

Jan's Path

Dorota Danielewicz

Sample translated by Tul'si (Tuesday) Bhambry

Dorota Danielewicz, born in Poland in 1964, has been living in Berlin since 1981. Her son Jan was born in 1993. He was a healthy and happy little boy until his development took an atypical turn. Danielewicz describes her path from despair to acceptance, highlighting the many lessons that Jan has taught her over the years.

The first time

[...]

When did it begin? It's hard to tell. Perhaps it was when Jan was four. We went to the paediatrician's for a routine developmental checkup. I remember this screening very clearly. Jan was trying his best, he was calm and in a good mood. His task that day was to describe a story presented in pictures. I remember it was about a family of birds. Everything was going just fine until we reached a conditional. "If mummy bird didn't... then the baby birds..." – something like that. Jan got confused, he mixed up the cause and effect chain. Next came an assessment of his vocabulary – a long series of images to name. He did alright, especially considering he was bilingual. I remember the paediatrician's astonishment when Jan recognised and correctly named a pomegranate. The doctor couldn't have known that we'd been eating pomegranates throughout the winter, as Jan and I were both very fond of them. Next came a motor test – catching a ball thrown by the doctor. Despite his best efforts, Jan was unable to react in time and the ball kept flying through his hands. I was familiar with this problem; he'd never been able to catch it, ever since he'd learned to walk. His kindergarten teachers often addressed his clumsiness so we kept practicing as much as possible, but to no avail. Why was Jan unable to catch a ball? This difficulty worried the doctor greatly; he said we should keep an eye on him, but on this occasion he didn't ask me to consult a specialist.

Meanwhile, Alexander arrived in this world. How fortunate, how very fortunate, I often thought in later years, that I had no inkling of the destiny that awaited Jan when I decided to have another child. I had a friend from Jan's kindergarten group, Elisabeth, whose daughter Ewa was born with numerous handicaps. She was blind, spastic, and never learned to talk. Elisabeth went on to have two more babies. Especially the decision to have the third – when Ewa was already approaching eighteen and her little sister Anna was six – was like "breaking the sound barrier," Elisabeth said. A few years later it turned out that the middle child Anna saw her older disabled sister as just a normal person. She accepted her with all her oddities and limitations. For the little boy, however, who met Ewa when she was already a grown-up, she represented a challenge he simply couldn't face. He was scared of her and steered clear of her as if she were "the devil creeping around". I remember their house and garden – they were lucky to work in professions that made them eligible for a mortgage. In the summer Ewa would lie on a blanket on the lawn and call out "Mummy," over and over again. Elisabeth told me candidly that she was sick of hearing "mummy" in a loop. She'd come to dislike the word itself – this continuous repetition from dawn to dusk had spoiled it for her. Mummy-mummy-mummy.

Jan stopped saying “mummy” at the age of twenty-two. “Mummy” is the last word that he pronounced clearly. I miss this “mummy” very much.
[...]

Poet, philosopher, artist

Children of a certain age begin to understand that when their parents leave the house they go to do something called “work”. They ask their parents what they do when they go out. They read stories about doctors, pilots, lion tamers and astronauts. They love postmen and garbage collectors, not to mention firefighters and police officers. Jan loved hearing stories about musicians, foresters and chefs just as much as any other child. But when he was asked what he wanted to be when he grew up – a question that most kids encounter around the age of five, when most of them have settled on the career of a garbage collector or police officer – he found no answer. At that time he was perfectly able to articulate himself in two languages; he had a substantial vocabulary and we knew that he could name more than a dozen professions. It was remarkable that he kept sidestepping the question and changing the subject with a laugh.

One day we had Leszek over for dinner, a poet and philosopher. Jan was playing nearby, paying no heed to our conversation, but when Leszek left he asked: “What does a philosopher do?” “He observes the world and thinks about how to live,” we told him, rather superficially, considering we were talking to a five-year-old. “Then I’m going to be a philosopher,” Jan announced to our surprise.

Another time Ryszard, a poet, had been over, and the following day Jan asked: “What’s a poet?” “That’s someone who observes the world and then writes poems, such as the one that goes ‘one fish two fish,’ or the one about the locomotive,” I replied. “Then I’m going to be a poet,” Jan said.

A year later Jan faced another question from the series “what will you be when you grow up,” and this time he replied that he was going to be an artist. This was unexpected, I had no idea that he knew this word, not to mention its meaning. “And what do artists do,” I asked, probing his understanding. “They play,” Jan responded straight away. There was much truth to this definition. After a while another change occurred in his career plans, but this time it was the upshot of his intention to become an “artist”. Whenever Jan was asked what he would be when he grew up, he maintained that he was going to play with children. Or, simply, that he was going to play.

I thought of Oskar Matzerath from Günter Grass’ *The Tin Drum*, who decided that he was never going to grow up. Was it possible that Jan had made the same decision?

All these conversations took place when Jan’s developmental problems were beginning to surface, when he was falling over on a straight path, mixing up languages, losing his motor coordination, and becoming poorer at drawing. The doctors were unable to identify a cause. Oskar Matzerath decided to remain little and to play with his tin drum. This decision helped him avoid the destiny of men in times of war, to dodge school and all the burdens and responsibilities of an adult life. It helped him retain a measure of freedom and independence from politics in difficult times. Was it possible that Jan had programmed himself in this way so that he might never grow up?

I kept wondering about that, telling myself in the mirror that I’d gone cuckoo. Was it even possible to decide on something like one’s metabolism, to stop the production of two enzymes, and thereby to remain a child for life? Who had made the decision, and when, about the functioning of the chemical factory in my son’s body?

In the capital of a highly developed country such as Germany it had taken medical professionals almost ten years to find the root cause of Jan’s health issues. The diagnosis they

eventually presented was extremely rare, and this is why getting on the right track had been such a long-drawn-out process. And when we finally knew what was amiss about Jan's organism, it turned out that the medical sciences had no remedy that might help.

Dear parent of a child that is agile and developing on schedule, according to all examinations and tests, healthy and typical! How you worry about banalities, how impatient you are about anything that makes your child demanding and zealous in its demands. You're lucky, very lucky, and you've done nothing to deserve your luck. How much I envy you, even if every child comes into this world with a unique challenge.

At the age of twenty-one, Jan needs diapers during the day, he still enjoys Bennie & Lennie cartoons as well as Mozart's music. At twenty-two he likes to be surrounded by people, and he uses a special walking frame that helps him keep his balance.

At twenty-six Jan is barely able to walk, and his feet are becoming numb. There is no walking frame for me. I am fighting for my own balance, because I lose it more and more often. Everything is becoming unbalanced along with Jan, everything.

There is no walking frame for the parents of children who cease to be independent. When Jan began to change I started to grasp at anything and everything so that I wouldn't fall over and pull down others. Little pleasures, such as a coffee in town or a trip to the cinema, new make-up or ice-cream. Big pleasures such as a dinner party for friends, exhibitions at museums and art galleries. Books, music and meditation, spiritual learning and yoga. Even work. Sleep, sex and strawberry cake. Did it help? Yes, it helped to survive another day, another night. Big problems do not necessarily call for big solutions. Little pleasures, moments of joy, moments of forgetting, have a particular taste when what you carry in your heart is a lake of tears left uncried. The ultimate plank to hold on to for life – a smile on demand, the make-up of sadness.

Stairs

When Jan returned from school, dropped off by a bus for kids with special needs, I used to come down the three flights of stairs to fetch him. But every day before he was brought home I'd imagine the following scene: the doorbell rings, I press the button on the door phone and I hear someone racing up, two steps at a time. It's Jan darting upstairs on his own two feet. He bursts into the hallway and tosses his school bag on the floor. "What's for dinner," he asks, and I tell him what I've been cooking. He and Alexander and I sit down to eat. We talk about whatever is on our minds, the boys tease each other, using teen slang, half of which I don't understand. Then they clear the table, playing their music a bit too loud. Or we squabble about whose turn it is to tidy up.

This vision of Jan running up to the third floor on his own haunted me for several years, more intensely as his walking was becoming worse. I started to imagine that this vision would really come true one day, if only I believed in it with all my might, never easing off. In my head the two worlds, real and imagined, were drifting apart. I was hauling Jan up, step by step, supporting his arm on one side to help him up the stairs. At the same time I was fantasising about a light-footed youngster effortlessly running up to the third floor. After some time I realised I was losing my mind. Longing for the imagined world I was rejecting reality as it was. The more intensely I thought about Jan hurrying up the stairs, the more I was negating the actual, tough and undeniable state of things. A film was released around that time, *Adam's Apples*. The protagonist, a pastor, staunchly maintains that his son is playing football, while the boy, severely handicapped, sits in a wheelchair with his head hanging low and cannot even go to the toilet unaided, not to mention running around on the playing field. I was fascinated with the pastor who refuses to accept reality, I recognised myself in this theme, but I did not go down the same path. An acquaintance who allegedly had the gift of

clairvoyance tried to console me by saying that Jan was healthy, that he was walking and talking in a different dimension, on another level of reality. So what, I thought, we're here, now; if there are parallel dimensions then we have different lives there and different problems, so they're of no interest. I decided to forget about Jan running up the stairs.

It took me several weeks to say goodbye to my vision of a healthy Jan. I worked hard to dissolve the image I'd carried inside of Jan running on his own, and all the while I kept plunging into a sense of guilt, as if there was a virtual reality where I was condemning him once more to the loss of his physical strength. What I was really doing, however, was to affirm Jan's experience, to accept everything the way it was. Here and now. I was slowly ridding myself of my resistance against an experience that could not be reversed.

Crisis

There came a day when I had an overwhelming feeling that I would not manage to survive even another hour. Jan's illness was progressing with long strides. What's more, he kept waking up at night and traipsing about the flat, and I was the only person to respond. Time after time, I would lie down next to him, hug him, doze off and then wake again to his crying. We had seen the X-rays, the sinister substance that was taking up more and more space in Jan's brain, disturbing the functioning of his motor centre and sight, muddling his thoughts. At that time I was in constant fear that Jan's rhythm of day and night would change, as this prospect was still up in the air. I was terrified by the corollaries of the illness, which brought suffering to him and left us feeling helpless. Permanently sleep-deprived, exhausted by an overwhelming amount of responsibilities, I was panicking at the thought of having to live without getting a couple of hours of sleep every night. Both boys, when they were little, had already run me into the ground by keeping me awake at night. I became forgetful about my appointments and commitments, I'd fall asleep on the underground, I had recurring tonsillitis. Now the uncertain prognosis concerning Jan propelled me into a state of permanent anxiety. Every morning I'd wake up with a ball of fear in my stomach, my heart thumping in alarm. Another day begins, another day with the great unknown, said my heart, and I took deep breaths to quiet it down on my way to the children's bedrooms.

I was also worried about the impact of Jan's illness on Alexander. This child never asked for anything, was completely undemanding. He was subconsciously putting Jan's needs above his own. At night I was haunted by visions of Alexander feeling lost in life, contenting himself with the first best thing.

I was also concerned about my marriage, since we never got proper rest or a carefree time off. We were living under constant tension, stifling fears and our sense of helplessness. There were moments of leisure, but the intellectual world in which we were trying to find an oasis was – at least for me – only partially satisfying. I was yearning for a well-functioning family, quiet dinners at home, conversation and harmony.

Having no control over Jan's health, I developed an irresistible urge to control my everyday life. Despite my natural easy-going temperament I was transforming into a woman of strict routines and slightly neurotic habits. The way in which I lay the table, hung the laundry or arranged clothes and towels became an expression of my good mood or sudden bursts of irritation. When you have no influence on the single most important thing – the health of your child – you start finding other ways to be in charge of reality. Such an everyday routine is draining. I learned to fall asleep whenever possible. Only in my sleep was I able to take it easy.

But one day my nerves just gave in. I cannot recall what triggered my sudden crying fit. I only remember the emotions, my energy escaping through a hole in my stomach like air from a

pierced balloon. A plug had come loose in my throat. There was a cry from the depths of my gut: “I can’t go on.” Over and over: “I can’t go on.” Because I really couldn’t. I threw myself on the bed and pounded it with my fists. The shelves were filled with clever books, there were flowers on the balcony, delicacies in the fridge. But in this apparently calm, middle-class backdrop my life had become a prison from which there was no escape. I didn’t know the nature of my guilt, but I felt its heavy burden. Perhaps this is how Josef K. felt, the protagonist of Kafka’s *The Trial*, when he was suddenly arrested for no apparent reason.

All I could manage now was to cry. This was a cry for help, tragic and liberating at the same time, a cry that was groundbreaking for me, but still too weak to achieve anything, for it could only be heard in my home – a cry of exhaustion and helplessness. How amazing was the piercing cry of Oskar Matzerath in Grass’ novel, shattering glasses and the windows in the townhouses of Danzig.

How I longed to cry for help, and yet I didn’t know how to roar like a lioness protecting herself and her children. I didn’t know it yet.

That very day we were expecting an overnight visitor. The guest bed needed to be made, I had to prepare dinner and a smile. And once again I did what I should not have done – I pushed my cry and my despair below ground, I buried them, I froze them the way an aching tooth used to be frozen. I put the children to bed, suppressing my tears and powerlessness, I prepared a meal, but I couldn’t join in any conversation. The lioness curled up into a ball again, pretending to be a house cat.

A short time later, a wise GP diagnosed me with “exhaustion” and sent me to a treatment centre. “You must finally begin to take care of yourself,” she said at our first consultation. It wasn’t hard to explain to Alexander where I was going. But I worried about Jan, who was losing his ability to understand everything and becoming poorer at speaking. There was no way of telling how he would receive the news of me going away for several weeks.

At 7 o’clock the morning of my departure we were standing in front of our *Altbau* residential block as usual, waiting for the school bus for special needs kids. I was explaining to Jan that I wouldn’t be at home when he returned from school, that I was going somewhere or other for a while, that I had to because I was tired and so on, over and over again. We were standing on the steps leading to our building, holding hands. Jan was listening intently. Suddenly he turned his head in my direction and looked deeply into my eyes, saying words that solved the entire dilemma in three seconds: “Mummy will come back.”

Mummy will come back. Yes, I would come back, and that’s the only thing that mattered. And this was another one of Jan’s lessons – a lesson about trusting myself, a lesson about trusting my own destiny. How magnificent he was right then, this boy who didn’t know the days of the week, who had no sense of the flow of time or the causality of things.

Of course I came back. After four weeks, during which I was asked to do nothing but do gym classes, go on walks, read books and talk to people who had arrived as exhausted as I. There was no need for counselling, the simple fact of having time for myself and having a break from everyday chores put me back on my feet. My husband was handling life with the kids just fine, during our phone conversations he made it clear that I had nothing to worry about and that I’m allowed to just rest. I must confess that I was enjoying having a break from him, too – such was my need to be alone with myself. Returning home I’d regained a part of me that had been lost, and during these few weeks I’d become aware that I am more than the mother of a child with special needs. I came back and decided not to forget that besides being a mother I am, first and foremost, myself. Only myself.

(The plug in my throat has come loose and it's dissolving with every sentence of this story. With every word type I feel it melt away, allowing me to breathe more freely. The more freely I breathe, the more space there is for the hot breath of the mother lioness.)

Diagnosis

During the ten years or so when the doctors were searching for a diagnosis, when we kept going to the hospital, nourishing vain hopes for a medical miracle, a cure, a therapy, Berlin was transforming. The 1990s and the beginning of the new millennium were very exciting. Clubs were springing up in old factories and abandoned houses in the city's eastern part, but my life revolved around Jan's illness and my job at the radio station. I was fortunate to have that escape from my routine at home. During the weekends I usually had more chores to do than on weekdays, holidays meant I was permanently on duty and almost always sleep-deprived. I began to envision a dark future. Every now and then I'd come across a notice on the last few pages of a newspaper. A 65-year-old woman living with her severely disabled child, 35, turned on the gas. They were both found dead. I cut out these tidbits and hid the clippings in a desk drawer, not telling anyone. I was distressed for Jan and for Alexander, who was losing his brother and not understanding why. The worst were the winters, around Christmas time. I was yearning for things to be just normal, just nice, to enjoy a festive, carefree time with my loved ones. I must have fallen under the spell of TV ads to be asking for the impossible. Jan would often weep for hours, unable to bear the tension building up on Christmas Eve, while I was prone to nerves and often came down with a migraine that would last for hours. Still, the tree was always spruced up and a multiple-course dinner ready on time, with one extra place set, following the Polish tradition, for an unexpected guest. But it's difficult to be filled with festive cheer when the stranger who comes to grace your family's celebrations is an unknown and malicious illness.

Every now and then my boss at the radio station would ask me if I wanted to take on new programmes, but I never felt up to seizing these opportunities. When a colleague suggested I could expand my role in our team, which would mean longer shifts every other day, I met with emphatic resistance at home – I would be returning late. I was unable to stand up for myself and gave in much too easily. Others came to fill this vacancy. Later I told myself I wouldn't have been able to compete with my childless colleagues, women who had unlimited resources of time and energy. There is no reduced entry fee for mothers of children with disabilities, not even in an all-female work environment; among freelancers in the media industry it's usually the law of the jungle.

These were years of darkness, years of delving deeper into a tunnel. In photographs my eyes look sad, very sad. Helplessness – my son's and mine. At this time Jan was beginning to lose his old friends – yes, it's possible to have old friends even at that age, in childhood time flows along a different track. Being more and more lonely, he escaped into children's stories, the imaginary world of cartoons. My husband was working a lot, he was mentally absent. After all, he was struggling with his own jungle – internalised expectations of having to be the breadwinner.

This is when the Sisyphus-like labours began, the eternal repetitions, practicing the same activities to maintain the status quo. The goal was to have Jan eat independently, go to the toilet, climb up the stairs and talk as long as possible. Rolling the stone up the hill, watching it roll down. Same thing the next day, up and down again. It felt like being on a treadmill. We were doing our jobs just fine, sometimes we managed to entertain guests. I'd put Jan in front of the TV and cook up a meal. At the dinner table we engaged in smart conversation about books, films, art. We didn't discuss our problems, we just wanted to have a short time off.

On the outside I managed to keep a stiff upper lip. “There’s been not a peep out of you,” a friend said to me years later. I’m not in a position to judge how my husband was coping at that time, he was uncommunicative, but he often remarked that men dislike other men who are weak, they’re prone to attack, to bite and to kill once they get a whiff of weakness. Leaving the house he would put on an armour. He left us like a knight defending our nest from enemy forces. Our bastion, surrounded by the bulwark of parental love, seemed to be unconquerable.

Still, I often felt a void inside, and in this void the demon of hopelessness was building a nest. I began to forget what joy is, I was losing my buoyancy. I was becoming weaker every day, and my heart was thumping silently like a soundless bell. The challenge I was facing seemed more than I could cope with. I associated the meaning of life with finding a cure for Jan, his becoming healthy, in other words something that was entirely unconnected to me. I washed mountains of laundry, picked up Jan’s toys from the floor, did the cooking and shopping and took Alexander to his music classes. I managed the logistics at home, filled in various forms and applications, took Jan to his doctors’ appointments. I learned to do several things at the same time so as to save time. I talked on the phone while ironing, or cooked while listening to the news, and I never walked around the flat empty-handed. Today this period of intense work is shrouded in a thick fog, I struggle to peer through and remember. My friends help me recall how things were then. They remember the person I was in those days, working according to a tight schedule from 6 a.m. until midnight.

One day, when I saw myself in the dark tunnel once more and felt I was heading for a nervous breakdown, when I found myself on the road to nowhere, I experienced a mystical decision-making moment. Suddenly, I don’t know how, a spark appeared in my head like a gracious gift from the gods – it was the idea that another road also exists, entirely independent of the circumstances in which I live. An illumination, an insight that something is always amiss, that misfortunes, pain and the simple traps of everyday life can befall us anywhere. Even if everything is turning out fine, life always has a layer with which we cannot be fully satisfied. The impulse can be momentous in its consequences or banal, it’s enough to talk to people about their problems to become aware of the infinite number of potential causes for frustration. Your annoying neighbours, your husband, wife, parents or children. Depts and bankruptcies, unpleasant experiences at work and in the street, broken household appliances and sick cats. Death, illness, environmental disaster, war. Jan’s health problems were my private war and disaster in one. My own private end of the world. This unusual and life-saving spark in my head cleared my mind and showed me a simple truth: you just have to choose the direction, to consciously choose a path. Either the dark one that leads into nothingness, into chaos and entropy, or the path of strength and joy, whatever might appear to be sapping your hope and your strength at a given moment. After all, I had already died many times, I had lived through my own apocalypse more than once, so I am free, I’m free to decide that I am happy. Becoming aware of this choice hit me like a bolt out of the blue. One moment was enough to transform my dejected heart back into an organ pulsating with life. Over the course of a few hours, while I contemplated with some astonishment the idea of choice that was revealed to me no one knows from where, I regained my former vigour and strength. Many years later I came across a clever book that described the secret of Japanese knights: “Live as though you were already dead.” I didn’t know that the samurai’s power lay precisely in his going through his own death. And unconsciously I had become such a samurai. This is another one of Jan’s lessons, a lesson that has changed my life forever and has given me the strength to pass successive trials. People who find out about my journey with Jan often wonder where I get my serenity and carefree attitude.

Ever since this moment on I understand happiness as a conscious decision. It’s not worth waiting for fate’s blessings, it’s not necessary to pose conditions, to beg the gods for mercy – they are as amoral as a cinema audience and they get the same enjoyment from drama as from

comedy. Each gift that comes from without, even the greatest, turns into banality in an instant. We're invulnerable when we become untouchable from within. Is it difficult to attain this state? And do we have another option? I simply didn't. And that's why it worked out. That's the only reason.

Another time

Jan's decision dilemmas appeared when he was about five years old, at the same time, more or less, as the difficulties related to his missing enzymes. It's a good thing for a child to learn early how to make choices independently. This is what I thought, so on our shopping trips I tried to teach him about deciding how to spend his pocket money. At a corner shop we'd take our time while Jan made up his mind whether he wanted chewing gum or Pokemon cards. No matter what he did, he would later regret his choice, and he would weep for as long as an hour. He didn't understand that the gum, which he'd already chewed and spat out, couldn't be returned to the vendor and exchanged for something else. This is when I came up with a consoling spell, the magical "another time". If not now, then surely another time, I told Jan, and gradually he, too, started to use this expression. With a heavy heart he decided to have this ice-cream flavour rather than that one, for instance. "Another time," he'd say with a deep sigh, for what he really wanted was to have everything at once. Life showed that there really was another time for many games, tastes, activities and needs. But Jan's advancing disability, the marked and grave changes in his brain that were crippling him little by little, they also forestalled many instances of "another time" – things and experiences that Jan had looked forward to eagerly and that he would have loved. In a way he had been right to hurry to try and taste as much as possible. I had used the notion of "another time" instinctively, especially since we weren't talking about existential things but trivialities. A roll or a bun, juice or water, Mickey Mouse or Maya the Bee?

The moment his diagnosis was pronounced I understood that for many experiences there would never be another time. It became instantly clear to me that now is the time to do everything that's possible, everything that Jan would enjoy or that might spark his imagination. For how much longer were we still going to be able to walk together, to travel, to use public transport, watch films and laugh our heads off?

Many of our extended family members failed to grasp why "another time" had disappeared. They postponed vacations, visits and activities to an unspecified date. Only my mother sensed that we had to act while she and Jan still had the strength, so she'd take the boys to the countryside in the summer, allowing my husband and me to recharge. How effortlessly we managed even the most intense professional workload in those weeks!

Another time is today, only today. Another one of Jan's lessons. When we give ourselves over to the moment, not thinking about what's past or dreaming about what's yet to come, then the moment expands into infinity. To sit together and watch autumn leaves fall and squirrels leap from tree to tree. To savour our ice-cream, the joy we get from the sense of taste. To bask in the sun, feeling its immense warmth on our skin. Simply to be together, idle existence. A hug that says more than words. To breathe together. This is when something extraordinary happens, time stretches into infinity like gum, it's as if the clocks had stopped, the past and the future melt away, they disappear. And then we are together, we simply are.

Teeth

Anyone can get a cavity. We know that it's best to act preventively, brushing your teeth carefully, having regular checkups at the dentist's, restricting sugar. Jan never learned to brush his teeth by himself – he started losing his motor skills too soon; holding a toothbrush properly was a real

challenge for him by the age of five. We practiced every day but nothing came of it. We had to brush his teeth and manage somehow when he protested, moved his head from side to side and pressed his lips shut. Of course, people show their teeth when they smile, so to get the brush to Jan's teeth we had to make him grin. One day I started to sing to him, making up funny rhymes, absurd lyrics to classic children's tunes. It worked. Jan opened his mouth. But the cavities appeared nonetheless. And they still do. A regular visit at the dentist's is not an option with Jan. He won't allow anyone to stick their hands in his mouth, he'll move his head from side to side, scream and bite his hand, as he always does in stressful situations. Fortunately there are dentists who are happy to treat people with special needs under general anaesthesia. To have Jan's teeth examined and to carry out any necessary procedures we must take him, about once every two years, to one of these exceptional people who work with difficult patients for a comparatively meagre profit. Things would be really difficult without them. Ela, our anaesthesiologist, is one of these doctors. The insurance covers just over half of the costs of the anaesthetic, so towards the end of the year she essentially works for free. But she never says no when she's needed. Then we take Jan to a first consultation, and a few weeks later, on the day of the treatment, he is anaesthetised and the dental surgeon carries out the examination and treats any cavities. It's a major undertaking every time. And every time I remember Jan's first prick with a needle when he was a baby. Over the years I have come to be able to bear so much more, so has he.

Every sentence in this story is true. Even when I enter into guesswork and imagination, they are always rooted in the stuff of experience. I write these words drawing on the memory of my cells, the network of concrete memories. Some of these sentences bring back the old pain, which stirs in one of my joints, in my head, in my spine, in my toes. Others provoke a hormonal reaction. Sometimes my dopamine levels soar, serotonin clears my head and my hyperactive pineal gland conveys me into a mood of childlike recklessness. The taste in my mouth turns from bitter to sweet, sometimes I breathe deeply, and then again my breathing becomes quite shallow. Writing about Jan, about us, I lost an upper first molar.

I look in the mirror, examining my face. Each wrinkle corresponds to emotions from the past. The furrow between my brows, the vertical lines from my eyebrows to my hairline. Each wrinkle tells some story described in this book. This narrative is my body, and it's Jan's body, too. The cavity in his tooth and the beauty of his full lips. His foot in an orthopaedic shoe and his hand spastically gripping the handle of his walking frame. It is his eye, his ear and his hair. I cut his hair, his nails. Commas, semicolons, quotation marks fall to the bathroom floor in a seeming disorder.

I give everything I have here, and I feel as if I were shedding my skin every day, like a snake in the late summer. And this is the only reason why this story can take on the shape of a book. This is the only reason.