

Sample translation from

*The Noble Autist* by Romana Vrede

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Translated by Emma Rault

## PROLOGUE

Dear Charlie,

I've been asked to write a book, about you. About your life, and how I see your life, and how I think it's going to turn out. I'm going to start with your death, because I don't think I'm going to be around for that, which breaks my heart. Even when you're dying, I want to be there to support you. A child needs his mother at all the big moments, and death is a big moment, and you will never not be my child. Many great things have been written about birth: all of a sudden, there you are with your parents, your mother in particular. Death, though, is something you truly experience on your own. I'm not able to tell you about death or any other big topics, partly because of your fleeting attention span, but mainly because you never ask questions. That's why I'm writing this book. So that you can 'read' it or someone can read it to you when—a long, long time from now—it's your time. I am giving you my presence in print.

Before I die, I mustn't forget to ask Joël to be there when you do. You can trust Joël and the doctors. You can relax, ask for sedatives if you want, just lie there and look out the window. If you're on your own, at home, I hope you'll just fall asleep. What happens after you die is something I suspect you know better than me, as you so often do. For me, death is something I can only guess at. My mother used to say, 'You'll sit at God's feet for all eternity.' Even when I was a child, that seemed more like an icy hell.

Personally, I think that it's good over there, that you'll get exactly what you need. That the situation there is flexible—sometimes a party, sometimes calm, sometimes the natural world as we know it here on Earth, sometimes a spectacular firework show like the one over the Erasmus Bridge in Rotterdam each New Year's Eve. More or less like your life here, except without any sort of inconvenience. No frayed cuticles for you to pull at, for example. Today—the day I'm writing this—you picked away at your pinky nail until it came off altogether. I saw the skin underneath. Oh sweet boy, I

thought, that must really hurt. That sort of thing turns my stomach, but I can't stop you. You don't even want me to look at it, let alone touch it.<sup>1</sup>

I'm sure heaven is pain-free. No pain in your tummy, like when you've eaten an entire jar of vitamins because they taste like candy. No ingrown hairs on your inner thigh that I squeeze out even though you don't want me to. No verruca on the sole of your foot that the doctor's long given up on.

'Yes, it's a verruca, ma'am. Nothing we can do. We suspect it doesn't hurt. If it did, wouldn't he have let us know?'

'Um, no. He wouldn't, doctor.'

No noise, no blisters because you have to break in your new orthopedic shoes. You always kept on walking, not complaining, and I didn't notice the big blisters on your heels until we got home. You're a soldier. No loose threads on your clothes, no unraveled wool from a scarf or rug that you can eat, like in the spaghetti scene in *The Lady and the Tramp*, except that there there's just the one dish. I've found so much yarn and thread in your poop—it's as if you're a whale with a stomach full of plastic.

If nothing else, I wish I could stop you from panicking when it's time, when you die. I want to be there to comfort you and hold your hand, kiss your sideburns. My biggest nightmare is you dying alone, like Sabine's cat, which probably died stuck in the tilt-turn window of a house nearby, slowly and painfully. Her four paws couldn't get a grip on any surface; she was hanging in the space between the tilted-open window and the window frame. The owners of the house were on vacation. She must have been hungry and thirsty; she couldn't manage to free herself. Her paws touched

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<sup>1</sup> The first time I know I'm stronger than pain: there's gravel on the path, I run ahead and slip, I'm wearing shorts, I'm three years old, and suddenly my knee is busted. It's not good, because it's open and red, and our house with water to clean it and bandaids are far away. There are tiny stones in my knee. You, Mother, you gasp out loud. Your face is close to my swollen red knee, then it goes away. You swallow down saliva, sucking it in through your teeth as if you're tasting my wound. Like a snake hissing inwards. You grab me firmly by the elbows. I panic—your eyes, your squeezing hands, the knee, it's too much. I want this to stop. Stop looking at me now, stop holding onto me. I hit my knee hard. I rub the wound, as if I can erase it like chalk. This wound doesn't belong to me. I growl at you, as I dig deeper into the blood and gravel. The wound gets bigger, and the pain more intense, but my will is stronger than the pain. I will win this fight; I keep rubbing furiously. Now you're even more startled. You don't recognize me. 'What are you doing?' you ask out loud, voice shrill, '*don't*, Charlie.' As if it's my fault. Stop with your staring, your open mouth, the open wound, your eyes set to 'danger'. Stop, all of it. I hit you. Everything has to stop. Stop now.

nothing, just thrashed in the air, and no one heard her meow. Eventually the cat fell asleep, we think, and that's when it happened.

When this is being read to you, I want you to be lying peacefully somewhere. Preferably with me by your side, and if I'm no longer around, with Joël and other kind people with you.

Like you, the cat doesn't know what death is—but you're not a cat, you're a human being, and human beings deserve to know about such things. Human beings know that they are going to die. So, dear Charlie, here it is: you are going to die. Just like the cat, just like everyone and everything. We die. And you can do it. It's just a matter of doing it.

But in order to describe your death, I want to tell you about your life, Charlie. There's no death without life. So let me tell you how your life has been so far, and how it will probably go on.

Of course, I've never died. I haven't experienced it yet, but I do think I can explain it to you. I'm your mother, and your mother can do anything. I'm with you, now that you're healthy as a horse and sixteen years old and, through this book, I'll also be with you when you're old and dying.

Know this: I'm holding your hand, I'm running my fingers through your hair.



This is what is going to happen, what must happen, Charlie. You're going to die.

Let's say it's light outside. Spring. A brilliantly sunny day. It's Saturday morning, maybe all of 7 am. My sweetheart, you're in bed. You're an old man now. Your hospital room fills the frame. There are probably three nurses gathered around you. Two large men are standing on this side of the room. They look like each other and their backs are moving in unison like waves. The third is standing by the window. He's bent over and seems to be doing something to your face, so from over here he can only be seen from the side. Maybe he's stroking your cheek—that's good. The nurses don't have faces; they are a pale-green mass.

Joël is standing motionless by the door. I think. You don't see him, he's just outside your field of vision, but you smell him. He smells of Omo laundry detergent. All the hand-me-downs Joël used to give you smelled of Omo.

You're lying in a private room. Let's say it's the same hospital where you were born. The room looks out onto the parking lot. It's busy. Cars come and go, carrying people who are sick or who've just been told they are better. Everything in your room is painted white, except the floor, which is pink. Linoleum, of course. Joël has raised the bed up high in case you want to look out the window when you wake up. He grabs a chair and sits down by the door, his coat still on. He's tired, because he doesn't want to cry. Holding in tears is tiring. We never cry when it matters, when we should, when the situation calls for it. We cry afterwards, when all the pain and hope have subsided. Everything's screaming it out, but the scream is absorbed by your calm. The pale-green mass is almost done with you. The nurse by the window is wearing yellow socks; they look kind of cheeky.

Jo doesn't look at them, because our family isn't that good at making eye contact. One of your first learning goals was: 'Charlie makes eye contact for a minimum of three seconds.' All of a sudden, it's completely quiet in your room. Only when the people who aren't us leave the room do we realize just how quiet we are.

You're so beautiful. You're always beautiful when you're asleep. Your lips are shaped like a heart. When I look down at you from above, my eyes

running from your forehead to your nose and your lips, every part of your face looks like small heart-shaped apples. Your nose, your cheeks, your lips, your chin. Pure perfection.

Your breath is calm. Joël has brought chocolate. Before the pale-green group walked in he had been tenderly holding your hand and stroking the thick little pillow of flesh on the end of your thumb. I've never seen him do that before, not even that one time at Christmas when I said 'Jo, can you get bean sprouts for the peanut soup? And take Charlie so you guys get some fresh air. But remember, Jo, you're the oldest of all the cousins, so you're responsible for Charlie now. Be sure to keep an eye on him.' Joël, Noah, Sion and Charlie, all the cousins, left. From the balcony, I saw how Jo was holding your hand—not out of love but because of the responsibility he'd been entrusted with. That was when I knew he'd never let you go. You loved it and shrieked with glee. You were skipping and jumping and walking backwards, eyes on the clouds, making it difficult to keep hold of your hand, but he didn't let go. Jo doesn't let go. It wasn't until you got back home that he gave you your hand back. You were sad about that, because the game, which wasn't a game to Jo, was over. Just now, he was gently holding your hand in his for a moment—cupping it so that yours rested in his, while with his thumb, he stroked your palm, your love line and your life line, the lines that together form an M. Then he sat down again.

That's how time glides past. Now that you guys are waiting for death—because that's what life is, whiling away the time waiting for death—I'll ask you a few questions, so that you won't get bored.

How did you come into this world?

You were going to be big, strong and healthy. We'd seen that on the ultrasounds.

Labor was bearable until I had to push. Everything tore. By the time they put you on my chest, I was exhausted, which, I thought, had to be why I failed to feel any connection right away.

The first night in the hospital, I went to find you. They were supposed to bring you to me every three hours for me to feed you. So when I woke up at 3 am after having fed you at 11, I climbed out of my hospital bed and waddled over to you, as if I was sneaking out to check the presents under the Christmas tree. The room with all the new babies was down the corridor. I glanced in the cribs at other babies, who were asleep or dozing, and then I found you, and I was startled. Your eyes were wide open and you were looking at me without really looking at me. You looked straight through me.

I didn't know what to do. I smiled at you—no response, not even surprise. It made me feel unsure—and with a smile frozen to my face, I withdrew from your field of vision.

At what point did I think: huh???

You respond to almost nothing. Peekaboo! Not the slightest reaction. Unless it's your dad, it seems. He's so much more fun than me. When he smiles, you look surprised. When he hides behind his hands, you widen your eyes. He tickles your tummy; you shake your head and frown. I'm lying next to the two of you. You're lying in his lap. I don't understand the game you're playing.

In the first few months, your motor development is textbook. For months on end, every night, I hoist you out of your cradle by your left arm. Most mothers probably get out of bed and lift their child up using both their hands, but I can do it without getting up. Eventually I begin to wonder whether your shoulder can carry the weight. What if I dislocate it?

My cue is your crying. Ten months of breastfeeding, followed by a bottle and porridge. You enjoy eating, and you get lots. At the compulsory checkups at the Mother and Baby Clinic—or the Meddle and Bug Me Clinic, as I call it—they're happy. In terms of height and weight, you're near the top of the scale. You meet all the physical targets—you roll over, crawl and walk in time. All normal. Except you laugh at the wrong times, cry at the wrong things. Nothing ever scares you, you have a poker face, you bounce around the world, unfazed. I can't tell what you're feeling.<sup>2</sup>

You keep getting cuter. So adorable, a mixed-race child. The best of both worlds. You have my nose and daddy's feet. Your fat little thighs are so cute anyone would just want to gobble them up. You're just a little different from the other toddlers. A little weird. Pointing, waving, you do none of that. Or only when the situation no longer calls for it. You barely make eye contact, and you can't be comforted. For nights on end we sleep next to your cradle on the floor, or you lie between us in bed. You'll end up sleeping in our bed until you're eight. You'll only sleep if you're in our arms, or at the very least in our presence.

Autism. The first time the word comes up. I'm doing a show and am casually talking to one of the techs about you. He asks how you're doing and

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<sup>2</sup> I experience *everything*.

whether I enjoy being a mother and having a child. He is staunchly anti-reproduction—he’s even had a vasectomy because he doesn’t want to accidentally impregnate anyone. I say: ‘Charlie makes very little eye contact. He doesn’t really respond in any logical way. He doesn’t say anything, not even “mommy.”’

‘That sounds like autism,’ he says.

Do you know I often felt ashamed of the sort of mother I was?

I was ashamed of the mother I was that time you got stung in the seaside café. It was a horsefly, I think. We were sitting in the café and suddenly you got agitated and started squeezing me, hard. I knew we had to leave at once, because you were about to go into major meltdown. We were sitting upstairs, right at the back—the place was packed, and a fat blonde lady, about thirty years old, wouldn’t move her chair, not even an inch to let us through, even though everyone could tell just by looking at you and me that it was urgent. She froze on the spot, like people freeze when they see something scary, even though by doing that they’re putting their lives in danger. In those days, you often hit me.

[I was ashamed of the mother I was when you got stung in that seaside café. By a horsefly, I think. We were sitting in that café and suddenly you got agitated and started squeezing me, hard. I knew: we have to leave right now, because you’re about to have a giant meltdown. We were sitting upstairs, all the way in the back—the place was packed, and a fat blonde lady, around thirty years old, wouldn’t even move her chair an inch to let us through. Even though everyone could tell just by looking at you and me that it was urgent. She froze on the spot, like people freeze when they see something scary, even though by doing that they are putting their lives in danger. You often hit me in those days.]

On the beach below the café, I grabbed you. I pinned your arms to your body, wrapping my arms around them as if I was giving you a low hug. I turned myself into a human straitjacket. I pressed my whole body against yours and put my head against your neck, planting my legs wide in the sand to give myself a firm footing. Your ‘Heeeee’ sounded low and loud in my ear. If you’d bitten me, I would have had a problem. Fortunately, you didn’t.

We almost fell onto a large rusty anchor that had been put there as decor, an anchor more than three feet tall. As you were trying to pull me down onto the ground, I thought: we’re going to fall onto that anchor and be skewered.

Whenever I think I’m spent, it turns out I’ve barely used even twenty percent of my strength and I have at least eighty percent left. That time with



the horsefly, I reckon I used twenty-five. In such moments, I feel invincible, but afterwards my legs are shaking. The scene in the seaside café was life-threatening for us, but also potentially for the children there, our audience.

Audience participation is not uncommon when you have your temper tantrums. People were staring at us; the adults pulled their children away. I was ashamed—I felt like an odd black woman with her odd black child.

We fell back onto a stack of loungers next to the anchor. I'd waltzed us over there and used my body weight to push you down onto the top lounger. I pushed so hard that I'd have broken a normal person's arms and neck. I noticed you begin to relax. I realized that I was only using twenty percent of my strength at this point. My strength is inexhaustible—I can prevent anyone from getting up if I have to. And I had to. I can protect you, even if I end up breaking your arm in the process.

In hindsight, I think the horsefly was still trapped in your sleeve, so I didn't so much break your arms as strangle the horsefly.

After ten minutes I could let you go, because your body was relaxing more and more. The horsefly was dead. We walked away from our audience, back to the parking lot, a twenty-minute walk that took a lot longer because you had to sit down every thirty feet, still shaken. When we got to the car, I saw the red weal on your arm. You were shaking with fever; I was shaking from tension. I gave you two painkillers and a gulp of water. You were sweating, and I took off all your clothes. 'Take it easy, Charlie.' I lit a cigarette, leaning against the car. You sat motionless in the back seat. Shame about the lovely weather, I was upset about that.

Back home, I had a glass of wine. You got to take a bath. I gave you another painkiller. After the bath, I rubbed you down with Nivea, lovingly tended to your bite, and put you on the sofa under a heavy blanket to watch a movie and calm down. Safety. 'We're home, we survived.'

I felt the most ashamed that one time at the market. You were thirteen, and already quite a big boy. Physically precocious, you seemed older than you were. When you walked down the street, several feet behind me, as you preferred at the time—no longer hand in hand, you were a teenager, after all—and you looked a young man or grown man in the eye, they'd shout, 'What you looking at?' I began to realize you'd reached the age where your glances could be interpreted as provocative. You had a tendency to tap people and things, as if they could be operated by a touchscreen. After shopping for groceries, we were sitting on a terrace in the market, and you tapped the butt of a lady walking by. She didn't react, but she said something to her husband, who was walking beside her.

As if in slow motion, I saw him turn, walk back and start going at you, his face like a wild dog's. His forehead almost touched yours. 'Keep your dirty paws off my wife!' You grinned broadly and went 'Heeeeee' and 'Weeeeee.' He shouted all sorts of things into your mouth, but I didn't hear, because it was like a silent movie. I was frozen to my chair. Everyone else on the terrace ignored us, and after three endless minutes of pure aggression, cursing and jabbing his fingers into your shoulder, the man walked away. During the entire episode, the woman had her back turned to us. After about thirty feet, he suddenly seemed to realize that your only response during his attack had been 'Heeeeee' and 'Weeeeee' and a broad, goofy grin. That's probably when he realized that swiping his wife's butt hadn't been a matter of territory. He called 'Sorry' over his shoulder, casually, and kept walking. We never saw her face. I wouldn't be able to recognize him either; his anger veiled his appearance.

I felt like a sad black woman with her sad black child. As we walked back home I said, and I'll never forgive myself for that, 'You can't go out again, Charlie. You're not fit for this life.' I'm sorry, dear boy. I'm sorry that I didn't stand up for you. I'm ashamed of that. I've been ashamed so many times. I don't know if you're ever ashamed. Do you sense the stares you get? Do they hurt? Does it get to you when people look at you like that, when their first reaction is to be scared of you?

Some other questions that are also explored in *The Noble Autist*:

Do you have an understanding of time?  
 Who are you?  
 Who's going to take care of you when I'm no longer around?  
 Do you wish you could have gone to school?  
 What did you want to be when you grew up?  
 Do you know what it means to be a citizen?  
 Has anyone ever hurt you?  
 How do you experience interaction with people?  
 Have you had any friends?  
 Could you tell that I loved it when you were sick?  
 Do you think you could have killed someone during one of your tantrums?  
 Do you know what your superpower is?  
 Have you enjoyed your life?