Emma's Guard



AESCULAP

Emma's Guard



Emma is wilder than her best friend, Anton. She is braver than he is. Louder than others. And she has hydrocephalus.

Everything was as it should be until she had to have surgery. Friends, teachers and the others in the class found out about her hydrocephalus – something she would have liked to keep to herself. Because Emma would like one thing above all: to be like everyone else again.

A story by





Underneath the cherry tree. Emma and Anton are in the hammock at the back of the garden between the two cherry trees. It's their favorite spot, where they are free to play.

Suddenly Anton asks, "Emma, when do you have to go to the hospital?"

Emma jumps up and quickly climbs onto the cherry tree. "Maybe in two weeks. Or maybe three. I'm not quite sure yet," she calls down cheerily from above.

But Anton feels that she is not always as cheerful as she sometimes pretends to be. By now, Emma has climbed up quite high to the smaller branches where her legs are dangling.

Anton leans against the tree trunk, looking up to her with some concern while secretly admiring his friend for her courage.

"Are you afraid?" he asks.

"Afraid? Of what? It's great up here. Come up and see."

"Of the hospital ...," Anton calls up.

There's no reply from the cherry tree. Then Emma climbs down slowly and lets herself drop onto the grass next to Anton. She is now very serious. "Yes." she says after a while.

Anton looks at Emma and sees the look of concern on her face. He puts his arm around his friend and knows that he would be afraid if he had to go into the hospital – even without an operation.

"What exactly are they going to do to you?" Anton had been meaning to ask this for a long time, but Emma had never wanted to talk about it.

Now she looks at him and explains calmly: "When I was very little, I had too much fluid in my head, and it gave me headaches. The doctors said it could have been worse if they hadn't found it in time. I wouldn't have been able to climb trees or go to school with you."

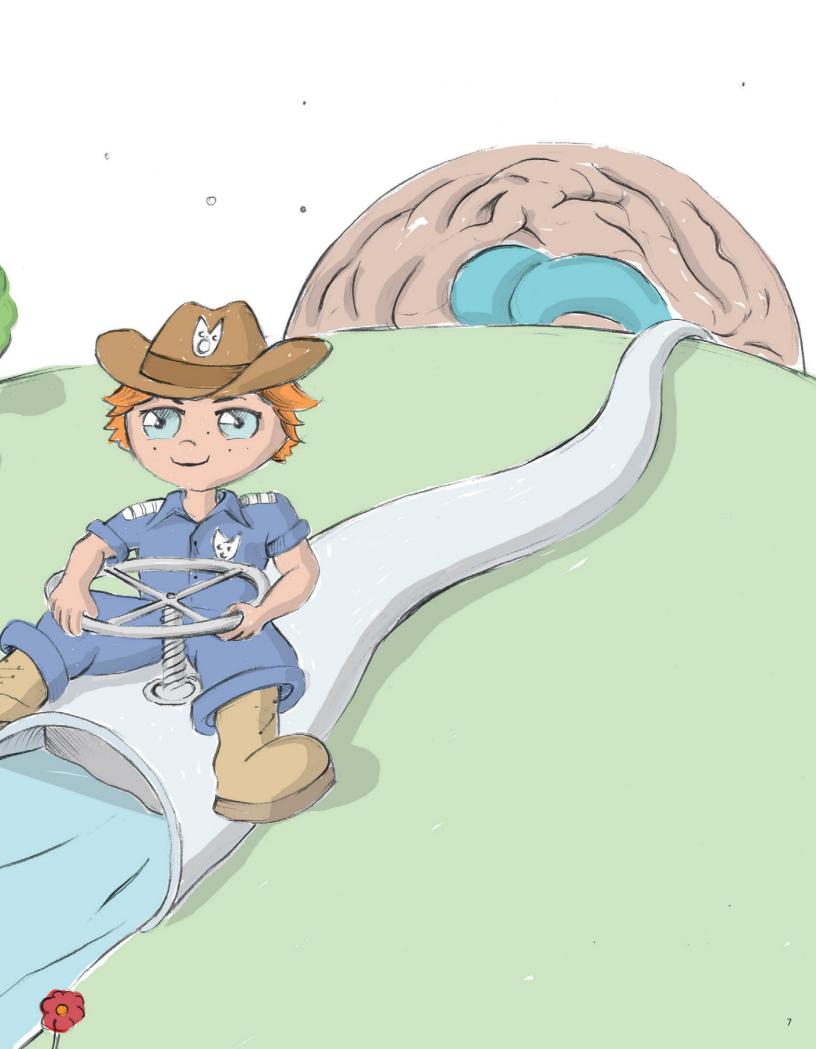
She gives him a cheeky grin, while Anton looks at her with alarm. "I have a thin tube in my body that simply drains the extra fluid up here" – she touches her forehead – "into my belly. Like a drain pipe.

"And in between is a guard that makes sure that not too much fluid is drained away because some of it has to stay in my head, just like yours. But now I have grown too much, and the tube is too short."

Emma becomes serious once again. "So they have to change the pipe to a new one that's longer. This is how mom explained it. But Anton, I don't really want to."

"I know," says Anton and holds Emma a little bit tighter.





At school. The next morning on the way to school, Emma behaves as she normally does: happily and cheerfully, as she jumps from the pavement to the road and back. She only makes a face when she remembers the math test. "But don't worry, Anton. That's not until the afternoon!"

However, just before the lunch break, Emma is looking a bit concerned. "Emma, what's the matter?" Anton whispers.

"I feel dizzy, and my headaches are really bad," she says in a small voice that sounded so unfamiliar to Anton. He alerts their teacher immediately.

Not long after, Emma is picked up from school by her parents. Anton stays behind at school, quite worried and a little bit envious that Emma was now missing the math test. After what seems like a very long day at school without Emma, he hurries to her home to pay her a visit.





As on most days, the front door is unlocked, and Anton is just about to run into Emma's room, when her mom shouts, "Anton, she's not upstairs! We had to take her to the hospital."

Anton is shocked, stops on the stairs and does not know what to say.

"I was just about to pack a few things for her to take to the hospital. Do you want to come with me?" Emma's mom asks.

Anton nods, but he's secretly afraid of the hospital. He wonders how Emma is dealing with being afraid.

In the car. Anton sums up his courage to ask for more details. "Does Emma have to have her operation sooner?"

"Yes," her mom replies.

"But why? What happened? Has the pipe been damaged?" Anton asks anxiously.

Emma's mom smiles. "How much do you know about Emma's pipe?" she asks.

"It needs to be replaced because it's too short," he says.



"You're right. And unfortunately, it's now also blocked. It's very important in this situation to act quickly. Anton, do you know what hydrocephalus means?" she says.

"Not really; only that there's too much fluid in the brain that needs to be removed," he replies.

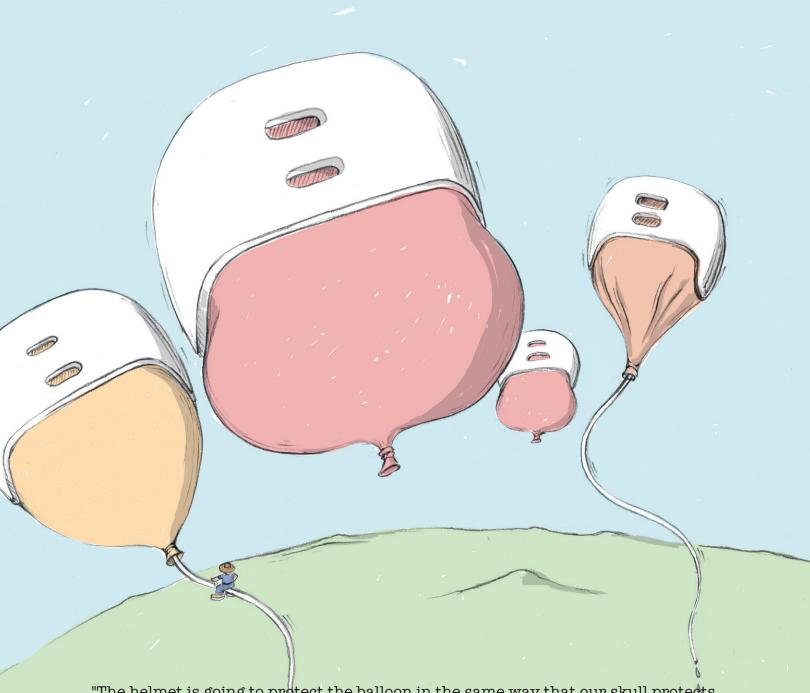
"That's right," Emma's mom continues to explain. "Imagine a balloon filled with water. The more water you add, the bigger the balloon becomes. With a balloon, that can continue for quite a while. It's the same in smaller children. Their heads can expand, because the gaps between the skull bones are not yet firmly closed. Their heads become bigger, and so sometimes you can recognize hydrocephalus. That's not a good situation. All of that fluid puts pressure on the brain."

"Do you know what we need our brains for?" asks Emma's mom.

Anton thinks briefly. "I think we need them for everything. Isn't the brain our control center? I think as important as the heart, only in a different way."

Emma's mom laughs, because Anton, as always, thinks like a walking dictionary. He never forgets anything he has seen or read.

"Exactly, Anton. Too much pressure on the brain can damage the control center. In Emma's skull and yours and mine, the bones have already grown firmly together. Now imagine that you fit a bicycle helmet on your water-filled balloon just big enough for it to fit inside," she says.



"The helmet is going to protect the balloon in the same way that our skull protects our heads. If you keep adding water to the balloon, the pressure increases further. Headaches are only the beginning. There's no doubt that the fluid has to go somewhere in order to protect the brain. BUT: not all of it. Because the brain needs a little bit of fluid. For that reason, the doctors not only have to fit a pipe in order to drain the fluid, but they also need a guard that makes sure not too much fluid is drained."

That's what Emma had told him earlier too. Anton begins to get a better understanding, but a few questions remain. "Who's this guard, and how does he know how much water to let pass? And how does he do it?" he wonders.

Emma's mom continues: "The guard is not a man like in a fairy tale. That's what I made up when Emma was little. But it works very similarly. The tube draining the water from the head into the abdomen is fitted with a valve, which, like a clever guard, only allows water to pass through if the pressure inside the head is too high. As soon as enough water has drained, the valve closes again. This has been invented by engineers who want to help children like Emma."

Anton is impressed and would really like to know much more about this guard invention, but now Emma's mom parks the car outside of the hospital, and they go inside.

In the hospital. Anton has never been inside a hospital – not since he was born – and he cannot remember that far back. But it's completely different from what he had imagined. Especially when they get to the children's ward, Anton marvels at the many colors, an amazing playroom and ... this is what surprises him most: cheerful children and friendly nurses.

Emma is lying on her tummy across her bed, talking to her roommate, a boy who certainly looks very sick. Next to his bed is a wheelchair.



Emma is overjoyed to see Anton. "Anton!" she squeals. "It's great that you are here! This is Karl! He is eleven, and he also has hydrocephalus and he knows EVERYTHING."

Anton sits down on Emma's bed and is simply happy that Emma can smile again, despite her headaches. Emma's mom has remained in the corridor talking to the doctor.

"Karl had his operation yesterday, and he is feeling quite well again today,"
Emma cheerfully informs Anton. Anton thinks that Karl looks a bit pale now.



In space. "Hey, Karl, tell me about this MRI tube. I have to go there very soon ... I was always asleep before. But Mom says that I am big enough to be awake this time. What's it like when you're awake?" Emma asks.

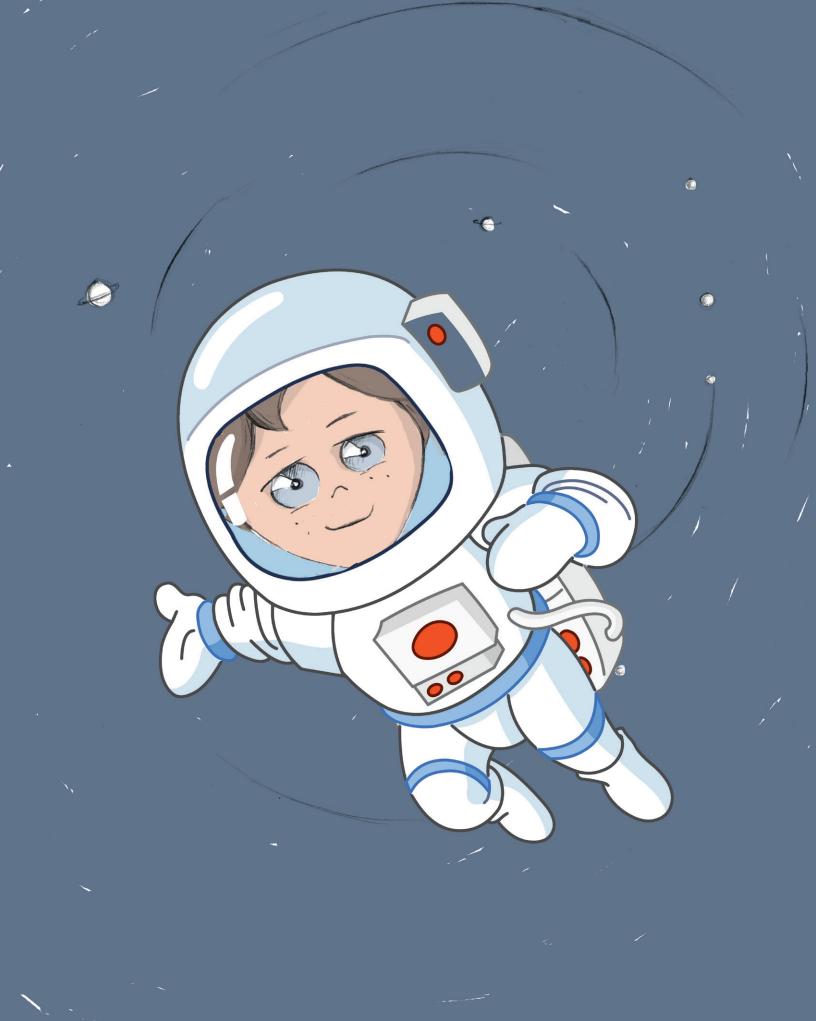
Anton can hear the effort in Emma's voice to sound calm and relaxed. Karl notices that too, but does not show it.

"Actually, there's nothing really to it, and it doesn't hurt. The noise is a bother, and you have to lie very still. I always imagine that I am in space and have to repair the outside of my space capsule – nothing there but my thoughts. I am an astronaut and must not move, not one millimeter, otherwise the mission has failed. That's what my dad had told me before my very first time in the scanner. He was there with me the whole time and sat by my feet. But now, I prefer to go there on my own. That's much cooler," Karl reports with pride.

"Your\dad was allowed to stay with you?" Emma is quite excited.

"Yes, of course! If you're shaking with fear inside the tube, they don't get a good picture," Karl laughs cheekily.

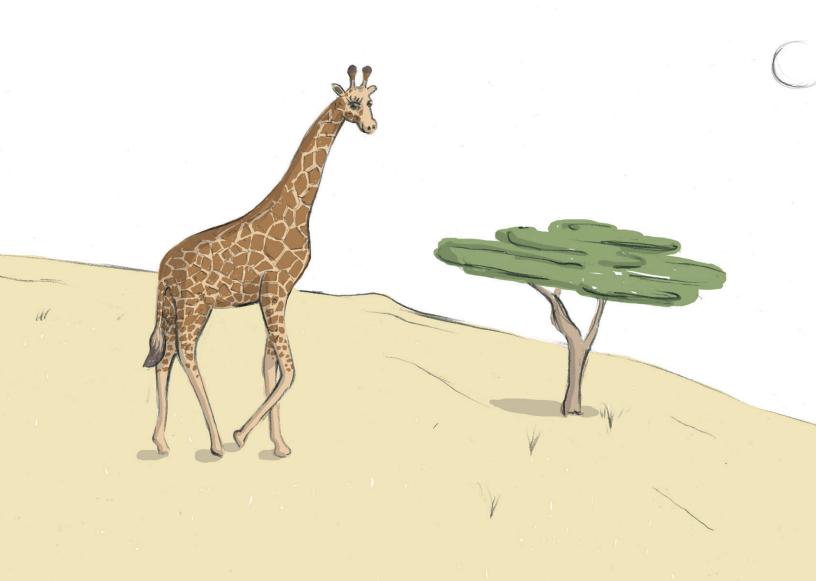
Emma is now full of hope that her mom can come with her. And if not, she will think of her own story, like Karl.



In Africa. And that is exactly how it goes: Emma's mom is with her, and while Emma is lying motionless, she is thinking about an adventurous meerkat story. Meerkats are Emma's and Anton's favorite animals.



Emma and Anton love to visit the new meerkat in the zoo. It is called "Crumbs," because it was so much smaller than the others when it was born at the zoo. Anton and Emma often pay it a visit and watch how Crumbs is growing. Sometimes they dream of kidnapping it and returning it to freedom in Africa. They often talk of this dream and laugh as they make plans. They have always made sure that Crumbs was well looked after in the zoo. In the darkness of the MRI scanner, Emma ponders what it would be like to take Crumbs home with her until they've saved the money to go to Africa.



Her garden at home is much bigger than the enclosure in the zoo. In her mind, she is planning to snatch Crumbs in the middle of the night. Anton and she would simply hide in the zoo until nightfall. They would find their way to Crumbs even in the dark. Then they would put Crumbs – and ideally all of his family – into a big box and take them home. They would need to be very careful when climbing over the zoo wall with this big box, and they would need to walk all the way home, because they would draw too much attention on the bus at night. After all, what eight-year-olds travel on the bus in the middle of the night? At home, she'd release Crumbs and his family in the very back of the garden underneath her cherry trees. There, she could meet him every day.





That would be great. While Anton wasn't allowed to stay with her during the MRI scan, Emma felt very close to him in this story. She had to tell him all about it afterwards, for sure.

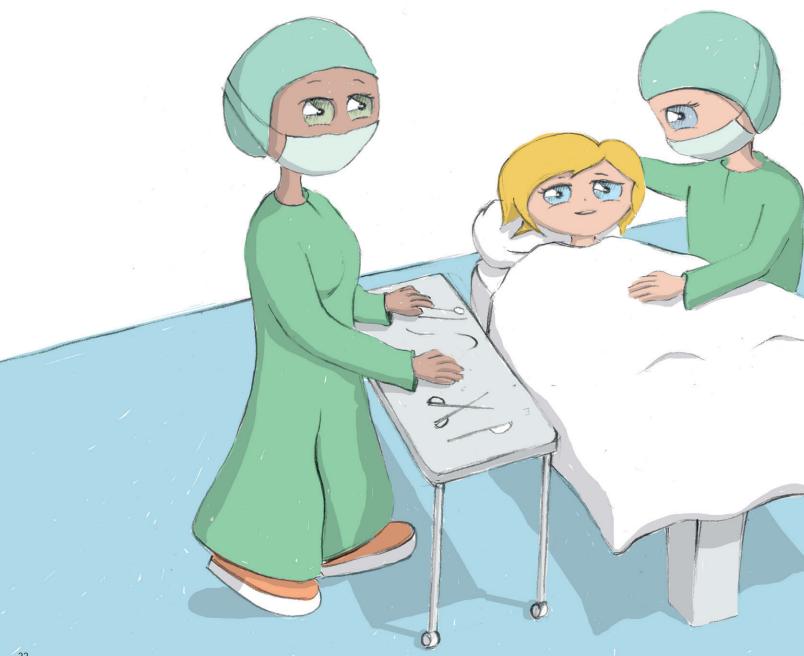
Now there was only one adventure to come: Her operation was the next morning. Emma was determined not to be afraid.

Karl is very helpful to her, because he is able to explain everything in such simple terms: "Oh, Emma, don't worry, you are going to be asleep the whole time. And when you wake up, you'll come back here and tell me everything."

Karl looks at her steadily, and Emma feels something like pride, because her new friend, Karl, is taking her so seriously. She is determined to pay particularly good attention and to remember everything ... for Karl and Anton, for mom and dad. She will work to remember every detail, and she will do it well.

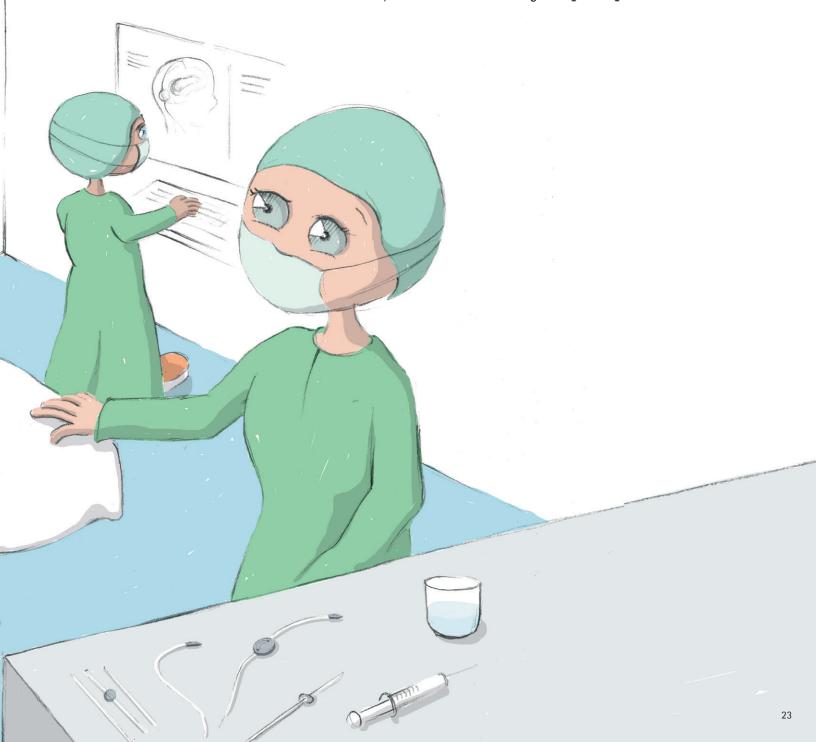
In the operating room. The next morning Emma is very calm. Mom is already at her side when she wakes up, and she accompanies her to the operating room door. From then on, Emma is on her own ... or that's what she thought.

But the door opens to an interesting bustle of many people, like in a different world. All are covered with surgical masks and head covers. Many kind eyes look at Emma, and their voices are calm and caring. Everyone here seems to have a specific task.

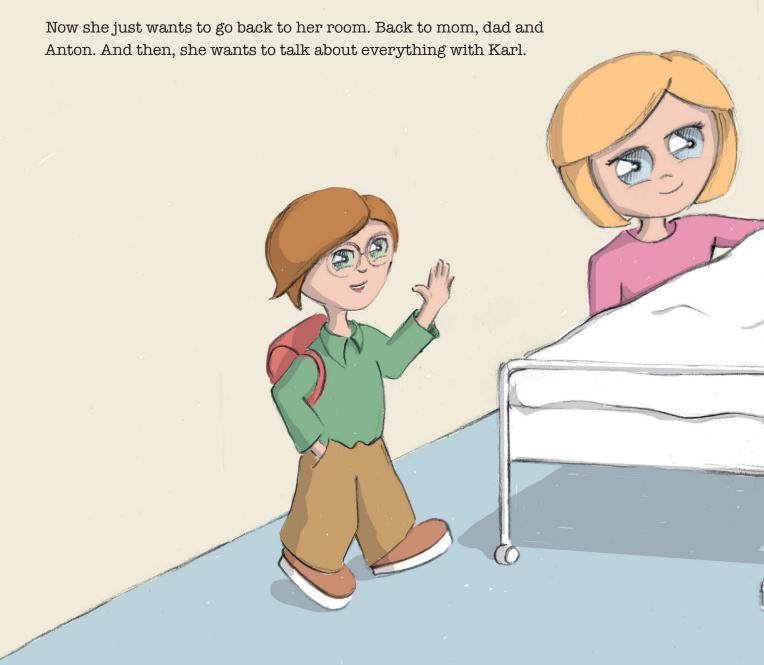


All of Emma's earlier fear has gone. She is fully occupied with observing everything and remembering it for Karl. Emma is quite disappointed when they give her the anesthetic. What a funny feeling. Everything seems to move further away and becomes even quieter. The hustle and bustle in the operating room appears like a play on TV.

Emma feels very calm and content. Almost a little bit happy. But when she thinks about how this could be, she falls into a very deep sleep.



In the recovery room. It seems that only a second has passed when Emma opens her eyes again. The operation is over. Emma is in the recovery room. A very nice nurse asks her how she feels. Emma doesn't really know what to say. Just a moment ago, in the operating room, she had felt a lot better. She feels a bit exhausted and a little bit sick, and her throat is scratchy. And then, she is flooded with relief. It is all over.



Emma doesn't have to wait long. Mom is peering around the corner, and only a little later, Emma is taken to the room with Karl.

Karl greets her like a heroine: "Emma, tell me how it went. I can't wait to hear." Karl is sitting happily at the table in his wheelchair. He is looking a lot better than yesterday and is eating his lunch.

Just when Emma is about to start her story about the strange experiences in the operating room, Anton pokes his head around the door.





"Anton, don't worry. Tomorrow I'll be looking as good as Karl is today," Emma greets him.

Anton looks at Karl and is surprised at how well he is looking today. "But why is he in a wheelchair?" he wonders. "Will Emma also need a wheelchair?" Anton decides to ask Emma's mom about that instead.

Feeling relieved and happy, he sits down on a chair between Karl and Emma. Emma tells the two boys everything that she has seen, and Karl agrees. Anton listens attentively and is very proud of his friend Emma who just seems to know no fear. When she tells him about her meerkat adventure, Anton smiles and takes a soft meerkat toy out of his backpack: "This is for you! We'll free the real Crumbs later!" Emma is beaming.

Back at school. Only a few days later, Emma is back at home. After two weeks, she is allowed to go back to school. Everyone is waiting for her with curiosity. What had happened? How did the operation go? Were you afraid? Teachers and classmates treat her with great care.

Emma is a bit frustrated. She has never been a very cautious child, and she doesn't want to start now. It's bad enough that she's not allowed to participate in sports for another four weeks. She would really like everything to be normal just like before the operation. Nobody should know about her hydrocephalus. She doesn't want to answer any more questions. She just wants to be Emma – without hydrocephalus. Why is everyone so curious about it?

Emma's mood at school is a bit down lately. Anton doesn't know how to cheer her up. And then a surprise happens.



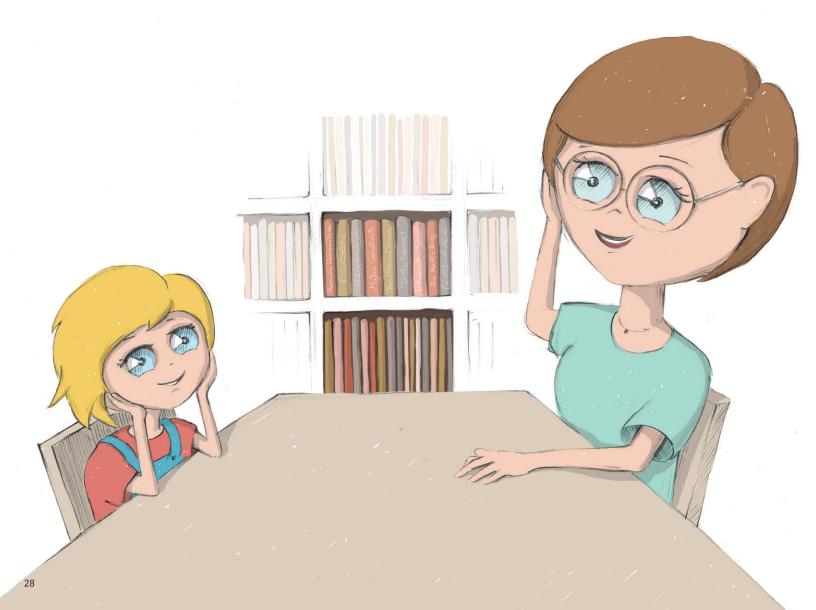
Mrs. Benner, one of the teachers, asks Emma and Anton to stay behind after class. Emma is already a bit irritated, thinking that she will have to answer more questions about her condition or operation. Anton waits eagerly.

"Emma, I think I know what has been getting on your nerves over the last few weeks," Mrs. Benner begins.

"I doubt it," Emma says to herself but keeps quiet.

"I'll let you in on a little secret that I haven't told any other pupil at this school. I also don't want to be the center of attention because I, too, have hydrocephalus."

Had Emma heard correctly? Mrs. Benner has hydrocephalus, too?!



"Yes, Emma, you heard right. A few years ago, I had a tumor in my head. The tumor is gone, but it caused hydrocephalus, and I've had a number of operations. And like you, I just want to be like everyone else: healthy. And that's what we are most of the time, but not always. And now I'll let you in on another secret: The less the people around you understand the condition, the more they talk about it."

Emma does not understand and looks at Mrs. Benner questioningly.

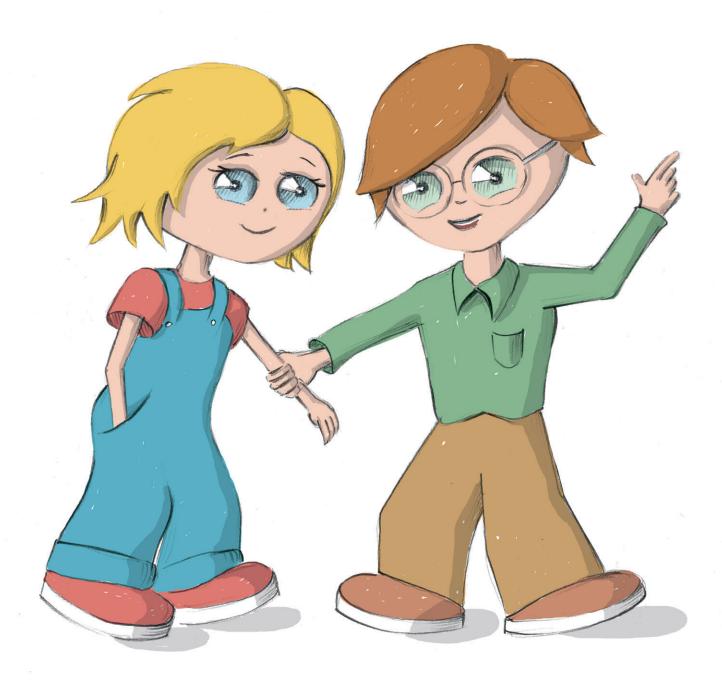
"If you explain your condition to others, then hydrocephalus is no longer your big secret. They'll understand you much better and treat you normally. That's what I have done with my colleagues here at school. I've told them exactly what hydrocephalus is, why I sometimes feel bad, what I need when I feel bad, and also that I do not want to talk about it all the time or be treated any differently."

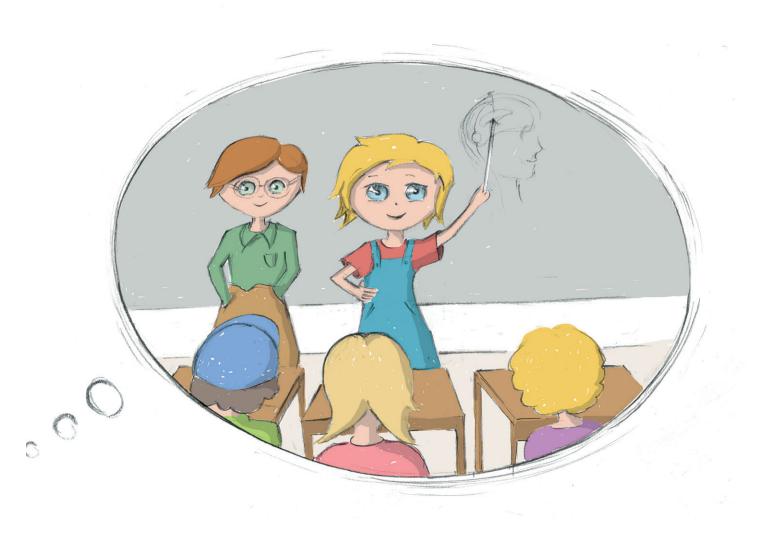
Emma is in shock and doesn't quite know what to make of it. She is still not comfortable talking about her hydrocephalus, and anyway, how should she do it? But Mrs. Benner has an answer to this question before Emma even asks.

"Consider giving a talk about hydrocephalus. Maybe do it together with Anton, and then you don't have to be alone in front of the class. Explain to the others about the condition, tell them how you feel, and say that you are still just a normal kid. What do you think about this idea?" asks Mrs. Benner.

Emma is again taken by surprise and does not quite know what to think. In truth, she'd rather not do it, but she doesn't quite have the courage to say that. So with a serious face, she nods slowly and leaves the room with Anton.

Anton really likes this idea and is already giving Emma suggestions and bubbling with ideas. "I know how we're going to do it! We're going to interview Karl. No, even better... we'll invite Karl to the talk and interview him in front of the class. Then you talk about your operations and the MRI scan."





Anton loves presentations. Now he has the opportunity to learn everything about Emma's condition, and best of all, he can do it with his best friend.

Anton's plans do indeed sound much more interesting than she had imagined. And she especially likes his idea to invite Karl. It would also mean that she would not be alone with her hydrocephalus. She would be with Anton, together in the front of the class. Having Karl there might also make this much easier. She smiles.

Anton and Emma make their way home, while talking about ideas for their hydrocephalus presentation.

After many hours of planning, which Emma actually found enjoyable, they are ready for their presentation. Karl is there too. He tells the class about another illness that he also has called spina bifida, which is why he needs the wheelchair. The three of them make a great team. Anton explains all the scientific stuff: What is hydrocephalus? How does the drain work? He uses a balloon and a cycling helmet to demonstrate what Emma's mom had told him.

Emma and Karl talk about their operations and answer all questions from the class. Did the operation hurt? Were you afraid? Can you feel the valve guard? Does it hurt when you lie on it? Can you stand on your head? Can the valve break? Why is Karl in a wheelchair?





Karl deals with these questions in such a serious way that Emma takes greater delight in answering them herself. At the end, Emma and Karl allow the others to touch their heads and feel their valve guards. The class is very impressed by these two hydrocephalus patients who do not seem sick at all.

"So I can fly, dive, climb trees, stand on my head, skip, run, dance and take horrible maths tests, with hydrocephalus or without. Just like you!" Emma proudly concludes.

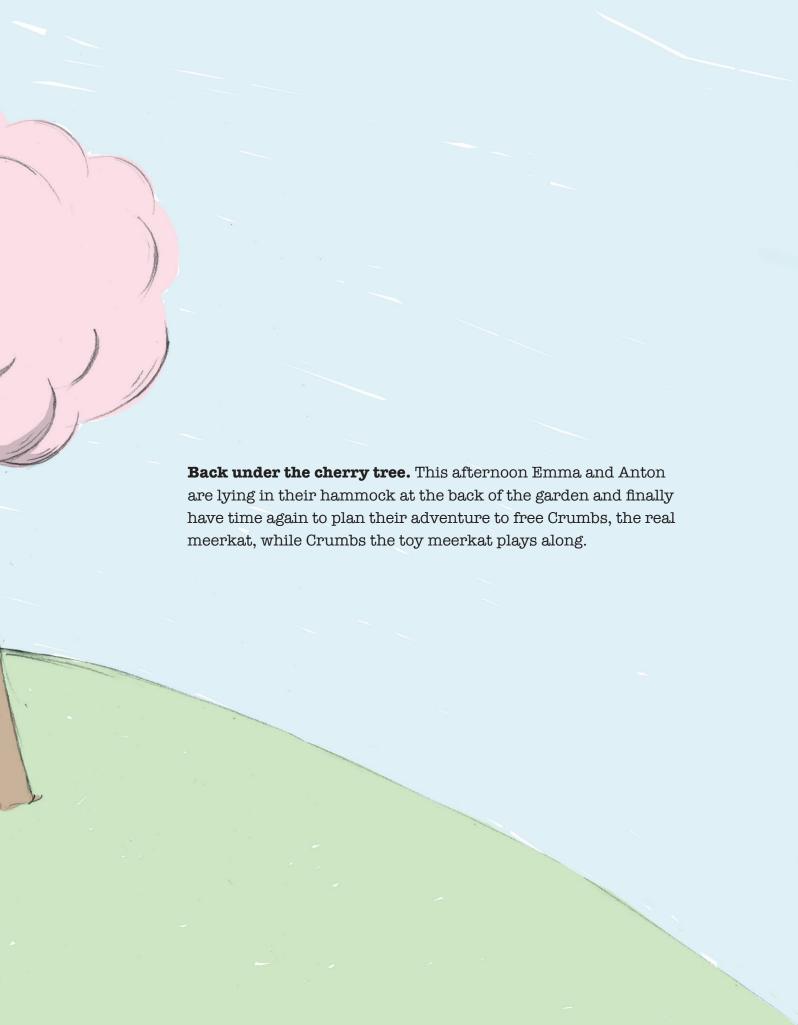
"And when I play sports or do a race, I wear a helmet, as you should too." Karl adds.

"I must say, you two are quite courageous," Anton adds quietly, but not quietly enough. Everyone heard and they all agree loudly.

Emma is happy that Anton is always with her. Very quietly, she admits to herself that she might not be as courageous if he weren't her best friend. But she does not say it out loud, not even in a whisper.

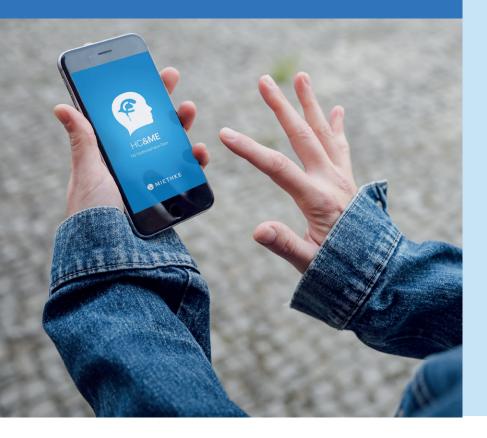
Mrs. Benner's plan had worked. Now, at school, Emma is allowed to be exactly as she is... just a normal kid.







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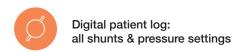


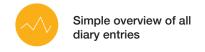




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