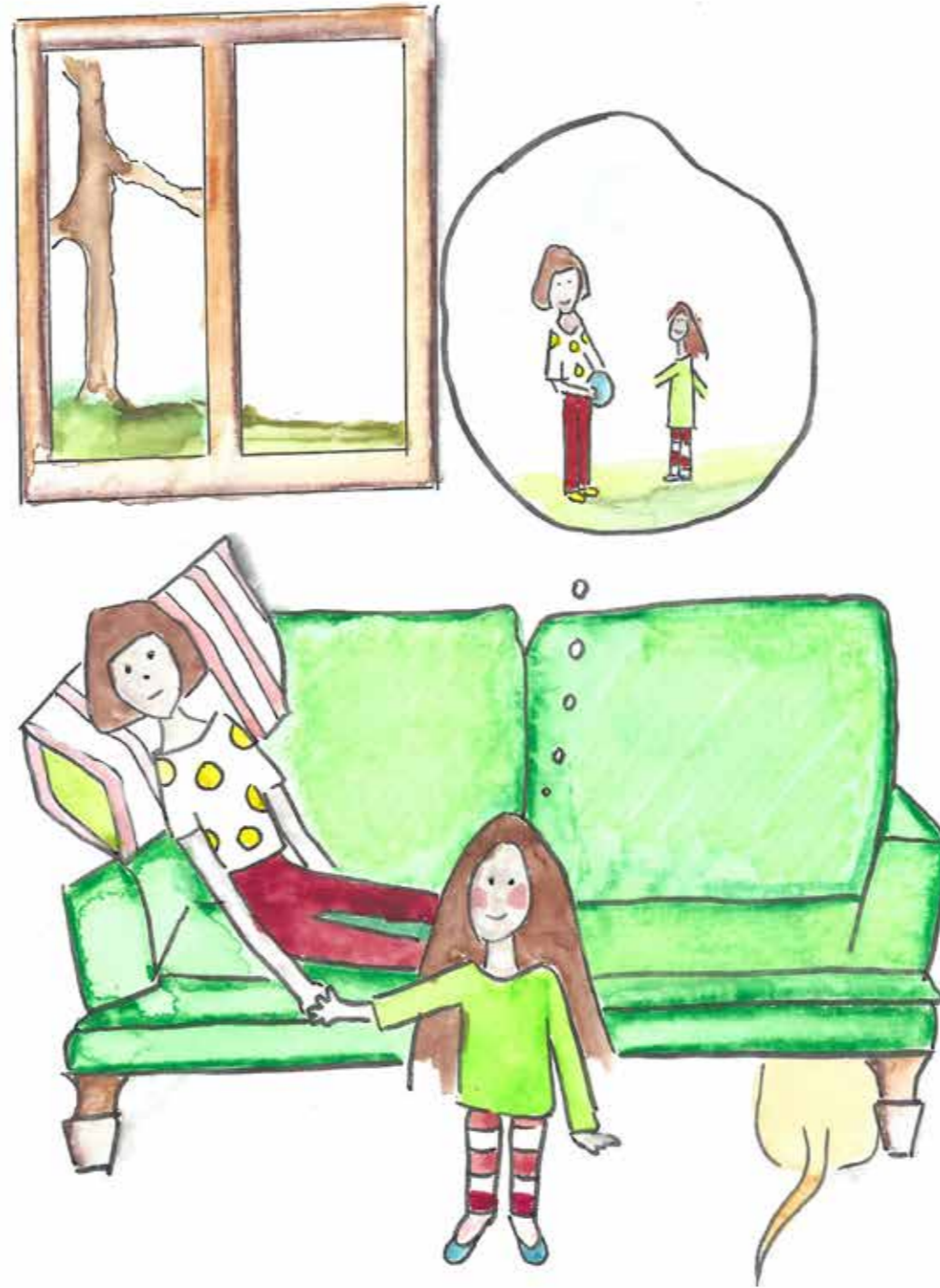
He likes emptying the washing basket, feeding crumbs to the dog, crawling up the stairs, and keeping everyone awake at night.





This is Sadie, Rose's big sister. Sadie likes being close to Rose and Tom and hearing them play.

Sadie isn't very well.



Sadie is poorly all the time. She doesn't get better, like Rose does when she has a cold. She lies on the sofa or sits in her special chair.

Sometimes Rose wishes that Sadie could play with her.



Sadie has Sandhoff disease. She has had it since she was born. This makes Sadie's life very difficult.

Sometimes people come to try to help her, doctors, speech and language therapists, physiotherapists, wheelchair specialists.

Rose and Tom sometimes feel left out.



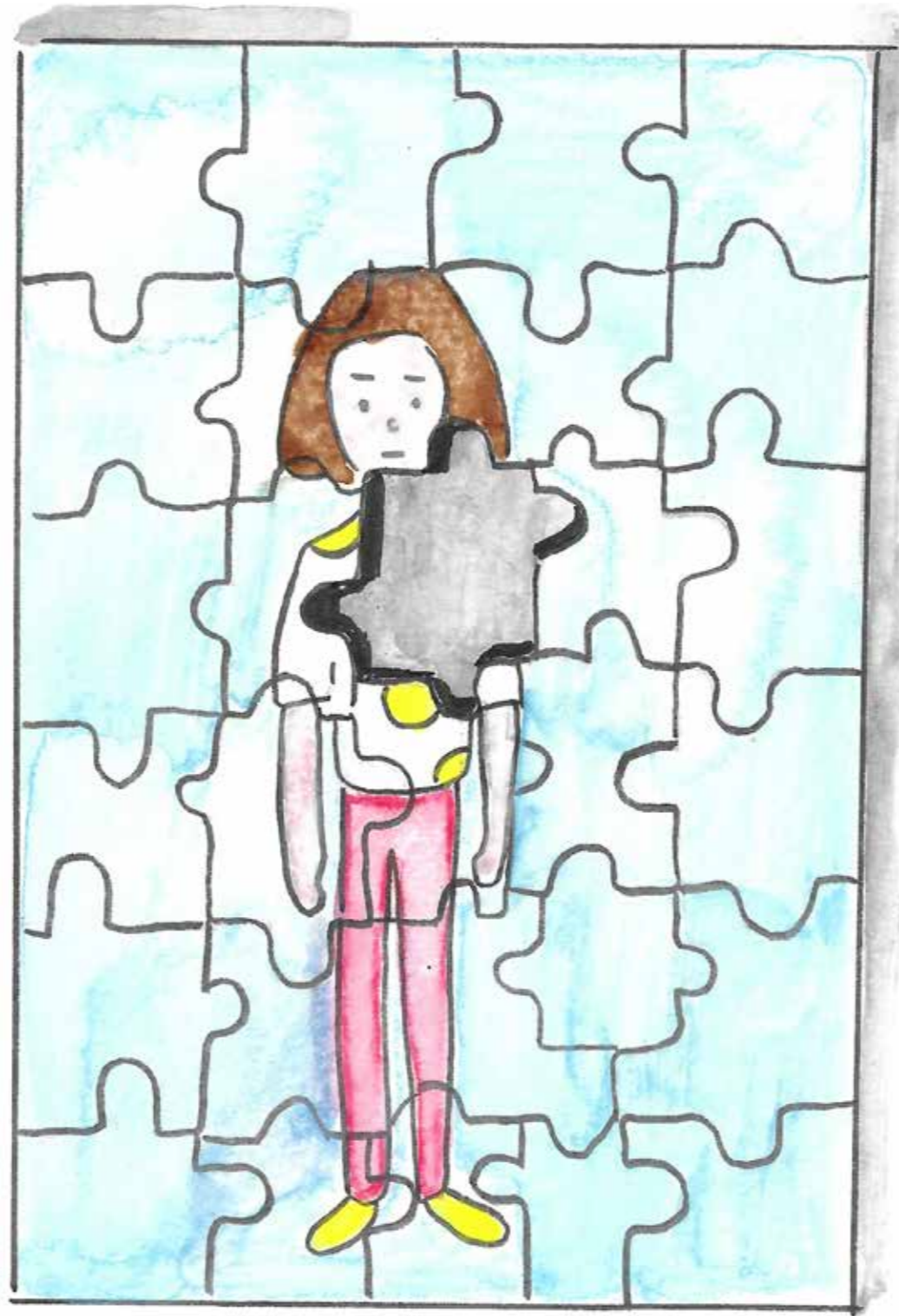
Sometimes, Rose and Tom feel very sorry for Sadie. Sadie can't sing or read or empty the washing basket. She can't even eat chips. Sadie's food goes straight into her tummy through a tube.





Every person is made out of different parts, like a jigsaw puzzle.





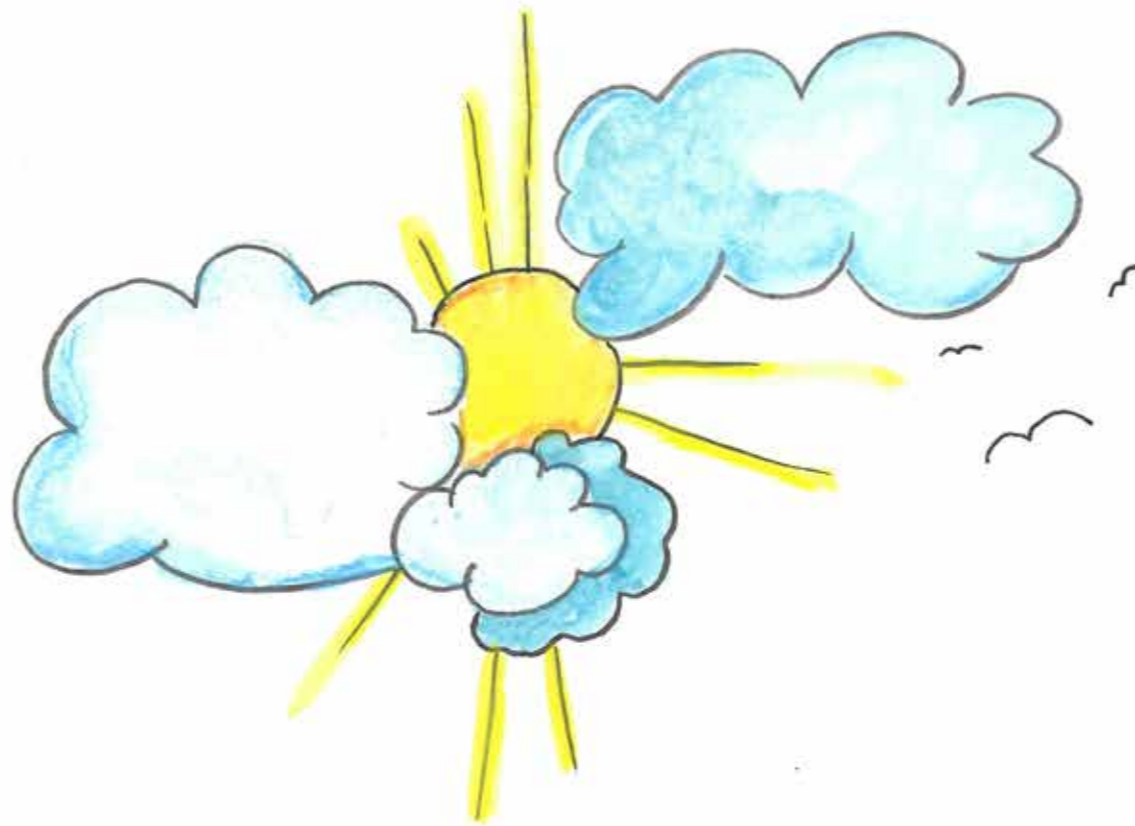
A very important piece of the jigsaw puzzle that makes up Sadie is missing.

It has been missing since before she was born.

Rose has looked for it everywhere, but mummy and daddy explained to her that it wasn't anywhere to be found.

Sadie is how she is, and that can't change.





Rose has an idea. She decides to give Sadie a present, to cheer her up.

She asks Tom what he thinks, but Tom speaks baby language.





A jack in the box would be too scary.
A kitten would be too jumpy.



A drum is useless if you can't bang it.
A book is dull if you can't see it.



A toy farm would have too many pieces.
A doll's house would be too fiddly.



A doll isn't much fun if you can't carry it round.
A car is no good if you can't vroom it along the floor.



Rose thinks of everything she can, but nothing seems right.



Rose asks her mum and dad what she should give Sadie.

‘That’s easy,’ says mum.

‘That’s easy,’ says dad.

Mum and dad explain that Sadie would like some of Rose’s time much more than any present she could give.

‘Time with Sadie is the best thing you can give her,’ they say.



'Sadie can't play, but you can play for her,' mum and dad say.

'She can't read, but you can read for her.'

Mum and dad explain to Rose that Sadie won't always be with them.

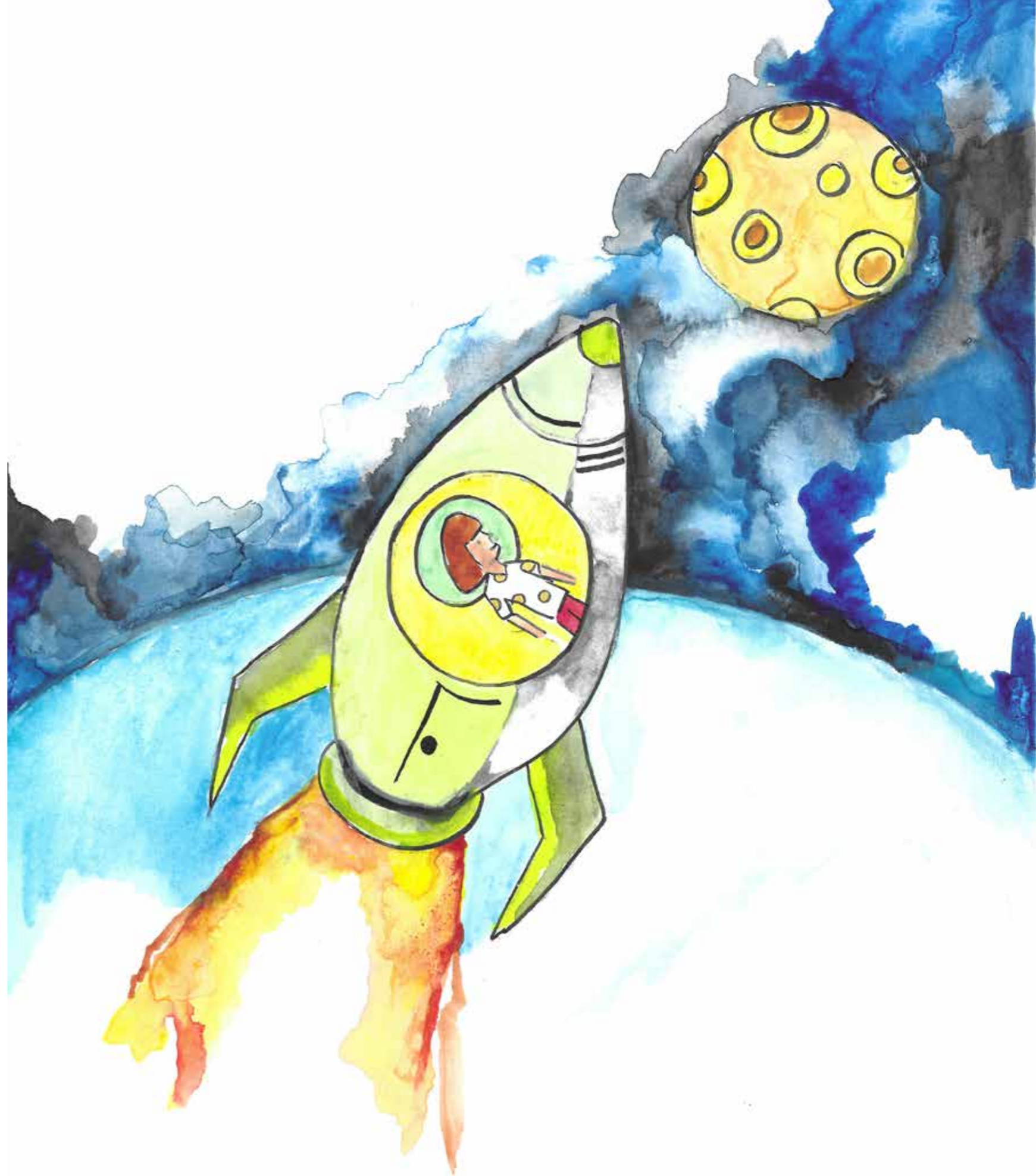
'One day she will die,' they say, because of the missing part that can't be mended.

Rose asks what will happen to Sadie when she dies.

‘Different people think different things,’ they say, ‘no one knows for sure. Some people think she may go to heaven. Some think she may be asleep in a comfortable place where she doesn’t have to wake up anymore. Maybe she will go up in a spaceship and visit the moon and the stars!’

Rose is very sad.

‘But what’s important is that you know she will always be looking down at you with a big smile on her face.’





‘Sadie will always be in our hearts,’ says dad, ‘you can always do things for her, like you play for her now.’

Rose decides to give Sadie a piece of her time every day, while she can. She knows that Sadie will die, and that will be very sad, but she will always have her big sister in her heart.

'A present for my sister' was created by The Cure & Action for Tay-Sachs (CATS) Foundation to help siblings of children diagnosed with Tay-Sachs and Sandhoff understand the impact that the disease will have on their brother or sister.

To find out more about Tay-Sachs, Sandhoff and the charity visit
www.cats-foundation.org.



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Join Rose as she goes on a journey to find the perfect present for her special sister Sadie. Although Sadie isn't very well, there is one gift that Rose, and her little brother Tom can give her that will mean more than anything in this world.

What do you think it is?

