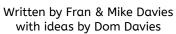


the Exp

A little story for children with heart conditions, their brothers, sisters and friends.







Illustrated by Hen the Pen Designed by The Paper Bird



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For Dom, our very own expert.

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Written by Fran & Mike Davies with ideas by Dom Davies

Illustrated by Hen the Pen Designed by The Paper Bird



Published by The Children's Heart Federation © 2021 The Children's Heart Federation Sprinting, jumping, swinging, climbing...
Rufus and Sky were joyfully running wild through their dreams.

Suddenly, Mum's voice dragged them both into the new day. "Rufus, Sky, rise and shine!"

Rufus rose and shone. Sky rose and paused. He had a poorly heart and often needed to wait a moment or two to catch his breath, though he preferred not to make a big deal about it.

Sky had become an expert at pausing.



Rufus thumped downstairs.

Sky stood up, took some deep breaths and rearranged the brave soldiers on his bedside table. Then he got up and made his way down to the kitchen for breakfast.

> Rufus had toast and juice. Sky had toast, juice and tablets.

"Finger," said Mum. Sky put the 'crocodile' on his finger and waited for the numbers to settle. When they did, they showed that there was enough oxygen in his blood - enough for him, anyway.

It was a school day, so they had to get ready.



Rufus rushed upstairs to do his teeth.

Sky's toothbrush was downstairs and he was still cleaning when Rufus came down.

Mum sent Rufus back upstairs to do them properly, but she knew she didn't have to worry about Sky - he couldn't afford not to take care of his mouth.

Time to go. Rufus picked up his bag and hung his coat on his head by the hood.

Mum wrapped a scarf tightly around Sky's neck, then helped him button his coat all the way up and picked up his bag.



"Scooters?" asked Mum. Both boys nodded.

Then they set off for school. Rufus scooted along in front. Sky stood on his scooter and held on while Mum pulled him along. Sky had become an expert at balancing on a scooter.

In the playground, Rufus ran around with his friends, while Sky stood near Mum as she chatted to the other parents.

Soon Mrs Gordon, the TA, came out to collect Sky
- just him - and take him inside. There, in Sky's place,
was his reading book, a maths challenge and a colouring
sheet. Today he felt like a maths challenge.



Before long, Mr Bennett, Sky's teacher, and the rest of the class came in.

They answered their names to the register. So did Sky.

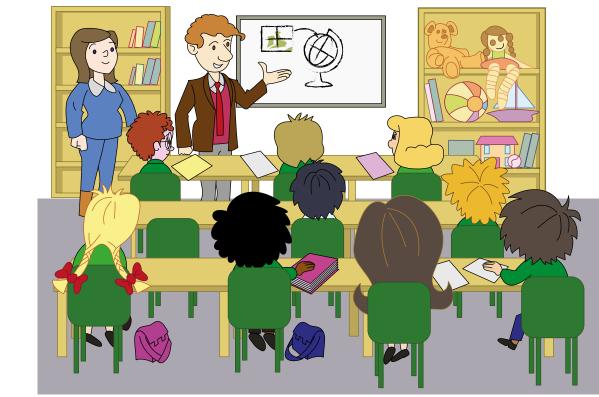
> They did some reading activities. So did Sky.

They listened to Mr Bennett talking to them, then settled down to write by themselves.

So did Sky.

At break time, the class put on their coats and went out to play...

So did Sky.



Sky ran a little and he chased a little. He even climbed a little. But then he felt his heart racing and his breath gasping, so he sat on a bench.

Sky had a snack to boost his energy. Mum made sure he always had a good supply of healthy snacks.

Two of his friends came to sit with him. Everyone needs a rest some time.

Sky was an expert at helping his friends realise when it was a good time for a chat.



After break, it was PE. The class changed together. The new boy saw Sky's scars and asked how he got them.

"Shark attack," said Sky.

The boy's eyes grew wide with wonder. One of Sky's friends laughed. "He always tells the new kids that," he told the boy.

"I've got a poorly heart," Sky explained. Sky had learned to be cool about his scars.

The new boy looked shocked and took a step backwards.

"It's alright, you can't catch it off him," said Sky's friend. "He's had it since he was a baby."



In PE, the class did a full warm-up. Sky did a gentle warm-up. The class practised some skills. Sky practised some skills.

Then, Mr Bennett told Sky that they would be having a game and there might be a risk of bumping into other children.

Sky had a think about it and decided it would be better if he didn't play.

"Could I referee? Or keep the score?" he asked.

Mr Bennett smiled. "Why not do both?" he said.



After PE, it was lunch. Sky's class lined up and went into the hall. As usual, there was an enormous queue. Standing for a long time was often quite tiring for Sky.

Mrs Gordon said, "Pick a friend and let's push in."

Sky's friends all put their hands up, hoping to be picked. He thought about it and chose someone he hadn't picked for a while. Sky was an expert at being fair.

Mum was waiting by the office after lunch. Sky had another appointment at the clinic.

Mrs Gordon helped him change his reading book and get his coat, scarf and bag.



At the clinic, Sky saw his friend Hassan. Hassan also had a poorly heart and they often had appointments on the same day.

Before long, a nurse weighed Sky and did some other tests. They also used a machine to look at his heart on a special screen. They spread clear jelly on his tummy; it was really cold! The pictures on the screen made no sense to Sky.

Next, Sky and Mum went to see the doctor. She asked Mum some questions and asked Sky how he felt. The doctor told Sky that they were thinking of giving him another operation - not straight away, but soon.



Mum squeezed his hand and gave him one of her gentle smiles. Sky was not particularly worried.

He knew there were many people he could talk to about what would happen and how it made him feel.

He was an expert at coping with operations.

Sky asked the doctor what they wanted to do. It was a little hard to understand, but he was determined to try. By the end, he knew enough.

The operation would involve making small changes to the way the blood moved around his body.

With luck, it would keep him going until he was nearly grown up.



Sky asked whether it was like when there are roadworks and they have to send traffic along a different route to keep it moving. "What a brilliant way of thinking about it!" said the doctor. "We will send your blood on a short diversion."

They drove home. On the way back they picked up Rufus from after-school club. Rufus chatted and chatted about his day. Sky sat quietly.

In no time, Rufus was changed and ready for Cubs.
"I think I'll give Cubs a miss this week," said Sky.
"It's been quite a busy day."

"Good idea," said Mum, as she picked up her phone. Soon, Rufus's friend Logan arrived with his dad, to take him to Cubs.



Mum sat with Sky and they chose what should be written on his new medical bracelet. They had heard that it was a good idea to wear something that could tell doctors and nurses what type of poorly heart he had. They could look at this, just in case there was an emergency and Sky, or some other expert, was not able to tell them.

Rufus came back from Cubs. He handed Sky a small bag of sweets he had been given by one of the other cubs because it was her birthday.

Rufus always tried to make sure that Sky didn't miss out. Mum said he could have them tomorrow. Everyone is allowed some treats now and again.



That night, the stairs up to bed were like a mountain. Like an expert mountaineer, Sky took it slowly and carefully.

He stopped half way up to take in the view.

He paused at the top to study an interesting map that Mum had hung on the wall.

Then he went to his room and organised the brave little soldiers on his bedside table, ready for that night's mission.



When Rufus finally got into bed, Mum came up to read them the next chapter of their adventure story.

Sky's mind wandered. He was thinking about his next operation.

Before long, he was sprinting, jumping, swinging, climbing and joyfully running wild with Rufus.

Sky was an expert at dreaming...

