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My Sweet Life

by Grit Ott
Translation: Steven Lange

Preface

Grit Ott's life story is a precious gift. She has found within herself the courage and the strength to portray her entire personal development in a captivating sequence of recorded Muments and episodes. Her story encompasses so much: We experience the difficult struggle – fought largely on her own – to come to terms with diabetes, leading to eventual "active acceptance" of a chronic condition, to use a fashionable phrase; We also witness how medical science hesitantly but surely moves toward a rational, effective and human approach to the diabetic patient; We are challenged by thorough-going honesty as we accompany Grit Ott through the various stages of her journey to independence and freedom as a diabetic and as a human being – making us aware how the two are inseparable as she takes an increasingly active role in self-help groups.

As an unsparingly open account of the author's life, her growth to adulthood and maturity as a person, as a woman and as a diabetic, this autobiography has special significance for all who have dealings with diabetes. Each of us, whatever our role, will be helped by Grit Ott's valuable portrayal of the different phases of her life and her confrontation with diabetes. I would like to personally thank Grit Ott for this book.

Prof. Dr. med. Michael Berger
(Düsseldorf)

An Unforgettable Birthday (Chapter 1)

February 20th, 1956 – today I am eight! Thick snowflakes are floating past the window, inviting children to rush out for a round of sledding, but I feel so tired and weak that I would rather stay in bed. It has been like this for about two months, really ever since the morning I woke up with a swollen jaw and a bad earache. The doctor said it was the mumps and told me to be good and stay in bed.

Looking back on it, this has not been such a bad time for me. The pain soon got better and every day I can have one of my favourite desserts, either chocolate pudding with chopped bananas or wheat pudding with cherries in syrup. Besides, Mum has been at my bedside very often, to play with me or read me an exciting story. Often, before going to sleep, she even hugs me and holds me close for a long time, and I wish she would never stop.

Mostly, Mum doesn't have much time for me because she is an artist and has to make up new songs on the piano so we can have enough to eat. She sits there for hours writing a big bunch of notes on piles of paper and can't be disturbed at all, otherwise she loses her train of thought and I get scolded. Sometimes she gives a concert. That's when I have to put on these disgusting knit stockings and my blue velvet dress with the white collar, and then I get to come along. Of course I'm a bit proud when the people clap real loud at the end, but the best thing about a concert is that we always have enough money to buy big servings of cake for weeks afterwards. Both of us love sweets more than anything, and since Mum doesn't have much time to cook anyway, we just have some delicious cake from the bakery for lunch, and then I always get to drink lemon pop to go with it.

I often go home with my friend Ursula after school. Her mother never has time either, because she works for old Humprecht in the vegetable shop to pay for the hi-fi console faster. But she comes home for two hours every afternoon and cooks for the whole family. Then she only has to warm up the meal when her husband comes home from work.

When I visit Ursula, I'm usually allowed to eat with them. Sometimes I'm pretty jealous because her mother can cook so well, but Ursula says she's jealous of me because at recess I usually take a delicious snack out of my lunch box while she has to chew on a dry old sandwich. And she also thinks that's the reason my Mum didn't want to marry my Dad, because she can't cook at all and was afraid he would always be mad at her for it. Ursula might be right, but I would just love to have a really nice Daddy anyway.

Frau Pfeiffer always urges me to help myself to more, spider-thin as I am, and thinks I ought to be a hefty little girl with all the sweets I'm fed at home. After all, my mother is not exactly underweight. But these dreadful mumps must be hollowing me out. It's true, Mum says that often, too. Most of all, she wonders how I've been able to pour so much pop and water down my throat lately. She gets upset because I have to go to the toilet so much during the night. I always wake her when I go because I don't have a separate room.

At school I get teased because I need to go to the bathroom so much. The teacher says it's about time I started going in the breaks, but I have to go then, too ... A while back I even wet my panties a little, but thank heavens nobody noticed.

As much as I want to stay in bed, I can't put off getting up any longer, otherwise I won't make it to the toilet in time. In the hall I almost bump into Mum. She wrinkles her nose and tells me I ought to give my teeth a good brushing and wash myself properly, there's been such a strange smell around here recently. I don't think it's nice of her to say that on my birthday. Or has she forgotten my birthday altogether? I'm really afraid she has.

But the pot of hot water on the stove is already a good sign. On most days we wash ourselves with cold water in the kitchen, which I really hate – I don't care much for water, anyway. But today

I lather and scrub myself all over and scour my teeth with my toothbrush (although the toothpaste tastes absolutely horrible again). I put on my dress for special occasions with the dumb scratchy stockings all by myself, just so Mum will be sure to notice that today is a special day. That takes me a long time because I feel so tired and my arms and legs are so heavy.

But as I peep into the living room door the first thing I discover is a butter cream cake in the middle of our round table. It has a marzipan "eight" and I count eight lighted candles in a circle around it. Piles of bonbons are stacked on the table, and I find a bar of chocolate under some ringed socks. But the best part of all is when Mum hugs me and holds me real tight for a long time. Suddenly, like magic, the most wonderful stuffed grey rhinoceros appears from behind her back! I fall so much in love with it that I decide right away that it can sleep in my bed every night. I name it "Reinhold" just like the rhino I saw in a magazine at the hairdresser's.

To celebrate this special day I get real cocoa, and then of course I'm allowed to cut the cake. Mum laughs and tells me not to forget that we've invited Ursula to come in the afternoon and maybe I ought to save a tiny little piece for her. I don't understand why I'm not very hungry and can only manage one piece – that never happens when I eat cake! But I gulp down four big mugs of cocoa before Mum and I start to play "Don't Get Angry". The game gets interrupted every ten minutes as I keep having to go to the bathroom after drinking all that cocoa. It takes me forever to get back since I always have to stop at the kitchen sink for a long drink. My thirst has gotten so bad that I feel like my mouth is all dried up and my tongue is stuck to my gums. I keep propping my head up with my arm so Mum doesn't see how tired I am. She still notices, of course, and tells me we've played enough and I need to lie down for a while to rest up for Ursula's visit this afternoon. Before I can take a step towards the sofa, everything starts to spin around me and I fall flat on the floor, but I don't feel how hard I land ...



My First Boyfriend Isn't Keen On Diabetes (Chapter 10)

I've been going very steady with Juergen for a couple of months now. We met at a fair I went to with Hellena and he treated me to a round of bumper derby. Since then we've been together a lot, but there are still problems I would rather not face at the Mument. At first I didn't mention my disease to him, because right on the first day he cracked jokes about a spastic boy who was standing in front of a carousel. I was simply afraid he might laugh at me, too. But during a long walk on our third date I had to decide. It was either miss my evening shot or sit down on a park bench and roll up my right arm. When I chose the shot, Juergen was consternated. He was still irritated after the long conversation that followed. Even now, I don't believe he can accept that I am not as healthy as other girls.

Of course Mum was all excited about inviting him over, because she wants to know everybody I run around with. She was all in favour of him from the beginning because he is a graduate of a higher level school, a "Gymnasium". Only boys who are headed for a university education are good enough to meet the standards she has set for me. Besides, she considers him to be trustworthy. That's a big advantage because I'm allowed to go everywhere with him.

After a couple of weeks, Juergen's parents wanted to meet me as well. I was getting up my courage and hoping they would like me when Juergen suddenly stunned me. He demanded that I not mention my diabetes to them. He didn't know how they would take it. And, idiot that I was, I went along with it! I eagerly ate the cake his mother had baked specially for me. Not that I had anything against the cake, much to the contrary. But that afternoon I felt completely inferior because I had to hide something that I can't just make go away, as much as I wish I could. Actually, both of his parents were quite nice, although they did ask prying questions about my family. I scored plus points with my mother (a real composer seems to make for interesting conversation), but when they asked about my father I quickly made up the story that he had been killed in a traffic accident several years ago. Afterwards I was furious at myself. Why all these lies? But then I told myself that if it might be hard for them to accept my diabetes, they would really get upset to find out I was one of these "illegitimate" children some people put down a lot.

In the meantime, Juergen's parents have learned about my disease. I just didn't feel like keeping it a secret any longer. Thank heavens they didn't respond as negatively as Juergen had expected, but now all this pity – especially from his mother – is more than I can take. She is constantly trying to do some nice thing for me: She bombards me with cake from the health food store that tastes absolutely horrible, and makes clothes for me that don't fit right. And this permanent "you poor child" look on her face! How can I make it clear to her that I don't want these things without making her angry with me?

* * * * *

After this dumb incident at Charly's party, Juergen has been acting strangely towards me, as though he isn't really interested in me anymore.

It was one of these parties where kids were dancing up a storm, and there was a lot of making out, too. One of the boys had brought along a bottle of his father's brandy. Not wanting to be a prude, I had some of it. After that I had the jitters and nausea and wasn't in the mood for Juergen's advances. But knowing how he's always looking for a chance to make out, I didn't want to spoil things with him and let him pull me into a dark corner.

Suddenly I began having one of these disgusting sweating attacks. All I could think of was that I really needed to get up and go take some glucose, but by then it was too late. When I woke up, I was in the hospital and that was the end of the party.

The next day Juergen was given a long lecture by my mother. Her trust in his reliability was completely shaken because he had not taken better care of me. And the others were totally down on me for spoiling their evening.

Of course I'm sorry it happened, but I can't help thinking that if I had landed in the hospital because of intoxication, it wouldn't have caused me any problems with my friends – that sort of thing shows daring and you can get mileage out of it for years afterwards. But being a diabetic and having an attack is not the way to act at a party.

The hardest thing for me now is the change in Juergen. He hardly even wants to hug and kiss any more. Sometimes I think he wants to punish me. It's strange; he used to tell me I shouldn't be such a wet blanket, other girls went a lot further than I did. And I was afraid! But now that he treats me so coolly, I feel like running after him and even doing what he claims the other girls do. It's crazy! Why is life so difficult sometimes?



A *“Helpless Person”* (Chapter 21)

Have I returned to my old games to get back at Gerd, or was this whole incident just a slip-up?

The evening before it happened we had got into another one of our increasingly frequent arguments. This one was nothing unusual, but the barbs cut deep enough to wound both of us. And I promptly forgot my shot the next morning. This is where I begin asking myself pointed questions: Was it really forgetfulness or did I – perhaps subconsciously – deliberately provoke this crisis? At any rate, I didn't leave out any of my numerous snacks and even treated myself to an extra piece of “frustration” cake.

Although I was already feeling rather nauseated, at five in the afternoon I decided to go visit a good friend for a heart-to-heart chat. I never reached her apartment. That normally short journey turned into a harrowing ordeal. It is still difficult for me to grasp how such a thing could happen in the midst of so many people.

After barely making it to the subway, I was relieved to sink into the last free seat in the nearest compartment. Exhaustion and leaden heaviness overwhelmed me immediately. I grew so faint that I lost all bodily control and was no longer able to speak. The remarkable thing was that despite my helplessness I was perfectly aware of everything taking place around me, an utterly frightening feeling when one is powerless to respond. First I slumped to the right and my head fell on my neighbour's shoulder. More or less kindly, he propped me back into place and only said, “But Miss, how can anyone fall fast asleep in the middle of the day!”

After a short while I must have drifted off to my left, sprawling onto an elderly woman. She savagely jabbed me away with her elbow – not without a vicious remark about my supposed intake of alcohol.

Caught tightly between the two of them, I sat upright for a time. But then everything began rotating before my eyes, and I landed like a wet sack on the floor. Incomprehensibly, my fellow passengers let me lie where I had fallen. Their comments made it unmistakably clear that in their minds, a drug addict was stretched out before them. It didn't occur to anyone to check my purse for my diabetic identification card. Indeed, who knows anything about diabetes or other diseases with similar effects? What a great need there is to educate the public on this subject! When someone collapses and doesn't happen to be dressed as fashion magazines dictate, the easiest response is to stamp that person as a drug addict or an alcoholic. By branding people as untouchables, we reveal our own helplessness. As though these outsiders were not in need of help!

After the train reached the last stop someone finally thought to notify the station personnel. Shortly afterwards, two husky ticket-takers dragged me by my arms and legs into their break room. They had the presence of mind to search me for papers, and when they found my diabetic ID card, help was called in swiftly. The police (who in Germany must always be called to the scene if a “helpless person” is found) and the ambulance which took me to the nearest hospital arrived almost simultaneously. The nearest hospital did not turn out to be the best. I left it after two days because I could not bear the way my diabetes was treated by the resident physicians.

As my sugar level after delivery was over 700 mg% with severe acetone, the doctors could be expected to give me a heavy dosage of insulin along with a mandatory salt transfusion. But after my levels fell to 8 (!) mg%, only to bounce back up to 548 mg% due to a much too hefty injection of glucose, followed by another nose-dive to 12 mg% after a renewed overdose of insulin, I concluded it would be best to leave these hospitable premises as soon as possible.

As a patient I would normally never have learned of these enormous fluctuations. In my half-conscious state, I was only faintly aware of what was happening. When I was able to ask, I was told that I had “given everyone a pretty big scare”.

When a fully distraught and remorseful Gerd came to visit, a lucky circumstance brought the facts to light. He recognized a nurse as an old school friend, and from then on the details began trickling out. If it had not been for Gerd, I would certainly not have dared to insist on my release. After all, the doctors decide what is to be done with a patient. The head physician of the ward

responded furiously and insisted it was impossible for me to leave the hospital with my latest level of 240 mg%, but I refused to back down and finally had my way.

Nonetheless a bitter aftertaste remains. It is the situation of complete dependency that is so frightening. If I sometimes treat my own body irresponsibly, that is bad enough. But at least I can question, and if necessary, correct my behavior. However, if I land in a hospital where the doctors have little or no knowledge of diabetes, my position becomes desperate. As a patient, I have no protection against medically false decisions. No one is willing to listen to my suggestions for improvements, because this could threaten the authority of the doctor in charge. I am left with the choice between unquestioning obedience to the doctors' orders – whether they make sense to me or not – and head-over-heels flight at my own risk.

I cannot accept either of these alternatives as a good solution. I wish to be taken more seriously as a patient, to have a voice in the way my diabetes is treated, not to have to pull teeth to find out my laboratory results. If the doctors (and the nurses as well) would stop treating me like a small child, I would be less fearful about my next stay in a clinic.

* * * * *

Truly an irony of fate – Mum has had diabetes for three months now! With her 68 years it is of course typical old-age diabetes. She only has to take one Rastinon pill every morning and evening and stay on a diet. This, however, is an impossibility for her. She is absolutely incapable of changing her eating habits.

As soon as I learn of her serious condition I pack a few things and board the next train home. I want to cheer her up after the shock of her diagnosis and support her in any way I can.

I see a bread unit exchange table in the kitchen, but according to Mum her doctor has not given her any instructions on how many bread units she is allowed to eat per day. It would make little difference; she is not about to accept any dietary restrictions. The scale I have brought for her lays unused in the closet. She insists that she can gauge weight at a glance more accurately than a postage scale. When I think of my childhood with her and recall how she would cut a piece out of my apple if it weighed five grams too much, it still makes me furious. And then her permanent addiction to cake. As long as I am there, she restrains herself and eats “two pieces at the most”. But how much does she eat when she is out of my sight? “You have no business prescribing what I eat and don't eat. After all, it's my life and I'm the one who's responsible for it.” Those are her words, she who kept watch over me with Argus eyes for the first thirteen years of my life as a diabetic (and most certainly never would have stopped if it weren't for the wonderful 450 kilometres that have separated us for the past eight years). She who gave me no peace with her constant fretting, who forbade me to take part in so much that would have been essential and beautiful.

Now, as I witness her destroying herself, she commands me to keep my mouth shut! The situation is unbearable for me, if only because I can't join her cake-eating orgies – otherwise my warnings would lose all credibility. So in her presence I'm forced to pretend to be the very model of a disciplined diabetic. In reality my mouth waters when she makes short work of her damned almond croissants and coconut cake rolls before my eyes. At the next opportunity I sneak to the bakery and secretly indulge myself. While I play the role of the perfectly sensible daughter I know I am being dishonest, not only to her but to myself as well. I, too, am stubborn and childish, and not a whit better than she is.

♣