Benjamin's mother is unwell. She is constantly forgetting or losing things and suddenly she has trouble walking, suffers blurred vision and is no longer able to dress herself. Benjamin's mother has Multiple Sclerosis (MS) and Benjamin is learning for the first time what it means when she suffers a relapse.

Benjamin begins to come to terms with his mother's illness. His relatives and friends help him in the process. He understands that he is able to help, but that he must not neglect himself in doing so. He learns the importance of talking about his problems and accepting help from others. He soon knows enough to be able to hold a talk in class about his mum's condition. The most important thing he has learned: his mum will not die from the illness.

This book tells us, in a gentle and discreet manner, the story of a mother and her son. It answers our questions and invites those affected to talk about their concerns.
Stefanie Lazai

Benjamin

My Mum is Special

Illustrated by Stephan Pohl
Foreword

Benjamin provides a view of Multiple Sclerosis through the eyes of a child struggling to understand his mother’s mysterious and sometimes frightening illness. This is a beautiful tale of coping, compassion, and caring that should be shared between all parents with MS and their children.

This book does not shy away from the harsh realities of MS - incontinence, tremors, limb weakness, and the inherent unpredictability of the disease. Each of these issues is articulated in an honest, child-friendly manner that will provide the cornerstone for discussion between parent and child. The book will also be an invaluable asset to children who themselves have MS, providing their parents with a tool to aid in discussions about the disease and its manifestations.

With the help of not only his mother, but also his grandparents, his teacher, and especially his mother’s best friend, Benjamin learns about the MS disease process. Through the empowerment of knowledge, Benjamin slowly lets go of much of his fear. As so eloquently stated by Hermione Granger in Harry Potter and the Chamber of Secrets, “Fear of the name only increases fear of the object itself.” This is a powerful reminder not to underestimate a child’s intuitive ability to know when something is wrong, nor to underestimate their ability to learn, and in so doing, accept. The ties between Benjamin and his mother are strengthened as they deal with MS together, forging new bonds of understanding.

In Benjamin, the author highlights the enormous contributions made by family and friends, and the positive experiences gained by those individuals as they see how important they are in the lives of Benjamin and his mother. Simply, by eating spaghetti with their left hands, they remind us of the importance of humour and support.

Benjamin will be welcomed by all persons touched by MS.

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Me
My name is Benjamin and I’m eight years old. I live with my Mum in a big city. I have quite a lot of friends. Luke is my best friend. And then there is Grandad and Grandma, Mum’s parents. Mr Murphy, my teacher, is a really great guy too.
I’d love to have a dog, but Mum doesn’t like pets. At least we have fish – over fifty!
Our flat has a big balcony and I’m the one to take care of the plants there. I grow strawberries, radishes, tomatoes and herbs – and lots of flowers.

Mum
Mum is 35 years old and her name is Julia. She works for the radio. Sometimes she has to travel for her job. But not too often. Mum has to read a lot of books and stuff and she often goes to the theatre. Mum is constantly looking for things. “Where is this now?” she is always asking. Sometimes she even forgets what she is looking for.

Kate
Kate and Mum have been friends all their lives. They went to school together a long time ago. Kate is actually a camera operator, but because it was so difficult to get work she went back to college two years ago. She is now studying economics. Kate has to read a lot and to learn things I am not at all interested in. But Kate is extremely good at maths. She often has more spare time than Mum has. So we spend a lot of time outside having fun together.
Daddy
Dad is older than Mum. He works pretty far away from us. But he comes to visit every month and whenever we can, we spend the holidays together. In autumn, Kate and I are flying to see him. Mum is totally scared of flying. She even turns green whenever we go to collect Dad from the airport.
He works in a hospital and is a heart doctor. Dad and I get along really well. Dad is a great football fan. He doesn’t know much about basketball, but I’m teaching him.
He likes to sleep in when he stays with us and he always has holes in his socks. When I grow up I want to be as tall as Dad, so that I can score a lot of goals in basketball.

Luke
Luke and I went to kindergarten together. Luke is like a brother to me. “An older brother,” he says proudly, although he’s not even a year older than me! Luke’s parents are stricter than mine, but other than that they are okay.
Luke comes over to my house quite often.

Mr Murphy
Mr Murphy is my form teacher. He teaches Sports and English.
He is a brilliant basketball-player.
He has this clever way of teaching us how to read: he reads really exciting stories to us and at the point when you can hardly take it anymore because it’s so exciting, he suddenly stops. “And now one of you must continue,” he says with a naughty grin.
In his class we don’t have to remain seated the whole time. Anything is allowed, as long as it doesn’t bother the other children. Well, almost anything.
Normal or abnormal

Now you know quite a lot about my life. But sometimes things are a little different from other families. Mr Murphy gave me the idea to talk about it and Kate helped me a lot.

Five years ago my Mum got ill. It was a long time until they found out what was wrong with her. Her illness is called Multiple Sclerosis. Because it is such a long and difficult name you can just say MS. It's not easy to explain what it is, because no one really knows where it comes from. Mum's got to inject herself with medication every other day.

Mum’s relapse

Recently, I understood for the first time what happens when Mum has a relapse. Kate picked me up from school. She was really sad. Mum should have been away the whole week for her work with the radio. But Mum was now coming home that evening, earlier than planned, by plane.

I was very excited about that of course but Kate looked very sad. “We're going to pick your Mum up from the airport because she's unwell,” she explained to me. Kate was so serious; I immediately knew something was wrong. I felt scared. We then went for an ice-cream. In my family we always discuss the important and serious things at mealtimes.
Kate and I have ice-cream

“You know, Benjamin,” Kate said “your Mum’s got an illness that will never go away. She’s had it for five years now, but you can only notice it when certain things happen. And now they have happened whilst she has been away working. Suddenly your Mum couldn’t manage to get dressed by herself and she found it difficult to walk.”

That was really hard to imagine. I was scared Mum would be paralysed. But luckily that doesn’t have anything to do with it. Mum was also unable to see very well. Everything was double, almost as if she were cross-eyed. And she was extremely tired too and sad because the relapse had come on so suddenly. She always hopes of course that they won’t happen at all.

I was so upset and confused that I didn’t really enjoy my ice-cream. I started crying. Kate gave me a hug.

“It might take a while until your Mum is well again,” she said. “But things will hopefully get back to normal, like they were before.”

Kate told me that MS causes inflammation in Mum’s brain and this was making her ill. Inflammation is what happens when you get a really bad cut on your finger and it starts to hurt with swelling and redness around it. Of course after a little time this inflammation goes away and you can be left with a little scar on you finger.

“With MS something like this happens in the brain,” said Kate “and, like the cut on your finger, with time the inflammation goes away – leaving your Mum almost as right as rain. It’s just that a relapse leaves these little scars in the brain and these scars don’t go away.” This is why a relapse does sometimes leave signs. Kate says, there are some souvenirs you can’t get rid of.

“Because of the MS, your Mum is often tired and forgetful,” Kate went on. “She’s got to go and see her doctor to find out how he can help her. We want her to be well soon, don’t we?”

Then we bought some ice-cream and flowers for Mum and went to the airport.
Mum arrives
Mum, of course, had turned green from the flight. This was normal, but what I’d never seen before were the crutches. Mum had crutches to lean on because her walking was slow and shaky. I had a kind of strange feeling in my tummy watching her and I tried hard not to cry. Mum always says that crying is good, but I didn’t want to make her sad.

And of course, I was very glad she was back. We hugged each other, and Mum said: "I only need the crutches for now – later we can use them for fishing." That’s my Mum.

Mum and I were both sitting in the back of the car. She looked at me for a long time and suddenly asked: "Do you notice that I’m seeing everything double? It looks as if you have a brother."

But it didn’t bother her because two of me would make her twice as happy! Then she said that she felt much better already, because we were together again and nobody needed to worry.

"Besides," she said "I even managed to fly!"
At home
We live in a big flat in the attic of an old converted house. We love the flat, but it doesn’t have a lift. It’s never bothered me. Only now that Mum was unwell was it a problem. It took her a long time to walk up the stairs. Four sets of stairs! Kate and I went ahead and let Mum take her time. Mum wanted to take a shower. Kate had to help her to get undressed, while I set the dinner-table. I wasn’t hungry but I needed something to do. Then I tried walking with Mum’s crutches. I imagined what it was like. They were quite practical, these crutches. Only hers was a little too big for me. But I got an idea what they were good for. When you feel shaky on your legs it helps to be able to lean on them. It makes you feel safer. Also you don’t need to depend on someone else to help you to walk. I can imagine that it feels uncomfortable to always have to ask others to help you. It is always better to be able to do things by yourself.

When Mum came out of the shower she wanted to lie down and listen to some music. I helped her to put the CD into the player and push the button. "I’m happy that you are willing to do all this for me," Mum said. "You’re a fine young man! But you must also do things you want to do, and not just take care of me. Promise me, Benjamin!"
Kate made baby-sized sandwiches for all of us. I thought that was funny because that’s what I used to eat before I learned how to use a knife and fork properly.
Kate tucks me in
After dinner Mum fell asleep on the sofa and Kate tucked me into bed and read me a story. After that we talked about Mum's illness.
"It is never certain when these relapses are going to come or even if they are going to come at all." Kate explained to me. "They can affect different parts of the body and then these parts don't work as they usually do. It depends on the areas of the brain that are affected."
The brain controls everything we do. With MS the information, or the orders that the brain gives, work as usual, but much more slowly. But you can try and train the body so that you can do everything almost as well as you could before. That's the way it was with Mum. But unfortunately there are some people with MS who don't recover as well and who feel worse than Mum.
Kate said: "The best thing to do right now, is to carry on as best we can and not to worry about all the things that might happen."
That's what she does and that's what Mum and Dad do too. And then she told me the most important thing: "Your Mum won't die. At some point of course she will, just like the rest of us, but not right now."
The next morning
The next morning I woke up really early. I felt confused and thought that maybe I had just dreamt all that about Mum.
I ran into Mum’s bedroom. She was awake and listening to the radio. I wanted to crawl under her blanket just like I often did. But Mum was holding tightly onto her blanket and said: “It’s better not to crawl inside – it’s flooded.” I didn’t know what she meant.
“Well, I have wet my bed.” she said. “I noticed too late that I had to pee and couldn’t make it to the bathroom in time.” Kate came in and asked me, “Do you still have your potty and nappies?” We all laughed, even Mum.

Kate helped Mum to take a shower and afterwards Mum asked if she could come to snuggle up with me in my bed.
“Of course I won’t wet it!” she promised.
Mum explained that she was unable to feel things properly. Her hands felt numb, especially the left one, and her legs felt very heavy.
“Could you fetch a knitting-needle?” she asked me. She used it to carefully draw letters on my tummy, my arms and my legs. It tickled and only twice did it prick a little. I then did the same to her. Mum closed her eyes and had to tell me where on her body she was feeling the needle and what I was writing. I had to press really hard to make Mum feel something. It went better with the right side of her body. I thought I should stroke Mum on the right side of her body as usual and on the left side I would just stroke a little harder.

Mum had an appointment to see her neurologist that morning. Neurologists are doctors who examine your nerves. But now I was late for school. Luke and his dad were already waiting for me downstairs.
Walking to school with Luke
Somehow Luke and his dad already knew.
“How are you?” they asked.
My tummy started to feel strange again and I realised that I didn’t feel like talking about it. Maybe I didn’t really know how I was doing. It was all so confusing. It was great that Mum was back, but it was sad because she wasn’t feeling well. Anyway, I definitely didn’t want to say anything about Mum wetting her bed. Maybe at some point I would tell Luke, but not his dad.
“Everything’s fine,” I said. “Mum even travelled by plane yesterday.”
Luckily by that time we had already arrived at school. We had Mr Murphy and I was glad I could think about something else or at least I could try. And I hoped Mr Murphy would read us one of his great stories.

Grandad comes to collect us
After school Grandad was waiting outside to pick Luke and me up. Luke asked whether he could come over to my place, but somehow that felt like too much today. Luke was a bit cross. But then Grandad suggested: “I’ll pick you up again tomorrow and take you to the swimming pool.” Kate had taken Mum to the doctor’s and Grandma was at our house. She was making spaghetti, but again, I wasn’t hungry. Grandad and I didn’t go into the kitchen. We sat on the balcony and talked about Mum.
Grandad and me on the balcony

Grandad asked if I wanted to stay at their house for a few days. Although I always love staying with them, I rather wanted to be with Mum right now. “Your Mum was always one to get pretty upset when she got ill,” Grandad said. “It was always the case. She really doesn’t like to be handled with kid gloves.”

I could understand that. But still, Mum would have to rest more than before and take it easy. Grandad said it would be good if Mum could work less than she used to. It would be difficult because of the money, but he was sure we would find a way.

He also said: “Your Mum is still young, but as she gets older her body may no longer recover as easily after each relapse. But you should always trust and hope for the best.”

And I should never keep my sorrow and worries and fears to myself, I should talk about them. If I kept them to myself I might become poorly too.
Everyone has dinner together
I was so glad to see Grandma, and that she had made us spaghetti. While Grandad and I were setting the table Kate came in. They were already back from the doctor’s. Mum was still working her way up the stairs. I ran down the staircase to meet her. I almost knocked her over with my hug, but neither of us cared.
We all had dinner together and it was almost like before. Well, almost. Mum made a bit of a mess around her plate and got really annoyed when Kate offered to feed her. The thing about spaghetti is that you have to wrap it around your fork and that was difficult for Mum.

“We could all use our left hand for eating, except for Kate who is left-handed anyway. She has to eat with her right hand,” I suggested. That way, we all made quite a mess and Mum didn’t feel so bad anymore. It was fun as well. It makes you realise how annoying it is when you want to do something and you’re not able to, even though you know how to do it.
After dinner
After dinner Mum and I lay down on the couch, but everybody else went out for a walk. I put my favourite 'Winnie the Pooh' tape in the cassette recorder and we listened to it together. At some stage I must have fallen asleep. When I woke up, Mum asked whether I wanted to go with her to the doctor's the next day. She said, “but of course you would have to miss school.” “We have sports tomorrow, but it’s a good idea though,” I said. Mum called Mr Murphy that evening and explained why I wouldn’t be at school. During the examination they would put Mum inside a tube and take pictures of her head.

Mum’s head is examined
In the morning Grandad came to collect me and Mum. We went to see the doctor who had examined Mum before. Mum didn’t talk a lot. She just said that it was uncomfortable to be inside the tube, almost as uncomfortable as flying. Mum didn’t exactly turn green, but she did go rather pale. I had taken some books along because Mum had said that the examination would take a while. But I didn’t get around to reading. Mum asked the doctor if I could watch the examination. “Yes, of course,” the doctor said. “Look, this is the tube your Mum will to be put into.” It looked a little bit like a rocket and it was pretty narrow inside. Then the doctor’s assistant came and helped Mum take off her trousers and her sweater.
The doctor, Grandad and I went into a different room. There were a lot of computers and monitors in that room. Through a window I could watch Mum being put inside the tube and my tummy felt funny again. The tube machine makes a lot of noise, that’s why Mum was wearing headphones and listening to music.

On one of the monitors I saw something that they said was Mum’s brain. Actually I didn’t recognise anything. The machine takes pictures of Mum’s brain from different angles and shows them on the screen. The doctor and the assistant were saying words I didn’t understand. Another assistant injected a fluid into Mum’s arm.

"Don’t worry Benjamin," the doctor said, "this is a contrast medium. We use it to see which inflammations inside your Mum’s head are new and which are old."

When the examination was over the doctor asked me if I wanted to know anything else, but because I was still feeling funny in my stomach I just shook my head.

"You know, the old inflammations in your Mum’s head are properly healed, but there are also a few new ones and these are giving her a hard time," the doctor explained.

The pictures would be sent to Mum’s neurologist, and she and Mum would decide together what to do to make Mum feel better soon.

After the examination

After the examination we drove home. Grandad and I played Ludo until Grandma called us to dinner. We had pizza and none of us had trouble eating. After lunch Grandad and I went to school to pick Luke up. Then the three of us went to the swimming pool. It was a pity that Mum didn’t come along, but she preferred to listen to music and take a nap.
At the swimming pool with Luke
When we got to the pool, Luke and I jumped straight into the water. Granddad pumped up the lilo and brought it over to us. The water was great. When Luke and I were sitting on the lilo he wanted to know, of course, why I hadn’t been at school that day.

“Oh ... you know ... I had a tummy-ache,” I quipped. Luke looked annoyed and I decided that it was better to jump back into the water. Back in the water my tummy suddenly really started to hurt. I swam back to the air bed and grabbed hold of the edge.

Luke was still somewhat cross. “I know your Mum is sick! Why don’t you talk to me about it? I’m your friend! And I also like your Mum a lot!” I started to cry. Luke pulled me up onto the air bed and said: “Really, I didn’t want to make you cry. But look, I’m your friend and I want to help you and your Mum!”

I told Luke about the examination. And I told him about everything else. “Mum can’t walk properly, her hands aren’t doing what they are supposed to and she’s wet her bed.” Luckily, Luke didn’t laugh when I said that about the bed. “I’d like to visit your Mum!” he said. I thought that was a good idea. Later on we played football together, and I was glad that I had told Luke everything.
A stork on one leg
When I got back home, Mum was in a fairly good mood. She and Kate were sitting in front of the computer and Mum was dictating a letter to Kate. Mum told me she thought she’d passed the peak of her relapse already. “I don’t see everything in double anymore and that’s a good sign.” And then she stood up and showed that she was able to stand on her right leg without holding on to something. “As soon as I am able to do that with my left leg everything will be fine again. But that will take a while and until then Kate will have to type for me.” I really knew she was feeling better when she reminded me to do my homework. Besides, she wanted me to read a story to her that evening – I couldn’t think of anything I would rather do.

Yet another morning
Mum and I were snuggled up in bed. When it was time to get up, Mum tried to stand first on her right and then on her left leg. She tottered quite a bit but on the right leg it worked. On the left leg unfortunately it didn’t, and Mum fell to the side. I really felt quite scared. “That wasn’t one of my best performances,” Mum said, “but I hope you will come and watch again some other time.” I had to laugh and was glad that Mum could still joke. Then we had breakfast and Kate took me to school.
Mr Murphy's idea

During the lunch break Mr Murphy came up to me and wanted to talk. He wanted to know how Mum was doing. I got that strange feeling in my stomach again, but it wasn't as bad as before.

“Benjamin,” Mr Murphy asked, “would you be up to talking about your Mum's illness in front of the class? Of course, I'll help you. Together we can give a class on MS and other diseases and talk about what it means when somebody in the family gets sick. Did you know Christine's dad is deaf?”

I didn't know that. Mr Murphy had already talked to Christine and she wanted to show us how she talks in sign language with her dad. I thought it a bit strange to tell everyone in class about Mum's problems.

Mr Murphy said: “Take your time and think about it. You don’t have to if you don’t feel like it. And I will certainly not tell any of your classmates about it without asking you first.”
The report
I had thought about Mr Murphy's idea. Luke thought it was a good thing and Mum said: "Okay! But I don't want to come to school as a living example." I didn't know how and what to tell my classmates about MS, so I decided to ask Kate for help. She can think up a solution to any problem. Kate agreed right away to help me.
Kate and I bought an ice-cream and then went to the library.
She read everything she could find about MS while I looked at some old comics.
It took her quite a long time to finish. I helped her with the photocopying.
We copied pictures that looked similar to the ones I had seen at Mum's examination.
At home Kate made a drink and the two of us sat in my room preparing the report that I was going to present in class. Kate explained to me everything she had learned about MS. It was really very interesting.

“Our brain is a distributing centre for everything we do,” Kate explained, “and also everything we think, feel, see and hear. Our brain sends and receives signals through the nerves we have throughout our body. Usually the signal travels very quickly along the nerves. However, with MS, the covering of the nerves is damaged and this slows the signals down. If everything in our brain, our distributing centre, is ok, it is as if someone turns on a light switch and the bulb goes on. When you have an MS relapse the electric wire to the bulb becomes damaged. The light might flicker or doesn’t work at all.”
I think I somehow understand Mum’s disease now.
At school
I'm still quite excited. Today I presented my report on MS in front of the class. It was very hard work. Some children were talking; others asked questions that I could only roughly answer. But it was a great lesson. Mr Murphy praised me for my report.

Mum and I
After school I ran home. "Mum," I said. "I'm as proud of you as I am of myself!"
Mum smiled at me and put two cinema tickets on the table. That was great. But the very best thing was her performance before the cinema. She stood on her left leg and didn't keel over.
Can you spot 10 differences?

What is Benjamin going to play with?

If you had your own aardvark, what colour would it be?

Do you still know ... 
... how many fish Benjamin has?
... who is lefthanded?
... why Benjamin had a day off school?
... what MS stands for?
... what the crutches will be used for, when Mum doesn’t need them any more?
... where Benjamin lives?
... who sits on Benjamin’s rooftop?
The author:

Stefanie Lazai was born on January 11th, 1967 in Osnabrück, Germany. She works as a radio director and lives with her son in Berlin.

The illustrator:

Stephan Pohl was born in 1977 in Berlin, Germany. Ever since he could hold a pen, he has enjoyed drawing. He is studying Communications Design at the University of Applied Science in Berlin. “Benjamin” is his first children's book to be published.