

MARKUS HÄNNI

Actually, I should be
dead by now. Learning
to live from someone who
sees every day as a gift.





Markus Hänni in front of the north face of the Eiger, in his homeland, the Bernese Oberland (Switzerland).

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In gratitude to the best parents in the world.

And for B.

*“I’m 29 and I’m supposed to be dead by now. But you
don’t always have to do that, what others say.”*

Markus Hänni

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Prolog

I knew where the ampoules were that paralyzed the heart muscle and promised a gentle death.

For a while, I sneaked around the place and looked around. No one was to be seen. So, I grabbed a pack, stuck it in the pocket of my bathrobe and disappeared into my room.

It was time to go.

The sad story of the twin brother Markus Hänni from Toffen near Bern in Switzerland should end here once and for all.

No one had to cry for me. Everyone should be glad it was finally over. Soon they would know that it was better that way, because I had no perspective.

In a will, saved under “My last will and testament”, I had written down how the funeral was to take place and who was to receive my computer. I had already given my tickets for the football match between Holland and Romania during the European Championship to my twin brother Thomas.

Off to paradise, where I don't need antibiotics anymore, no cystic fibrosis therapy in the morning and in the evening. Sometimes, years pass before we understand how precious moments can be.

See you soon!

I already had a needle in the vein of my left arm; an access for medication. I pulled the remedy into a syringe, opened the small top on the cannula, and put the syringe into it. I had observed how this worked a thousand times before.

It had become dark outside. A strong wind was blowing. They had predicted bad weather for the next few days. I couldn't care less.

The ward was quiet, nobody was walking back and forth in the corridor. I had my peace and quiet.

Live and breathe!

I took a deep breath, then I squeezed the clear fluid into my veins. The effect started in no time. Immediately, I felt an enormous burning sensation on my skin and my tongue felt paralyzed. Before my eyes, the world first began to blur, then a dense, dry fog covered it. Finally, she disappeared completely.

After that, there was silence.

The fact that I am still alive today, in spite of the actually failsafe method, must have something to do with a great guardian angel. Theoretically, my dose would have been enough to send three people to heaven without stopping.

But I woke up and lived.

And if I'm honest, I wasn't sad at all.

What on earth happened to me? I've always been so tough. However, I was at wits' end. The fact that I needed all my strength just to sit upright in bed did not seem to me to be a life worth living. The fact that I was dependent on the help of others was so humiliating to me that it was no longer bearable.

No hour is more unvarnished, more intimate and more final than the hour of death.

But she hadn't come yet.

Somebody objected to me leaving the stage ...

My name is Markus Hänni and I have cystic fibrosis.

Anyone who enters this term into Google will automatically find the word "life expectancy".

With over 100,000 hits. There it says at the top of a medical information page: "Patients who became ill in the

90s live to be 40 to 45 years old; before that 30 years.

My diagnosis was in the '80s. I'm 29 now.

I could choke. But I don't want to.

For life is far too beautiful ...

Winter dreams in Valbella

Maybe it sounds a little kitschy and may look like postcard romance. But what am I supposed to do? When I look out of the window here, I see rugged Swiss mountains in front of the blue sky. A thick layer of fresh snow lies on the fir trees. A little further down, on the frozen lake, children in wraps jump back and forth and have a snowball fight and couples in love stomp their rounds, holding hands. Here in the warm room, I hear the fire crackling in the fireplace and the smell of a vegetable gratin, baked with strong Swiss cheese, pulls into my nose. I couldn't be better. I feel well and strong. It's been a good day."

That wasn't always the case when I was a child with my parents and drove up from Bern to Valbella. Once, I felt so bad that after only two hours, father had to pack everything up again and bring me to the hospital.

"This time it will be close, dear Hänni family, this time it will be very close", the doctors said not seldom. "Hopefully, he'll make it."

Should I remind myself of all that? I don't think I can help it.

But just today, on this glorious winter's day? Yes, just today! I feel that every beautiful day in my life is a gift. Especially since I don't know how many more there will be. If it's up to me, plenty more. That's what I'm fighting for. On the other hand, you shouldn't always rely on earthly happiness.

That's why I'm starting to write my story today. Right here and now. It's quite possible that a cough might

interrupt me from time to time, a stabbing pain in the lungs, but that's part of it. It is part of me.

My cough reminds me that I am basically like everyone else – like all 29-year-olds all over the world. But there is a difference: With me, the clock may tick a bit faster. Which is not insignificant to my story. Therefore, a day, a winter day like this, is a doubly beautiful day for me.

I want to enjoy, laugh and hear others laugh. My greatest hobby is acting. I like to take on the funny roles because I think that there is nothing more beautiful in the world than to make other people laugh. Because the one you make laugh has been made to think. Laughing without thinking doesn't work.

Sometimes, mostly on Sunday, I also perform a small play or some other artistic contribution in the ICF (International Christian Fellowship) in Bern, a Protestant faith church. They deal with many topics that are also dealt with in this book: life, the things between heaven and earth, the explainable and the incomprehensible, happiness, the future.

Fortunately for me, I have my family. I have wonderful parents who have accompanied me on my journey in a way that is unprecedented. Thank you very much for that, right at the beginning. (Mama, your vegetable gratin smells sensational!)

I have two brothers, one of whom is my twin brother, and one sister. Our dog, a two-year-old Appenzeller-Labrador hybrid, is called Tina.

Maybe you're wondering if I'm married or single. That's quite justified for a 29-year-old. Well, I'm a little in love right now.

Probably a little much. She doesn't know yet.

That some of my genes have a crucial defect, she knows that. However, she probably has no idea that my hormones release a lot of colorful, excited butterflies in my stomach.

That doesn't make things any easier. Although, I think I'll

be smarter on that point when I finish this book. Maybe then I'll tell you how it turned out, depending on how it turns out. In my thoughts a secret dedication resonates which inspires me to type these lines as personally as possible.



Outside, in front of our house in Valbella in the Graubündner mountains, between the Parpaner-Rothorn on one side and the Piz Scalottas on the other side of the high valley, a few cross-country skiers go on the cross-country trail. If they were to ski further and further in this direction, they would perhaps eventually cross the Lenzhorn to Davos in a few hours, where the economic forum is currently being prepared. I'm at 1,500 meters above sea level in a cabin in the mountains where the ice crystals compete for a place on the windows and the people in the next village speak a language, Rhaeto-Romanic, which is difficult to understand.

Yet I feel like I'm on a global stage. Last summer, I put up a signpost on the road with the kilometer distances to destinations all over the world in case all the cross-country skiers and hikers are looking for new destinations. To St. Peter's Square in Rome it is 587 kilometers, to Las Vegas 9,285, to Santiago de Chile 11,937, to Chur 16. Athletes need to be able to plan how long they will be on the road.

Maybe I'll go there sometime, into the wide world, outside of Europe. It would all be a dream.

On the other hand, I can't take the strength out of my body too much. Anyone who has already asked God for an audience several times, albeit involuntarily, also learns to appreciate life. Here and now with mother's ingenious vegetable gratin with melted cheese.

For me, being with my family here in our house, which

we call Valcasa, means both recovery and inspiration at the same time. Yesterday, for example, I got up and wrote a short play. I like the seclusion up here, the change of scenery. That's why I come here two or three times a year for a week.

We used to be here during school holidays. Today, the family meets completely, sometimes only my brothers and I, sometimes my parents with the family of my sister. I think it's a gift. For me, family is not an outdated, old-fashioned or even stuffy term, but rather a community that has helped me survive. And perhaps will continue to do so in the future.

After I've recovered here for a few days in solitude and re-grounded myself, I have to go back down to the city. The silence up here is something beautiful. At some point, however, it can also have a constricting effect. Sometimes I feel that way after a successful project. Shortly before Christmas, I was involved in an important musical in Bern, which was not only written by me, but in which I also played a leading role. The whole team met often, we rehearsed, got things done, prepared intensively for the two performances.

But then, suddenly, one day before Christmas Eve, it was all over. The last curtain had fallen, the applause had faded, the last hymns of praise had faded. Everything was quiet around me and I was alone. But I am a person who doesn't like to be alone unless I have something that needs to be done, something creative for example. Otherwise, I always need people around me. My family, my friends, people to whom I can and may say something.

When everything was finished, I fell into a void. A feeling I also know from my hospital stays: when the visitor said goodbye, when the door slammed and I could only hear the footsteps in the corridor that went away.

The short play I wrote yesterday is about Ruth, a book in