

Sophie's Guard



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A story by





Preface to Sophie's Guard
Priv.-Doz. Dr. med. Ulrich-W. Thomale

Hydrocephalus is a build-up of fluid in the brain; this condition can be treated with an operation. Of all surgeries performed on the brain, the operation for hydrocephalus has historically, been the most successful for treatment. Whereas prior to 1950 many of these patients either faced death or severe impairment. The main focus of treatment currently, is to make the child's development as normal as possible. However, hydrocephalus is not an illness in itself, but is caused by other pre-existing conditions. Specialists in the treatment of hydrocephalus are by now able to treat the clinical symptoms so successfully, that the development of affected children is less determined by hydrocephalus but by their respective underlying condition.

This operation permits the cerebrospinal fluid to drain into another body cavity, generally the abdomen. This drainage system is called a Shunt and includes a valve to regulate the amount of cerebrospinal fluid to be drained. It has been the close and continuous collaboration between various medical specialists and engineers, that have made it possible to design valves and shunt materials in such a way that they allow for minimal complications and have come very close to the natural drainage of cerebrospinal fluid. As humans produce approximately half a liter of cerebrospinal fluid per day, a patient's shunt has to function minute by minute, hour by hour, day by day and year by year. During a child's years of growth through adulthood, at least one further operation is most likely required for the maintenance of the shunt system. This is something that parents and children have to anticipate. It's necessary in order to prevent a malfunction of the shunt, which may result in pressure of the cerebrospinal fluid, causing damage to the brain. All those affected have to remind themselves at all times that it is not the shunt which turns a child into a patient, but that the shunt constitutes the prerequisite for the child to develop as normally as possible.

Patients with a well-treated hydrocephalus and an underlying disorder that has not caused any additional damage generally cope well with a shunt in their everyday life. However, situations of increased stress and strain may result in headaches, concentration disorders and other limitations that may also constitute a mild form of impairment. Hydrocephalus or a shunt are not generally visibly obvious. For that reason, it may be difficult for those affected to experience any consideration of their problem by those around them. For that reason, it is of utmost importance to increase awareness and exchange information about this clinical condition so that those affected can be given the appropriate support.

Physical disorders are not a disorder of people. For that reason, we should treat those affected how we would want to be treated.



Underneath the cherry tree. Sophie 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: "Sophie, when do you have to go to the hospital?" Sophie 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, Sophie 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. Sophie replies, "Afraid? Of what? It's great up here. Come up and see." "Of the hospital ..." Anton calls up.

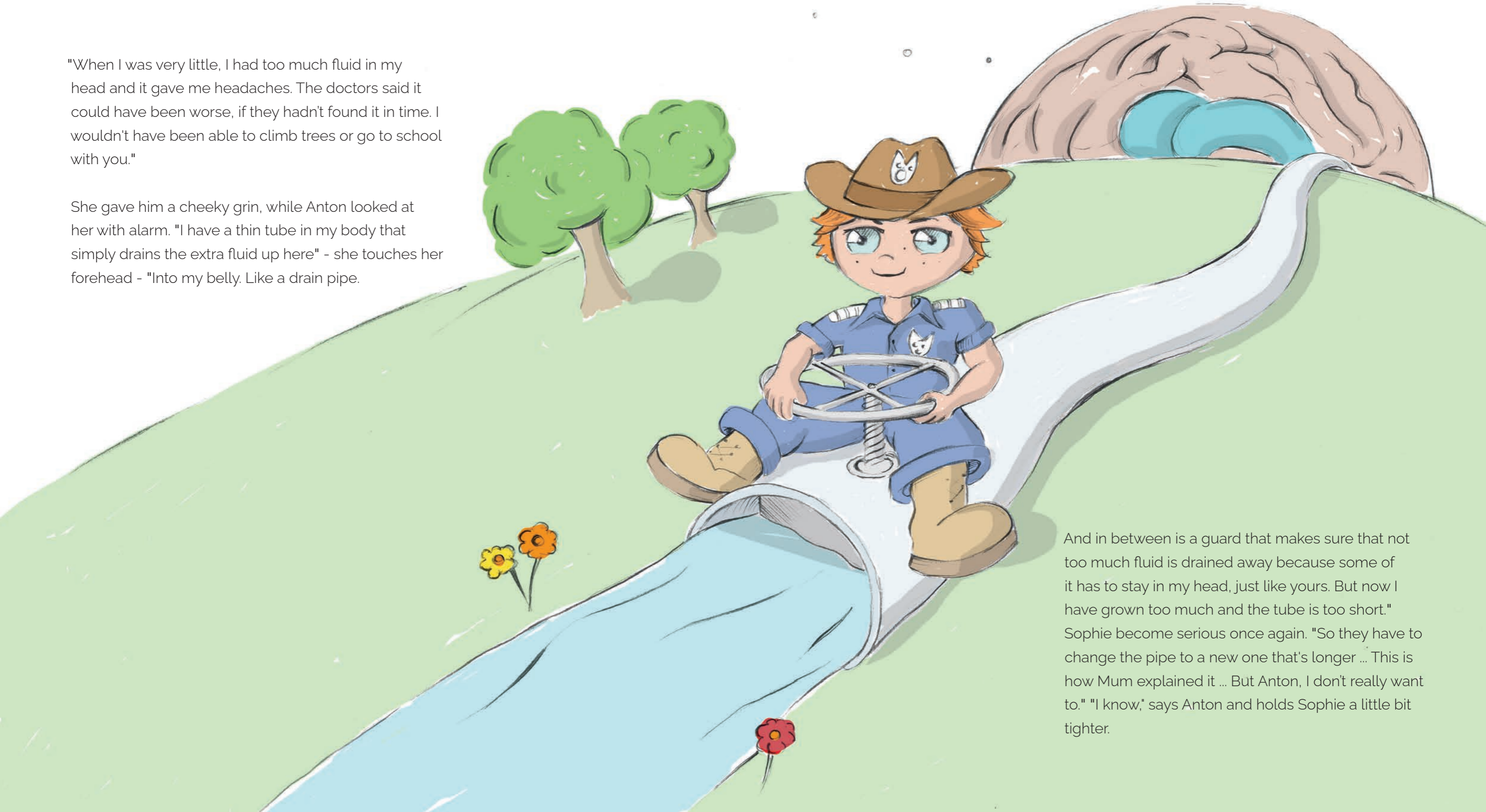
There's no reply from the cherry tree. Then Sophie climbs down slowly and lets herself drop onto the grass next to Anton. She is now very serious. "Yes." she says after a while.

Anton looks at Sophie 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 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 Sophie 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 gave him a cheeky grin, while Anton looked 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." Sophie become serious once again. "So they have to change the pipe to a new one that's longer ... This is how Mum explained it ... But Anton, I don't really want to." "I know," says Anton and holds Sophie a little bit tighter.

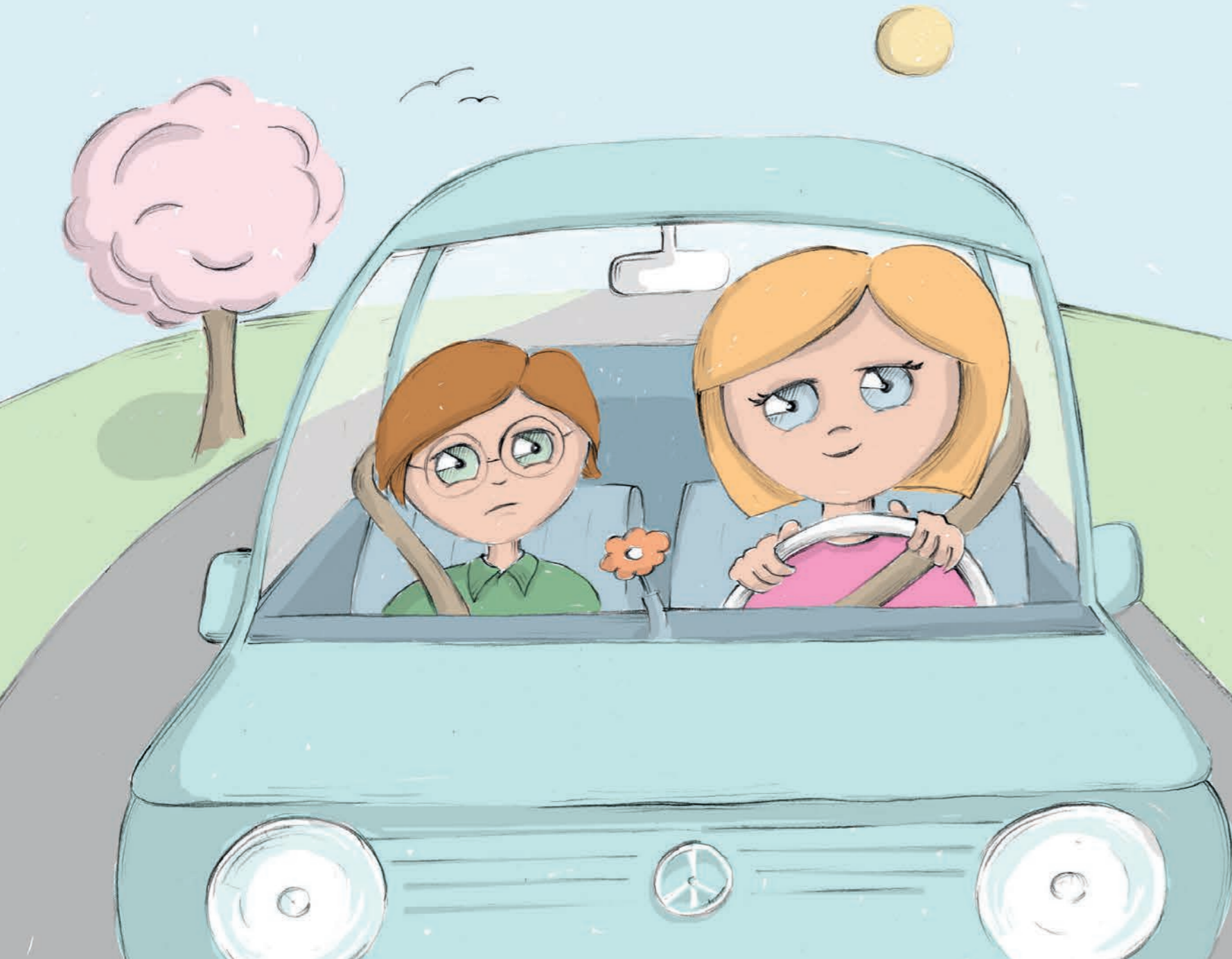
At school. The next morning on the way to school, Sophie behaves as she normally does: happily and cheerful as she jumps from the pavement to the road and back. She only makes a face when she remembers the math test. "But don't worry, Anton. That's not until the afternoon!" However, just before the lunch break, Sophie is looking a bit concerned. "Sophie, what's the matter?" Anton whispers. "I feel dizzy, and my headaches are really bad," she said in a small voice that sounded so unfamiliar to Anton. He alerts their teacher immediately. Not long after, Sophie is picked up from school by her parents. Anton stays behind at school, quite worried and a little bit jealous that Sophie was now missing the math test. After what seemed like a very long day at school without Sophie, he hurried to her house to pay her a visit.



As on most days, the front door is unlocked, and Anton is just about to run into her room when her mum shouts "Anton, Sophie's not upstairs! We had to take her to 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?" Sophie's mum asks.

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

In the car, he sums up his courage to ask for more details "Does Sophie have to have her operation sooner?" "Yes," her mum replies.



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

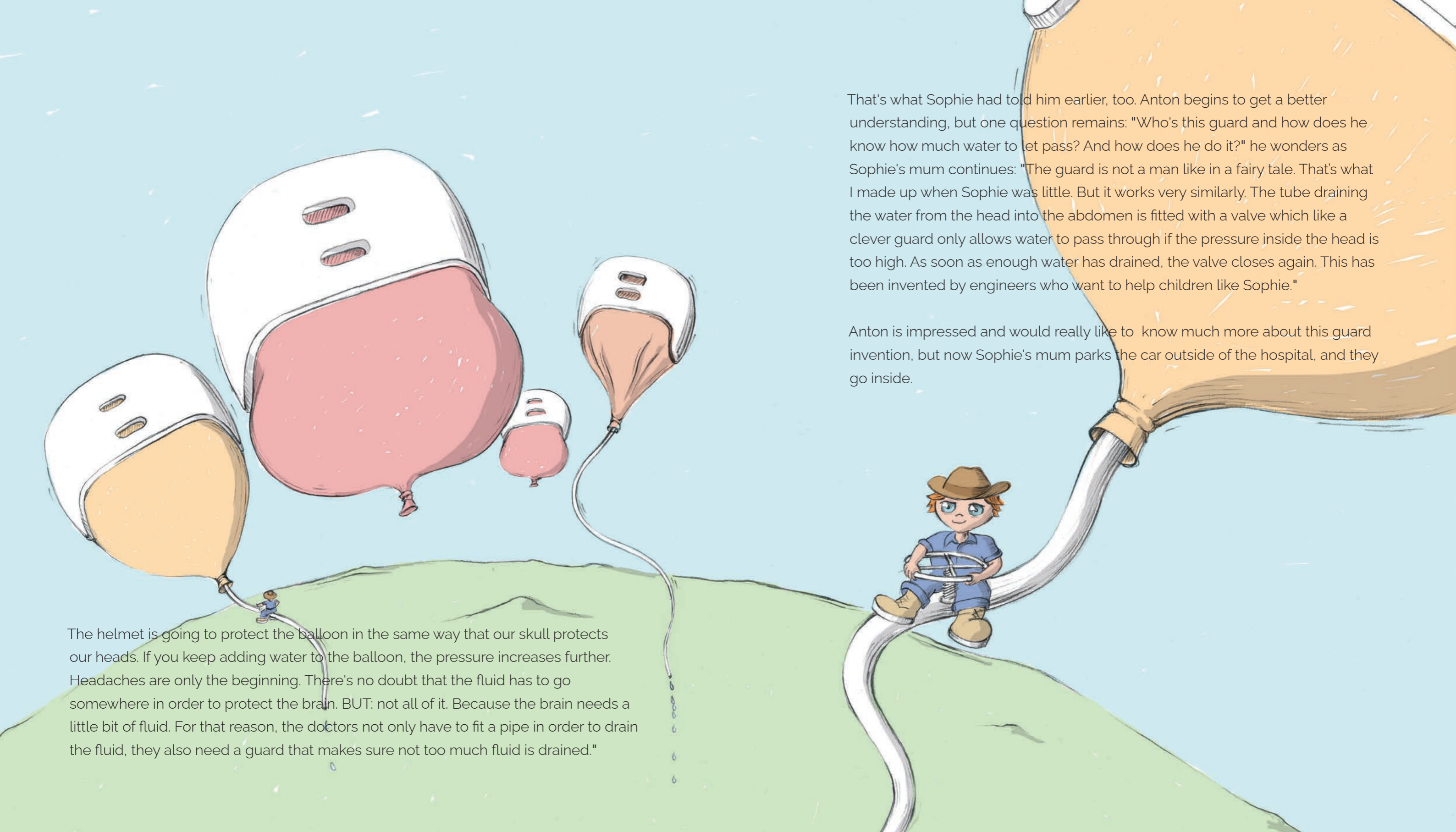
Sophie's mum smiles: "How much do you know about Sophie's pipe?" she asks.

"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 replied.

"That's right. 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 Sophie's mum.

Anton thinks briefly. "I think we need it for everything. Isn't the brain our control center? I think as important as the heart, only in a different way." Sophie'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 Sophie'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, they also need a guard that makes sure not too much fluid is drained."

That's what Sophie had told him earlier, too. Anton begins to get a better understanding, but one question remains: "Who's this guard and how does he know how much water to let pass? And how does he do it?" he wonders as Sophie's mum continues: "The guard is not a man like in a fairy tale. That's what I made up when Sophie 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 Sophie."

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

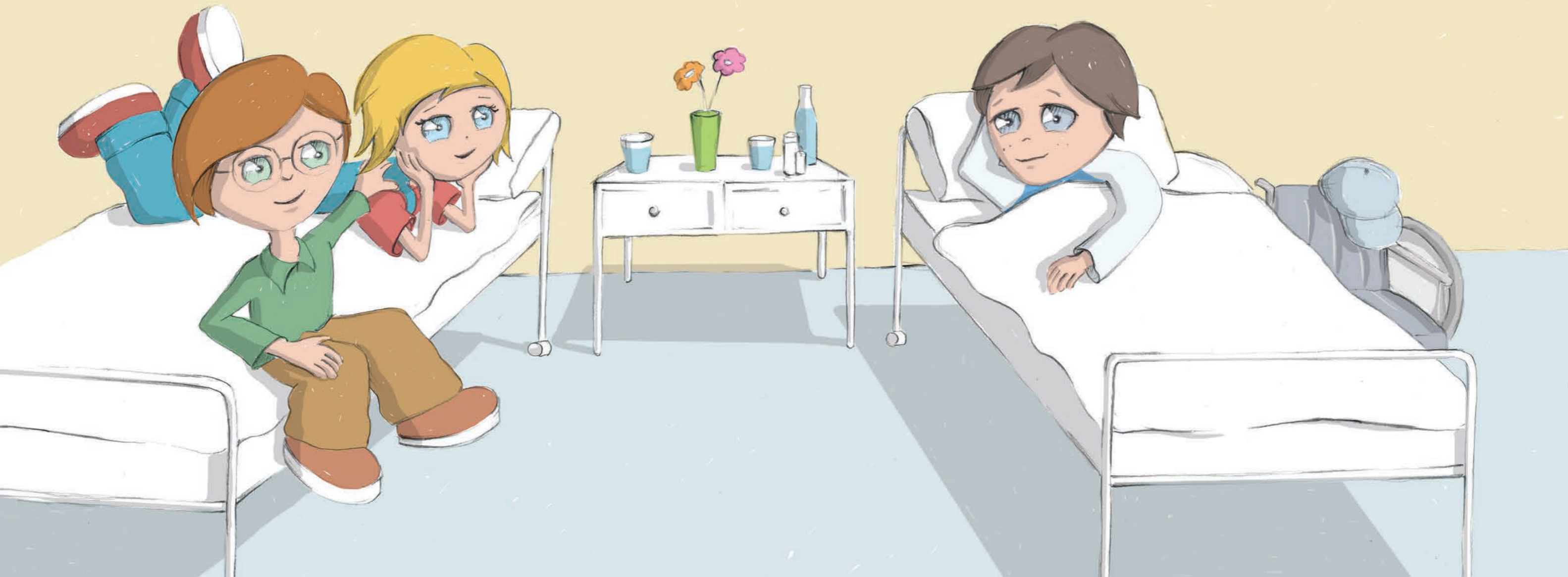
In hospital. Anton has never been inside a hospital - not since he was born, and he cannot remember that far back. But it's completely different from what he had imagined. Especially when they get to the children's ward, Anton marvels at the many colors, an amazing playroom and ... this is what surprises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

Sophie 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.

Sophie 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 Sophie's bed and is simply happy that Sophie can smile again - despite her headaches. Sophie's mum has remained in the corridor and talks to the doctor: "Karl had his operation yesterday, and he is feeling quite well again today," Sophie 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 Mum says that I am big enough to be awake this time. What's it like when you're awake?" Anton can hear the effort in Sophie'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. Just like in Star Wars. Do you know Star Wars?" he asks. "I am a Jedi knight and must not move, not one millimetre, 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.

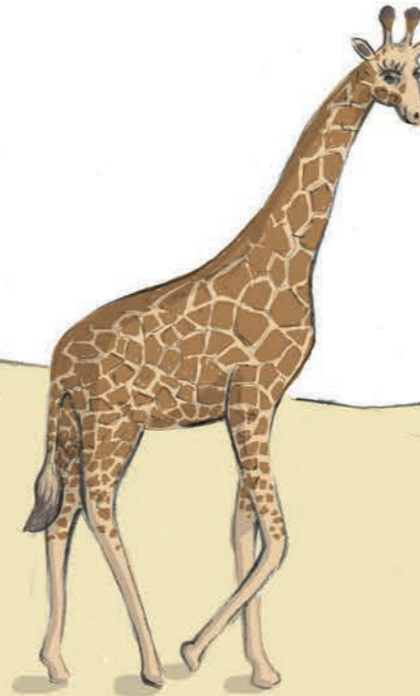
"Your dad was allowed to stay with you? Sophie is quite excited.

"Yes, of course! If you're shaking with fear inside the tube, they don't get a good picture." Karl laughs cheekily, and Sophie is full of hope that her mum can come with her. And if not, she will think of her own star story, like Karl's.

Sophie does not know Star Wars or Jedi knights, but she has an idea.



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



Sophie and Anton have even become joint sponsors for 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 Sophie 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, Sophie ponders what it would be like to take Crumbs home with her until they've saved the money to go to Africa.



Her garden 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 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, he



felt very close to her in this story. She had to tell him all about it afterwards for sure.

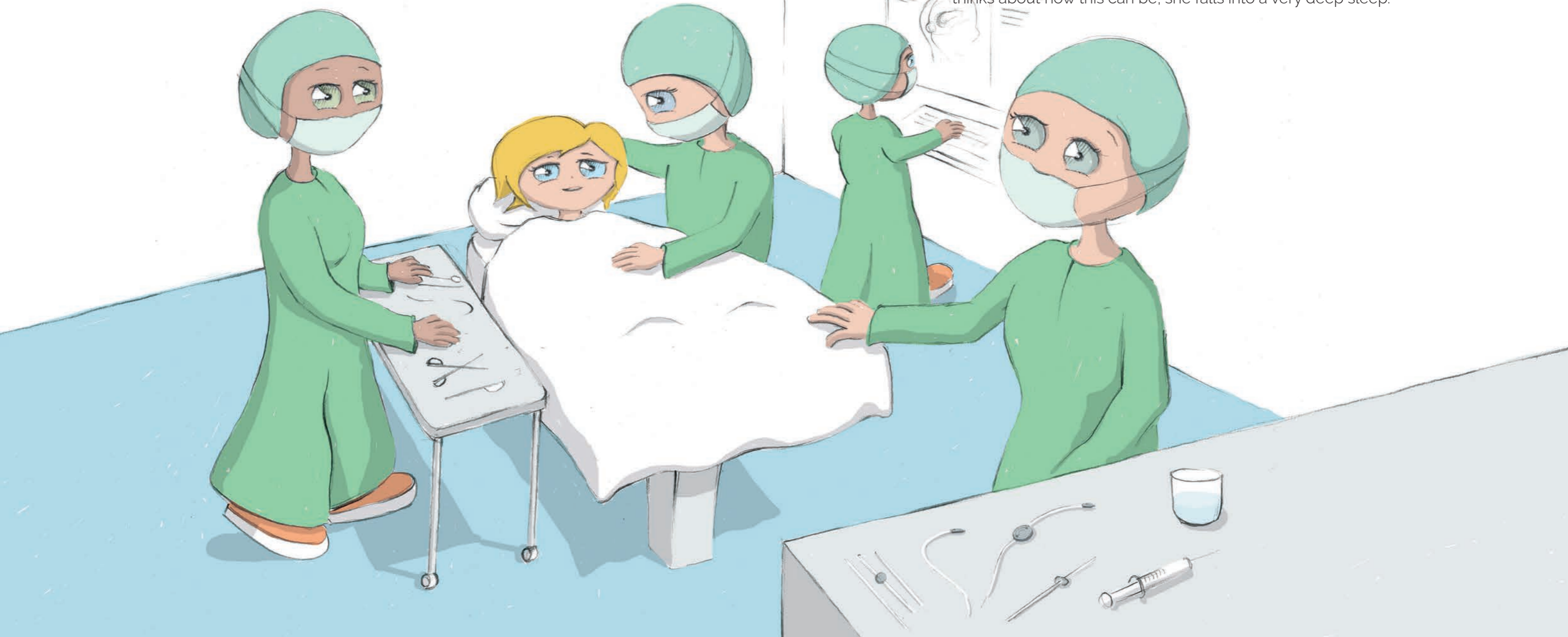
In theatre. Now there was only one adventure to come: her operation was the next morning. Sophie was determined not to be afraid. Karl is very helpful to her, because he is able to explain everything in such simple terms: "Oh, Sophie, don't worry, you are going to be asleep the whole time. And when you wake up, you'll come back here and tell me everything." Karl looks at her steadily, and Sophie 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 mum and dad. She will work to remember every detail and she will do it well.

The next morning Sophie is very calm. Mum is already at her side when she wakes up, and she accompanies her to the operating room door. From then on Sophie is on her own ... or that's what she thought. But the door opened to an interesting bustle of many people, like in a different world. All are covered with surgical masks and head covers. Many nice eyes look at Sophie, and their



voices are calm and caring. Everyone here seems to have a specific task. All of Sophie's earlier fear has gone. She is fully occupied with observing everything and remembering it for Karl. Sophie is quite disappointed when they give her the anaesthetic. 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.

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



In the recovery room. It seems that only a second has passed when Sophie opens her eyes again. The operation is over. Sophie is in the recovery room. A very nice nurse asks her how she feels. Sophie 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, a little bit sick, and her throat is scratchy. And then she is flooded with relief. It is all over.

Now she just wants to be back to her room. Back to mum, dad and Anton. And then she wants to talk about everything with Karl. Sophie doesn't have to wait long. Mum is peering around the

corner, and only a little later, Sophie is taken to the room with Karl. Karl greets her like a hero: "Sophie, 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 Sophie 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," Sophie 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 Sophie also need a wheelchair? Anton decides to ask Sophie's mum about that instead. Feeling relieved and happy, he sits down on a chair between Karl and Sophie. Sophie tells the two boys everything that she has seen, and Karl agrees. Anton listens attentively and is very proud of his friend Sophie 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!" Sophie is beaming.

Back at school. Only a few days later, Sophie is back at home, and 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 pupils treat her with great care. Sophie 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 Sophie - without Hydrocephalus. Why is everyone so curious about it? Sophie's mood at school is a bit down lately. Anton doesn't know how to cheer her up. And then a surprise happens.

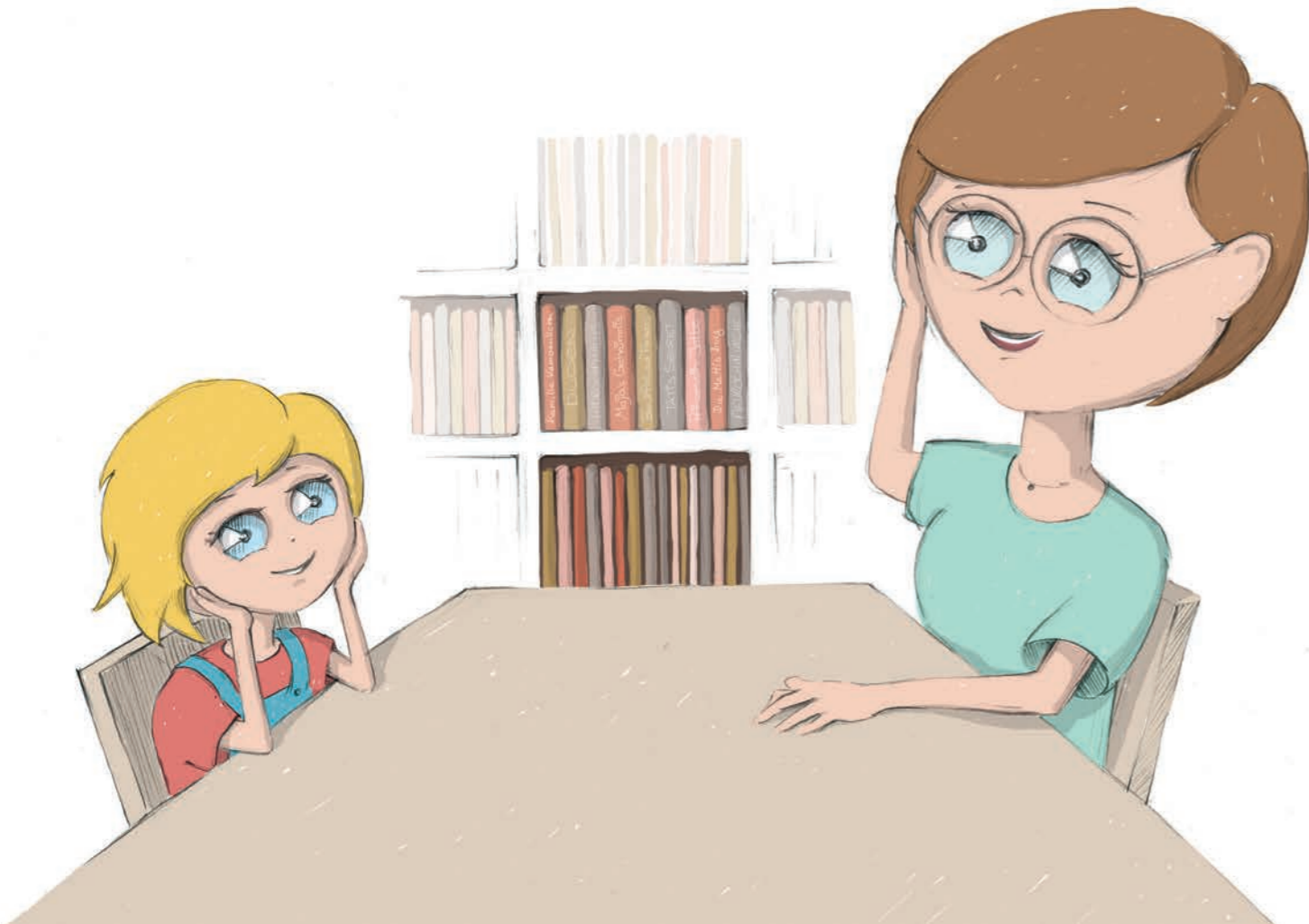


Mrs Benner, one of the teachers, asks Sophie and Anton to stay behind after class. Sophie is already a bit irritated, thinking that she will have to answer more questions about her condition or operation. Anton waits eagerly.

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

"I doubt it," Sophie 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 also have Hydrocephalus."

Had she heard correctly? Mrs Benner has Hydrocephalus, too?



"Yes, Sophie, 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." Sophie does not understand and looks at Mrs Benner questioningly.

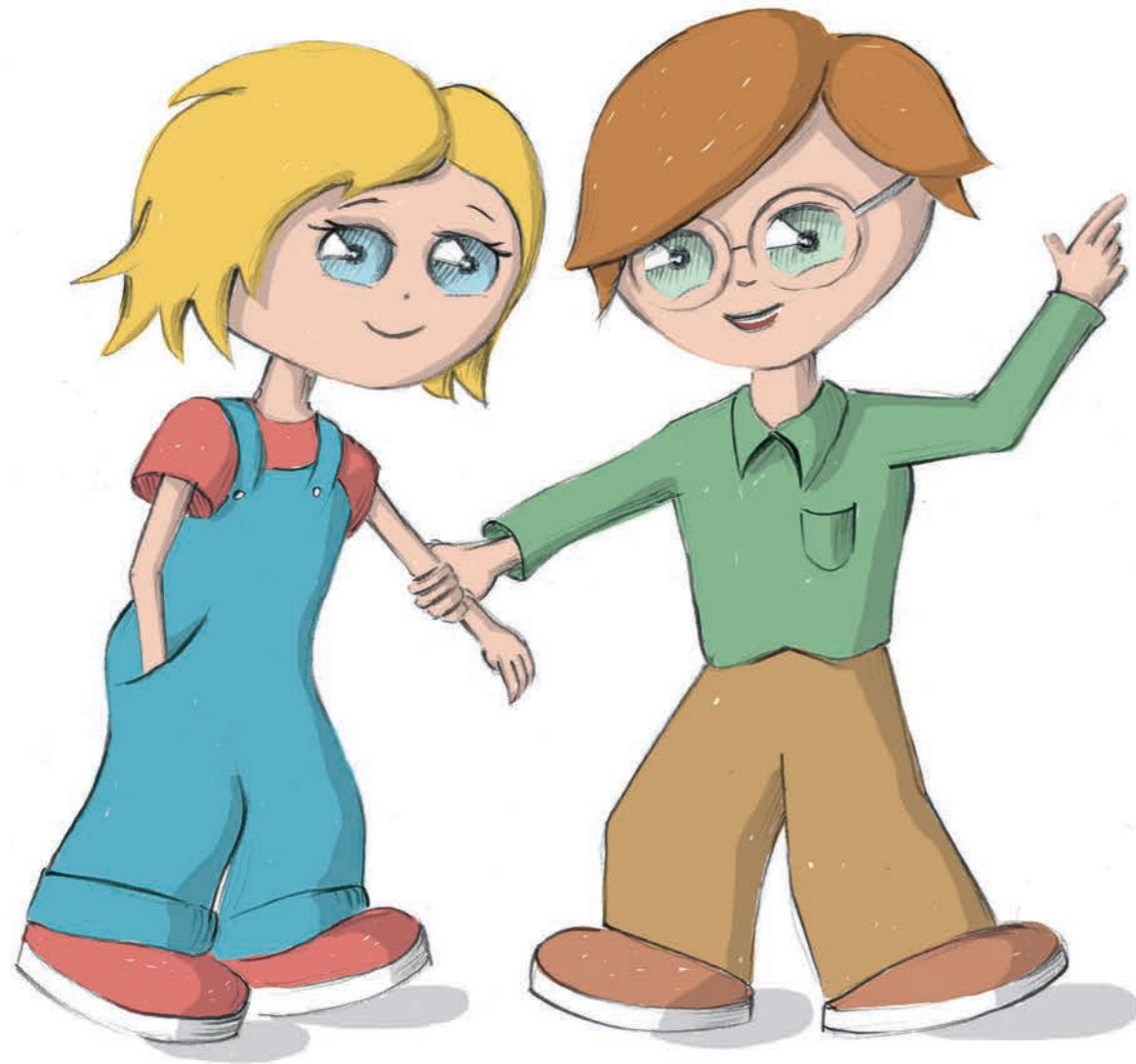
"If you explain your condition to others then Hydrocephalus is no longer your big secret, they'll understand you much better and treat you normally. That's what I have done with my colleagues here at school. I've told them exactly what Hydrocephalus is, why I sometimes feel bad, what I need when I feel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

Sophie 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 Sophie even asked.

"Consider giving a talk about Hydrocephalus. Maybe do it together with Anton, then you don't have to be alone in front of the class. Explain to the other kids about the condition, tell them how you feel, and that you are still just a normal kid. What do you think about this idea?" asks Mrs Benner. Sophie 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 Sophie 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. And my dad will call the people who have invented your valve guard. Maybe we can get this tube and guard from them and can show the others what's inside your body and we'll invite your doctor to the class ...!"

Anton loves presentations, and now he has the opportunity to learn everything about Sophie's condition, and best of all, he can do it with his 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 Sophie make their way home, while talking about ideas for their Hydrocephalus presentation.

After many hours of planning, which Sophie actually found enjoyable, they were ready for their presentation. Anton had actually managed to get a real implant from the makers of the "valve guard". Karl was also there and he shared another illness that he has with the class called Spina Bifida, which is why he needs the wheelchair. Sadly Sophie's doctor was busy that morning, due to other operations. But even without the doctor, the three of them make a great team. Anton explains all the scientific stuff: What is Hydrocephalus? How does the drain work? He has also brought a balloon and a cycling helmet to demonstrate what Sophie's mum had told him.

Sophie and Karl talked about their operations and answered 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 Sophie takes greater delight in answering them herself. At the end, Sophie 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!" Sophie 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. Sophie 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 has worked. At school, Sophie was allowed to be as she was, just a normal kid.



Back under the cherry tree. This afternoon Sophie and Anton are lying in their hammock at the back of the garden and finally have time again to plan their adventure to liberate Crumbs, the real Meerkat, while Crumbs the toy Meerkat plays along.

MEDICAL DEVICE CONSULTANT

If you have any questions about the valve guards, their inventors or their function, give us a call or write us an e-mail. If you live in the Potsdam area, feel free to stop by with your parents. Our colleagues are happy to show you how the valve guards are made and function. We are looking forward to your visit. Give us a call, so we can arrange a time to meet.

If you as parents have any additional questions, you can contact our Medical Device Consultants at any time: +49 331 620 83-0 // info@miethke.com // www.miethke.com



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If you have any additional questions about Hydrocephalus, please contact your Neurosurgeon or local Hydrocephalus organization.

HC&ME App My Hydrocephalus Diary

The HC&ME App is a digital hydrocephalus diary that allows you to comprehensively document your life with hydrocephalus and everyday life with a shunt.



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