

Marina Viola
The Story of My Perfect Child

1. Luca

Luca is happy.

Luca loves music, but not all music.

Luca laughs when his sister Emma sings him the children's songs that he listens to two thousand times a day, like *The Bear Cha Cha Cha*, and the soundtrack to *Oh Brother Where Art Thou?*, a Coen Brothers movie.

Luca loves his computer and his iPad; he learned to use them perfectly all by himself. He especially loves YouTube, which he navigates without knowing how to read or write. At the same time, he doesn't know how to lace his shoes, or shower by himself, or cut his meat, or be alone without an adult.

Luca is afraid of going to the barber.

Luca is always smiling.

Luca touches people's hair, even if he doesn't know them. He sits in their lap because he wants to share with them the song that he is listening to.

Luca has never learned to classify colors, and he hates drawing.

Luca doesn't know how to write.

Luca sometimes shits in his pants, and if you make him laugh hard, he pees in them too.

Luca stole the hearts of all of his therapists', and some of them still send us email asking how he's doing.

Luca loves Lola, our Boxer, but doesn't seem at all interested in Oscar, our Golden Retriever.

Luca loves chocolate pudding, pasta and french fries. He hates the cold, broccoli and shampooing.

Luca is learning to type, and he has learned to read the words that are the most important to him: computer, all done, *Fly Me To The Moon*, Sting, iPad and goldfish.

Luca does not understand social rules, and if he feels like hugging a passerby, he will.

Luca loves to dance, and his style is always the same: jumping in a circle while laughing.

Luca has no interest in learning to ride a bike, or meeting the woman of his life.

Luca does not have a sense of danger, of private property or of intimacy.

Luca, when he's tired of walking, sits on the ground and stays there.

Luca, since the fourth month of life, has had a therapist in his house every weekday who works with him until it's dinner time.

Luca was never able to win over his American grandparents, who didn't know how to handle him, so they always ignored him.

Luca loves unconditionally, and does not fear being rejected by other people.

Luca, when he's upset, pulls his hair and the hair of the people around him, and punches his own head.

Luca taught me to enter into a different reality, and to be happy in another dimension.

Luca is the most vulnerable person I have ever met; and if someone hurts him or treats him badly, he doesn't know how to let me know.

Luca is unaware that in the world there are people killing each other, raping, falling in love, climbing mountains, or sewing.

Luca loves my mother and when she calls him "sweetie", he smiles.

Luca is some other kind of creature, he is not a human.

Luca is a difficult person to go grocery shopping with, or to the movies with, or to travel with.

Luca lives his condition of difference in complete serenity, and he couldn't care less about the strange faces people make at the restaurant when he gets up and steals french fries from their plate.

Luca has a metal spring in a vein right above his heart, a long scar on his belly and tubes in his ears. He does not have his tonsils anymore.

Luca can't speak; he can only say a few words that he learned in order to meet his primary needs.

Luca has no friends his age.

Luca loves to unwrap Christmas presents, and he steals his sisters'.

Luca has broken a thousand pairs of glasses, and in every city we have lived in, his best friend is, without exception, the owner of the local eyeglass store.

Luca sometimes cries, and we don't know why.

Luca loves James Taylor.

Luca has an amazing memory.

Luca, according to an ex-hippie, sees angels.

Luca is particularly handsome, even if he has small ears.

Luca comes home from school, takes off his jacket and backpack, throws them on the floor and announces: "Upstairs!".

Luca still believes in Santa, who this past year brought him an electric razor, a baby toy, and the latest iPad, which he sleeps with.

Luca sometimes comes to our bed and wants to cuddle, and then he falls asleep and I don't dare move, for fear of waking him up.

Luca is the person I respect the most in the world, but he is also the most difficult one I know.

Luca is pure love, unfiltered.

Luca has been labeled autistic and Downs, but never a kid.

Luca is the jewel in my crown.

2. A tavola!

“A tavola!” I yell from the kitchen. Luca is upstairs, in front of his iPad watching videos on YouTube; Sofia, who is fifteen, is chatting with friends on Facebook and Emma, who is eight, is practicing her dance moves on the living room carpet, but she’s clumsy, and there’s really not much hope.

The table tonight is set particularly well, with the red tablecloth that my grandmother gave me many years ago. Five plates: four big ones and a small one for Emma. Two wine glasses, three Ikea water glasses. I even feel like lighting a candle tonight, like you see in the kind of movies where everything is going great. From the speakers in the living room, comes the sound of Louis Armstrong playing his trumpet.

“A tavolaaa!” I shout again but this time louder. I can hear Sofia jump up and head to Luca’s room to tell him to come downstairs; to convince him she grabs his iPad and brings it downstairs. She know him very well by now. Emma scurries into the bathroom to wash her hands. Dan, already at the table, pours me a glass of wine.

And here we all are, seated at the table with the red table cloth, a candle, wine and water. I look at all three of these babies, who by now are kids, tip my glass at Dan and a powerful sensation comes over me, like when I come across something that moves me, but even stronger.

And there it is, once again... It happens to me every time, because I love seeing us together; like five pieces of a strange puzzle, which together form our unusual and, yes, almost harmonious family. “What a nice family we are” I find myself saying out loud.

Sofia smiles and reminds me that I say that every night. Luca mumbles “*buon appetite*” in Italian, under his breath and hurriedly eats his food, without stopping and with his head practically inside his plate, because he wants to get back upstairs to be alone with his iPad.

It’s an evening like any other, although to reach this kind of normality involved many struggles and sacrifices. I had to try and create a new world, almost out of thin air, far away from my Milanese reality; after almost twenty years of distance and therapy sessions, I have finally accepted my status as an eternal foreigner, without always fighting it and longing to one day return home. I no longer have a constant feeling of guilt for having left behind my mother, on the other side of the world, along with my sisters, our faded family photos hanging on the wall and the city, my city, which I miss like oxygen.

It’s an evening like any other in a family that, despite everything, has found a sense of normality. Despite the dark moments, the incessant loneliness and the many long waits outside of operating rooms. Despite the almost violent, dark pronouncements spit out in our faces by eminent physicians, without offering so much as a pat on the back. Because at a certain point in my journey as a woman and a mother, I understood a very important thing; Luca is Luca and I wouldn’t want him any other way.

That may not seem like a very big deal to some; a simple, almost obvious realization, and yet it took me years to understand and accept the fact that Luca is different from me and everyone else I know, and that Luca belongs to a different world from mine. He too, like me, is a foreigner, estranged in his own way, an outsider who despite being a part of it for almost eighteen years, still has a hard time understanding the language, customs, traditions and values of my world.

After many years of darkness, I was finally able to understand and accept my existence here in America, with a son like Luca, and I learned that there are many layers of my being a foreigner: a foreigner in a world of Americans, a foreigner in a world of parents with normal children, and also a foreigner in Luca's world.

Luca's world is the world of the disabled; of people who are not cool, or brilliant, or successful. Luca is a person who doesn't know how to behave in the kinds of social situations which we, because we are from here, take for granted. Luca is a person for whom having a career means sweeping the floor of a supermarket, cleaning the windshields of cars and being happy with the fact that in his world having a career is not a sign of intellectual prowess, nor does it define his social class as it does for us.

Luca lives on the margins, almost hidden or invisible; the kind of person we glance at and think 'poor guy'. He is not part of my world; the world that produces things, that graduates, that gets married, that has kids and a career, that makes money, buys a home, makes love and has plans.

It was enormously difficult for me to accept the fact that I don't have a normal son, and that Luca and I are, and will always be, very different. For years I found it unbelievably painful to accept that he, my son, was on the losing team of people excluded from society.

At first, without him in my world, I felt very lonely; I had a child in front of me that I had created, who I thought I would have to teach how to speak, how to play, how to swim, who I would help with homework, trade jokes, go for a hike in the countryside. I'd show him how the world works in all of its facets. I would have a sort of symbiosis with him. And instead my son wasn't even capable of looking at me in the eyes or asking me for help. In the darkest moments of my desperation I even felt somewhat betrayed by him, as if he had decided to be different and chosen that path, to walk it alone, far from me; as if that other world was better than mine. As if I wasn't worth the trouble. He had decided to not invite me to his party.

And then, not by choice, I was forced to go with Luca to schools and groups with other disabled children and their parents, some had Down syndrome, others were in wheelchairs; there were children with autism, and kids wearing helmets to prevent their epileptic seizures from breaking their skulls, and children who would suddenly start screaming or crying for no apparent reason. In short, people from that other world.

At the beginning it was difficult for me, I kept staring at these children, just like people do now in the subway when I am with Luca; and I also carefully observed the parents, projecting onto them my anger and my pain. I didn't want to be one of them.

I was surprised by the fact that many of them seemed at ease; some even appeared to be happy: they were chatting with each other in a very natural way, and even joking about their kids. They would meet to share discoveries about services offered by the schools, or the city, or phone numbers of babysitters who were willing to care for their children. But they also talked about films they had seen, books they were reading – about normal things.

Their happiness seemed sincere to me, and yet I was left wondering if it was all just a charade; after all Americans always say “everything’s fine” even when everything around them is crap.

Almost immediately I met Phil and Valle, the parents of Aidan, a child with Down syndrome who was a year older than Luca and who always had red cheeks from the cold, a messy mop of blond hair and a contagious smile. He never stood still and, whether I wanted to or not, I always found myself playing with him as he was always bringing me lego pieces, farm animals and books.

Phil and Valle had another child, Tim, a year or two older than Aidan. All three of them adored this child, they spoke to him like he was a normal person and they were proud of him and amused by him. Phil, who had sharp sense of humor, would always tease Aidan desecrating my conviction that you shouldn’t make fun of the disabled. And they also adored Luca, who didn’t participate much in Aidan’s games, preferring to sit alone in a corner, turning the pages of books.

Phil, Valle, Tim and Aidan taught me, over time, that instead of fighting the situation in which we had found ourselves, we could set aside our prejudices and embrace it, and even appreciate it. And even be proud of it. Instead of always throwing ourselves against the wall, we could open the door and go through to the other side without getting hurt.

I, on the other hand, was just at the beginning of my journey, I had just turned back from the path taken by people with normal children, to head down the other road, the one for children who are different. I had only just parked my car and started off on my long, and thorny walk, in the dark. Painful and solitary. Full of questions for which there were no answers and fear. My instinct, while walking, was to turn back, take the car and disappear forever. During this walk you come across feelings of jealousy towards other children, the normal ones; you have nightmares breathing down your neck, that turn into reality. You come across black holes, chasms in which you could fall and have no chance of re- emerging: moments in which nothing and no one can help you.

It’s a journey you take alone, at night, in silence, and the only force pushing you forward is the violent anger infused in the question, “why me?”.

Months and years pass before the path becomes wider, the terrain less steep, and a few rays of sun find their way among the branches and show you the way. And even more years before you free yourself of the urge to run, to escape and more years until you have the courage to look ahead, to raise your head. Before you glimpse, in the distance, another world. And discover that there’s a spaceship there, ready to take you on a journey to a world that you have been taught to think is sad, doomed, and to be avoided. Every parent’s worst nightmare.

A one-way trip made up of premature death, marginalization and mental retardation. Aidan, his family and all the other parents I saw at the center, had

already made this journey and they had come back with a lot of stories to tell. They had returned full of enthusiasm, as if they had just taken a wonderful vacation. And they were trying to convince me to go there. It was my son's world. I observed Luca and he too, like the other kids around me, seemed completely at ease; without saying anything, without even been able to look at me in the eye, he seemed to want me to understand that these were his friends, his fellow travellers, and that he had much more in common with them that with the children from my world. Because they were exactly like him. In that world, the disabled world, I was the different one, not him. I was the guest. The foreigner, in fact. He had finally invited me to his party, and made me feel like an honored guest.

At the end of my journey, after a very long time, after so many sleepless nights and moments of panic, I finally managed to understand that *Luca is Luca*. I understood, at the price of endless tears, that it wasn't necessarily Luca who had to always conform to my world, to feel like a foreigner, an outsider, but I too, like him, had an entire world to discover and to appreciate.

These days at times, like Phil and Valle back then, I'm also happy, and even a bit incredulous at the fact that my son has found a place where he feels at home, that he has his world, a world in which expectations are at his level. I admit it; accepting all this was the most difficult test I ever passed in my life, and I think the same is true for Luca.

So, years later, all five of us are here, at the dinner table and I understand that I've finally arrived at a point of my journey when I can be at peace with myself, where I no longer need to struggle to understand, to suffer.

I pour a second glass of wine and change the subject.

While chewing his last bite, Luca gets up from the table with his plate, that he places in the sink. He grabs his iPad and announces his next move, "Upstairs". A few moments later Sofia and Emma follow him; Sofia goes to her room, and Emma sits on the couch in the living room to watch her last cartoon before going to bed.

It's the moment when Dan and I, finally alone, get to chat in front of our last glass of wine and talk about our day in peace.

At eight thirty I usually go to tell Emma it's time for bed. Tired, she stands, goes to the kitchen to give her father a kiss, and together we go upstairs.

She knocks first on Sofia's door, to say goodnight to her. Then she goes to Luca. I taught her to knock on his door, open it almost immediately saying, "Luca, open the door!", close it and knock again, and wait for him to come and open it. We both hear him get up from his rocking chair and, with his legendary slowness, open the door.

I taught Luca to say, only to Emma, *buonanotte* instead of goodnight. Because when she was small, she didn't speak a word of English.

He leans down and kisses her head, saying, "buonanotte, sweet dreams", in that way that only we can understand.

She hugs his legs and Luca, while returning to his usual spot, reminds her to "shut the door".

I go up another flight of stairs and, while Emma brushes her teeth and pees, I lay down on her bed and wait for her so we can read a book together. She cuddles up

next to me, and carefully listens. At the end of every story she asks a thousands questions, she identifies with the protagonist and tells me what she would have done in her place.

Then it's time for sleep; she lies on her belly and waits for me to sing her favourite song (You Can Close Your Eyes, by James Taylor) while tickling her back, a ritual we religiously follow every evening. I give her one last kiss and go down to Luca.

It's too early for him to go to bed, but he knows that I'm coming to help him anyway. I knock, enter and sit on the side of his bed. He takes my index finger and makes me point at the screen of the iPad; it's his way of sharing with me what he's listening to. Usually, they are videos in Polish, and I pretend to be interested in them, to make him laugh. Then I tell him it's time to go to the bathroom. At this point, he usually starts to negotiate every little thing with me, to convince me to stay on his bed; he asks me to sing him 'his' song (that Dan invented and which always makes him laugh) and I say to him, 'first let's go get ready, and then we will sing'.

He jumps to his feet, takes my hand, and pulls me to the bathroom. I sit on the edge of the tub as he sits down on the toilet. He pees and says 'good boy'. Which is how he lets me know that he is finished. He gets up. pulls up his underwear, flushes and asks me to "sing the song", which I do because he earned it. He likes to hug me, as I sing, and dance as if it were a slow song, something we do every night in the middle of the bathroom, as if it were a dance hall.

Then it's time to brush his teeth. He starts, but I give him a bit of help. He rinses his mouth and takes my hand, and together we go to knock on Sofia's door to say goodnight.

He goes to her and kisses her on the mouth. "Goodnight, Mr Shmoo!", she says, wiping off the reminiscences of her brother's toothpaste.

Luca takes me back to his room, and lies down on his double bed. He asks me, in his own particular way, to turn on his night light while again asking for his song (which I sing to him again), he laughs, and the says to me, "Good night. I love you. Sweet dreams". I then stop by Sofia's room, chat with her a bit, and give her a few kisses.

I finally meet up with Dan, who in the meantime has finished cleaning the kitchen. In the past that Luca would sometimes stay up all night to listen endlessly to the same song, which we deeply hate, but which makes him laugh. Now he knows that around ten we come back to his room, and turn off his iPad and light because it's really time to go to sleep.

He knows this because we taught him, by staying outside his door seven thousand times, waiting for him to get up and ask us to turn on his iPad, only to have us, without saying a word, bring him back to his bed.

The first night, which was my turn, this happened roughly every thirty seconds; he got up, he opened the door, I took him by his hand, I brought him back to his bed (the same story from ten until around two in the morning). The second night, with Dan, it lasted about an hour, the third night five minutes. Now that he has finally understood, we all sleep much better.

3. One, two, three: Luca goes to school

Although Luca rarely keeps us up at night with his music these days, the alarm clock still seems to always go off too early. Fortunately, I don't hear it. Every morning at 6:20 Dan gets up and, in the silence of the house, takes a shower in our bathroom on the third floor; then he goes down to the kitchen to prepare Luca's breakfast, which, for a dozen years or so, has consisted of a bowl full of hot oatmeal cooked in milk and served with a smushed banana. He then comes back upstairs, opens Luca's bedroom door and, singing the song he likes, wakes him up.

I have always said that what Luca really needs is both a dedicated secretary and butler, so over the years Dan and I have split up the tasks; there's no way I could possibly shut off the alarm and jump out of bed all perky and ready to go, so I play the role of secretary and manage his therapy and school. Dan, who has to get to his office early anyway, has become the all-around butler, dealing mainly with Luca's morning routine.

Luca, like many of his autistic colleagues, and despite many doses of melatonin, doesn't sleep very much. So sometimes when Dan goes to wake him he has only been sleeping for an hour and is deeply wrapped up in sleep.

He often tries to convince Dan to let him stay in bed, usually with the single word, "pillow". He knows by now that it's a plea that will always be ignored, but he never gives up trying.

Since he was little Luca has always undone his bed and slept directly on the mattress, wrapping himself up in his sheets, so that he looks like a silkworm, while his pillow, rather than being under his head, usually ends up on the floor, or in the middle of the bed.

Before heading off to wash, Luca stretches and twists his limber body in an almost unnatural way. Then, he unhurriedly rises and, with heavy steps and a smile, heads toward the bathroom. He pees, sitting down, and then enters the shower.

His therapist, Maria, spent one or two months every morning at 6:30 trying to find a simple and repetitive way of teaching Luca to wash by himself: Mister Shmoo, as we call him, is supposed to take the sponge, put soap on it, and then count "one, two, three, four, five" while he first rubs one arm and then the other, his right leg, his left leg, his armpits, torso and rear end. In fact from my room I can hear Dan counting, "one, two" and right after Luca's voice saying "three, four, five".

When Dan shuts off the water in the shower, Luca implores him; "More please, please more! Please!". "He always wins that battle" I think, smiling, as I hear the water running once again. Then Dan dries him, helps him brush his teeth, and teaches him to shave with his new electric razor (which terrifies Luca) that Santa brought him (in whom he wholeheartedly believes); for now Dan counts "one, two, three" as he touches the razor three times to his face. This is only the first step – "desensitize him," Maria tells us.

But Luca is afraid of everything that vibrates and touches his face or head; managing to cut his hair is an almost heroic accomplishment, his electric toothbrush is a nightmare and now his razor too is becoming a battleground.

Luca, escorted by his father, shuffles nude into his room and sits on the edge of his bed – where Dan has prepared pants, underwear, shirt, socks, glasses. Then, with his legendary slowness, which he draws out in the hope that Dan will eventually help him so that he doesn't have to do it, he gets dressed.

It's 7:15. Luca goes downstairs to the kitchen with his iPad and sits down at the wooden table to eat his breakfast which is steaming hot and ready for him.

I come down as well, and turn on the espresso maker. Our gazes meet, "mommy! Good morning! Did you have a nice nanna?", he says to me smiling with his hard-to-understand speech. It's actually one of the few phrases that he knows how to pronounce pretty well, even if he's not very interested in hearing your reply. "I did, Mister Shmoo! And you? Did you have a nice nanna?", I ask as I cover him with kisses.

He laughs but does not answer, so I repeat the question while clicking on pause on his iPad, and soon I hear him mumble "yes" between bites.

With startling speed he presses play and the usual video, that by now he has been watching for several months, starts to play on his iPad; clips from a kids television show called Bear in the Blue house. He found the clip on Youtube in Polish and he watches it incessantly, and has even learned a few words, which he repeats out loud when he wants to include us in his joy.

As I said, he "shares" the video with us by grabbing our index finger and placing it on the screen, which is still dirty from last night's dinner; "titik!" he says, imitating a word that the Bear says, the meaning of which is a mystery to us. He won't let go of my finger until I reply 'titik,' so I waste no time providing my contribution in Polish before scooping up some sugar with my spoon and mixing it into my coffee.

Luca's musical obsessions are often the center of debate in our family; Sofia says she prefers the Bear Cha Cha period, while Emma always says that for her "Fly me to the moon" was his best phase, because at least a lot of different people sang that song, which made it seem a little different every time. Dan always tries to rekindle Luca's love of the Police, hoping he'll return to his one time passion. For three extremely long years he would only listen to the soundtrack to the film *Oh Brother Where Art Thou*: that too was a difficult period for all of us. Personally, I mainly listen to Italian singer-songwriters, so I don't really have much to say in the matter.

In the meantime Dan prepares the lunch that Luca will eat at school, which is always the same; ravioli in red sauce, that he places in a tupperware container, together with a box of apple juice, and then into his backpack, which holds a notebook his teachers use to write us everyday about how his day went, and another iPad which Luca only uses for communication, thanks to an application created for Autistic people; instead of words he uses images, called PECS – Picture Exchange Communication System.

7:30: the sound of a horn outside signals that his bus has arrived and is waiting to take him to school, which is about half an hour from Cambridge where we live.

It's actually not a true school bus, but a minivan driven by Joel, who probably weighs somewhere around 450 pounds, and has an extremely strong Boston accent. Since he discovered that I'm Italian, he asks me if it's true that olive oil is better over there, or we chat about the weather, which he obsessively tracks like other people follow a soccer team or a TV series.

Mary, a Haitian woman who speaks English very poorly, and who adores Luca, who she calls "Lou Lou," emerges from the minivan. In winter she proudly displays the hats that she knits. In the summertime, though, she wears a different wig every day, often a bit crooked, almost as if they too were hats. "Come Lou Lou, be careful" she says to him as she takes his hand and reaches for his backpack. Luca lets himself be escorted down our three steps and into the van, while Oscar runs out and lies down on the sidewalk. After few minutes, we often hear Mary knocking on our door to remind us that we once again have forgotten to let our golden retriever back in.

I stand in the doorway in my pajamas and proudly watch my Mister Shmoo tackle another long day. I say "I love you" to him; he replies "ok," under his breath.

I watch as he climbs into the van, my Mister Shmoo, and he suddenly seems very big to me, almost an adult. There on the doorstep, as the van pulls away, my thoughts take flight and in a flash return to the past to when this adventure of ours began, eighteen years ago. To me it seems like yesterday, but also a century ago.

By the time that the minivan is signaling to turn right at the end of our street, my memories have landed on a very far off moment. I remember the period when I so badly wanted to have a child, all the times I tried to convince Dan, and the countless pregnancy tests I took which always came back negative.

I also remember the moment I discovered that I was finally pregnant. After a year of trying. I had by then almost lost all hope.

I was once again seated on the toilet in my bathroom with my kit in front of me; four different types of tests. I started with the first one, knowing that I would have to wait the usual two minutes for the line to appear at the tip of the stick, and hoping, pronouncing the verdict, it would form a plus sign.

By then I had become an expert as I had been checking for months, after spending just as many months convincing Dan that we should try to have a baby. At that point I had, without a doubt, spent more money on pregnancy tests than on food.

So that morning I knew it would take two endless minutes; I was already fairly resigned to seeing yet another negative outcome which, as if the result itself was not depressing enough, was underlined by that little line in the shape of a minus sign, a symbol of negation.

That morning, instead, the test sweetly and unexpectedly said to me: "you are in business". I thought immediately that, with my luck, the test was probably defective. I decided to do another one before calling my mom, all of my sisters, Milena and Bruno, Dan's parents and sisters, all of my friends... better safe than sorry.

My hand was shaking and I couldn't pee. When it finally arrived, it was loaded with hormones that confirmed that inside of me, in an until then unutilized part of my body that I had never even thought about, a puzzle of cells – some mine and some Dan's – were working and multiplying, completely unaware of my infinite

joy. Me. And Dan. Together. Before launching into a string of phone calls, and before telling Dan, I lay down naked on the floor alone to enjoy that moment of pure ecstasy.

And while my thoughts were flying at light speed, that cotton ball of cells in my uterus continued to multiply, creating an unthinkable rebus of chromosomes, frightening, difficult to decipher, and difficult to accept.

My pregnancy made me feel invincible, euphoric and showed me the inherent power of womanhood; that my body was capable of creating a human being. I felt almost like God, but with more of a Milanese accent. I greeted everyday with open arms and I was serene and full of enthusiasm.

As my belly grew so did my desire to meet the person inside of me. Suddenly Dan and I felt grownup. My pregnancy, so long desired, made us realize that we had to take a big step forward in the quality of our lives, to stop living like students and create the foundations for bringing up a family.

I had been working for a year both at Smith College, where I taught courses in Italian conversations, and at a language school, while Dan had become a headhunter, forever leaving behind the idea of finishing his thesis and obtaining that damn doctorate in Italian literature.

We decided to stay close to where we were living, which is to say in the westernmost part of the state of Massachusetts, but to move into a larger house. We found one in Amherst, the same town in which I had met Dan years earlier, where his family lived, and where we were to live for three years before moving to Cambridge.

It's a small town with a main street full of pizzerias, fast food restaurants, ice cream parlors and bars and other stores geared toward the masses of students from the three local colleges: the University of Massachusetts (colloquially known as UMass), which is the state university, Amherst College, prestigious and snobby, and Hampshire College, the alternative university for people who don't believe in grades, because they are too reductive, and hippies who had rich families to support them. Dan's father was Italian and had moved to Chicago in the fifties, his mother was American, from Chicago and together they had moved to Amherst to work as university professors and remained there for the rest of their lives.

Dan and I found a good deal on a house; it was fairly isolated in that you couldn't really get anywhere on foot, and around us, other than a couple of houses exactly like ours, there was only forest/lakes/birds as far as the eye could see. The opposite of an urban landscape. The sounds that came from outside were unequivocally generated by the nature that surrounded us; no horns, no busses, no tapping of heels running late to work. Apart from a subtle sense of isolation, that I tried to drive out of my head, the house was cute; dark blue, constructed of wood, with a small greenhouse that looked out over the forest.

Inside there was a dining room, a kitchen, a wood stove in the living room, two bathrooms and three bedrooms. For years it had belonged to two elderly people; the man went around with an oxygen tank, and she was always in slippers. The house smelled a little bit of pharmaceuticals, of canned food and of their dog, who was old and half blind.

To liven up the atmosphere we chose bold and bright colors; red, green, yellow, blue, so that every room evoked a different atmosphere and wiped out any presence of the old and sickly previous owners. In the greenhouse, in addition to the plants, there was enough space for a raggedy but comfortable armchair which I would sit on when I came back from the university to spend the afternoons correcting my students homework, or reading, while listening endlessly to James Taylor.

So within a few months we had jobs, a house and Luca would soon arrive. His room was set up and in perfect order like a little gem; we set up his crib, clothes, diapers, blankets and toys. But for now they were all just sitting there with the door closed, while the little prince was hanging out in the warmth of my belly, which by now was unrecognizable.

Dan and I started prenatal classes, to learn, among other things, breathing exercises which we would discover, not really to our surprise, were completely useless; giving birth hurts like hell and that's all there is to it. Forget about the breathing, you scream!

Dan's parents also seemed enthusiastic, but the happiest was Claudia, his sister. She and her husband Matt had lived many years in New York but had decided to return to Amherst to raise Isa, their first child, who was a year old. They were very attentive parents, actually more than attentive they were a bit anxious, and their child, who was quite shy, had become the centre of their world... they were happy that she would have a cousin to play with.

Claudia lent me a lot books on pregnancy that she had read years earlier, the kind that give useful advice for every week of your pregnancy: what to eat, how to sleep, how to not hurt the fetus, how to not end up in the hell reserved for the mothers who drink a glass of wine. I was a good student, and carefully read and obeyed everything, without ever cheating, fearful that had I not, my son might be born different or sick.

Claudia and Matt lived about twenty minutes by foot from our house and, although they were very busy with their daughter, we would occasionally manage to get together.

Then there was the Milanese front, obviously. The excitement vibrated inside the handle of the phone; the emotion was genuine, as was the impatience if there was even a hint of sadness on my part over not being able to share the first kicks, the first blurry black and white images of the fetus or his first heartbeats. He was our family's very first male child. "It's a boy", I told my mom after the ultrasound.

"What do you mean, a boy?" she answered, as if the possibility had never occurred to her. She, the queen of four daughters.

Then one day, during a private Italian lesson, I felt a contraction. And then another one.

Oh God, it's time. I got rid of the student and immediately called Dan, who showed up thirty two seconds later, more nervous than I was, armed with a watch with a second hand, a pad of paper and a pen. But the rules we had learned in our class were very clear; the contractions had be regular for at least two hours. We walked, and walked and walked. I must have walked six or seven miles in the forest, somewhat afraid, and stopping with every contraction.

By then it was almost evening. We watched Seinfeld to distract ourselves, our favourite sit-com that came on at seven thirty, and it was that episode that gave us the idea for the nickname we have always used for Luca, Mister Shmoo. We called the hospital, and the midwife told us to put the car seat into our car and come in.

Mornings begin early in hospitals. The contractions, in this case my contractions, don't have a schedule and they can go on for hours and hours. Claudia came to visit for an hour or so, with her smile and her contagious joy. At lunchtime a kindly nurse brought a chicken salad sandwich for Dan, which he, by now exhausted, happily accepted.

Around five the contractions became unbearable. As i started to think, full of excitement and fear, "Here we go, it will all be over soon", Dan began to vomit. And vomit. And vomit. Until they finally carried him off. I was left alone in that room which suddenly began to seem frightening. Truly alone. I couldn't believe it; after all these months of preparing and getting excited, when the moment finally arrives, he vomits?

"Isn't there someone who can stay with you?", a nurse asked me as she was busy elsewhere. But who? I kept wondering where they had taken Dan; I was told he was having a reaction to the spoiled chicken salad sandwich he had been given by the nurse, and had been admitted to the emergency room, with an IV and tranquilizers. I couldn't believe it, "I'm gonna kill him!"

Luca popped out after two hours of violent pushing. I was crying, Claudia – who had come to rescue me – was also crying. Luca on the other hand came out and maintained an alarming silence. The nurses started to give him pats on the back, but nothing happened. I felt panic growing inside of me and in them as well, but after a few moments, which felt like six hours to me, we heard his first cry.

Then finally they put him in bed with me. His little face popping out of a white blanket, that covered him so tightly, he looked like a silkworm. I remember being surprised by how warm his little body was. "Welcome Luca. I am your mom", I said to him flushed with emotion.

He was extremely ugly; one eye was all red from the effort of being born, his head was conical in shape and a nurse had place an idiotic hat on his head that was crooked. This was my first look at Luca. his eyes, which had never seen light sought mine, and our glances met for a moment. Here we are, you and me. After all these months. He was tender, calm, and tired. I latched him onto my breast and almost immediately he knew exactly what to do; he sucked for a bit and then fell asleep on top of me.

After having called half of Milan, and cried my eyes out, I was transferred along with Dan and Luca to a quieter room, with two beds; one for me and one for Dan, and between us they placed a plastic crib. Dan had no strength, and asked if I could call someone to bring him some tea.

"I'll make it for you" I offered, like Wonder Woman, and stood up with difficulty from my bed and moved toward the kitchen.

"What are you doing here, Madam? Didn't you just give birth?" the nurse working the night shift caught me immediately.

“My husband wants some tea”, as if to say I had an excuse. I’ve never been a very good patient. By now adrenaline had taken the place of my blood as if I had run the New York city marathon. After being yelled at and brought back to bed, a tea also showed up. It was one in the morning. Luca was sleeping next to his cow shaped stuffed animal that I had brought him from home. Dan was finally able to study him and cuddle with him. A romantic moment, full of everything.

The next morning I hurt all over, even my ear lobes felt as if they were in pieces. My body was completely butchered from forty hours of labor and the birth of a nine plus pound baby boy.

Today, on the other hand, I look at my big little Luca and see a boy who is almost eighteen years old, taller than me, who already has the shadow of a moustache. Despite his size, he lets himself be escorted to the door of his bus by Mary, all the while holding his iPad in the palm of his hand.

Mary encourages him to get into the van, with her strange English, to move to the backseat, and to shuffle his butt over so that she can put on his seatbelt.

Then, she gets in next to him and closes the door with a bang.

Marina Viola Biography

Marina Viola has lived in the United States since she decided to move in with her boyfriend Dan in 1991. Although she currently resides in Cambridge, Massachusetts, their first house was in New Jersey, where she earned a degree in Graphic Arts. She has 4 kids and 2 dogs. Marina Viola hates eggs because they smell bad, but she would gladly sell all 3 of her kids for a *maron glacé*. She has a BA in Sociology from Brooklyn College, in New York City.

For several years Marina has published a popular blog which she uses to narrate moments from her daily life. She was a weekly contributor to the satirical website, smemoranda.it, providing an irreverent look at life in the United States. Marina has a regular column in the legendary Italian magazine *Linus*, she contributes to and helps edit the satirical website Prugna, and pens weekly articles for journalist Gianluca Nicoletti's website on Autism – pernoiautistici.com.

In June of 2013 Feltrinelli published her first memoir, *My Father Was also Beppe Viola*; her second book, *The Story of My Perfect Child*, was published by Rizzoli in 2014, and tells the story of her son Luca who has autism. Both books spent time on national bestseller lists.

*

What was said about her first book *My Father Was Also Beppe Viola*:

“An extraordinary writing style marked by simplicity, clarity and economy of language. I read her book with a great deal of emotion... She has an amazing ability to recount things in a simple way and, by doing so, completely reinvent them.”

Dario Fo, recipient of the 1997 Nobel Prize in Literature

“The story of the legendary journalist, author and wordsmith in the words of his daughter Marina; full of sometimes paradoxical anecdotes, and deeply human life lessons.”

Panorama magazine, June 2013

“A manifesto of love and an ode to life. *My Father Was Also Beppe Viola* by his daughter Marina Viola, isn't just the story of a journalist... it's also the story of a family and of a romantic Milan that no longer exists.”

Marie Claire magazine, July 2013

What was said about her second book *The Story of My Perfect Child*:

“Marina Viola speaks frankly of love and of courage, without denying the difficulties, the moments of pain, the anger and disappointment. She writes about accepting people for who they are. An important lesson not just for April 2nd, international autism awareness day, but to carry with you every day.”

Corriere della Sera newspaper

“Marina tells her story in a way that brings both tears and smiles to the reader, but especially smiles.

Sergio Meda

“For a parent it’s always hard to face a disorder that will permanently impact the lives of their children. Marina Viola... had the strength and the courage to do it. And after many tears and a tortuous path to acceptance, she established a relationship of complicity with her son that makes them invincible in the face of any obstacle.”

Il Fatto Quotidiano