

A Special Day

A Mother's Memoir of Love, Loss, and Acceptance after the Death of Her Daughter

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Translated by

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The decibel level of my alarm goes up a notch. It's insistent now. It must have been going for several minutes, trying to drag me from the depths of a night weighed down by a thousand dreams. I wish I could sleep through 'til tomorrow, buried beneath my comforter. I stretch and reach my hand into the crumpled sheets next to me, but the space is empty and cold—Loïc is up already. I listen intently and make out the sound of the shower.

A jumble of letters and figures spools through my head behind my still closed eyelids. My sleepy mind swirls them around each other before eventually arranging them into a logical order. A date emerges: February 29. Reality takes shape. It's February 29. Today is Thaïs's birthday. My daughter would be eight years old.

Eight already—it doesn't seem possible. What does an eight-year-old do on her birthday? Does she jump out of bed singing? Does she dress up like a princess to mark the day? Does she invite her friends over to blow out her candles? I won't be seeing any of that today. Thaïs's life came to an end more than four years ago. Four and a quarter years, to be precise. The proportions have been subtly inverted: the time she has spent in heaven is now longer than her years with us. Thaïs lived for three and three-quarters years. A short life that totally changed mine.

Her photo always lives on my bedside table. I see her every morning, sitting on the grass with her fuchsia-colored dress fanned out around her, and holding a cookie in her dimpled hand. She's smiling right at the camera, her eyes sparkling. I study her, full of emotion, then my gaze shifts to the book sitting beside the photo frame. I know every detail of its cover, the beach at low tide, the clear sky, the little girl walking with her head turned to look at the ground, her arms stretched out for balance, her bare feet on

the wet sand. I pick up the book without opening it, and hold it to me. I know every sentence by heart. They tell the story of Thaïs as told by me. And as lived by me.

I thought my life had been robbed of happiness forever that December night just before Christmas when I felt Thaïs exhale her last breath. I don't need to delve very far into my memory to recall those grim, dark hours. I don't need to dig very deep into my heart to relive the pain. The memories are there, just beneath the surface. A shadow fell across my eyes the moment she left, and I was afraid that I would live in a world deprived of light from then on. I thought I would never experience joy again. Who could still believe in happiness when their child has died? And yet. . . .

I spent many years happily ticking boxes. Pretty little square boxes with nice, clear outlines. I didn't have to draw up a list; I instinctively knew what would be on that list—it's dictated by the collective subconscious. So, I had a clear idea of what I needed to be happy. As life went by, I checked off entries like drawing a line through items on a shopping list: "done that." In the space of thirty-two years I'd checked most of the boxes. I was just about to embark on the supplementary list, the one for really lucky people . . . when I came to realize how vacuous the process was.

I had no trouble ratifying the first part about childhood and my teenage years: I grew up in a flourishing, loving, united family. I got along well with my brothers and sisters, and loved my parents. My time at school went by practically without a hitch. After graduating high school I embarked on the course I'd been wanting to do for a long time, studying to be a journalist. My transition to adulthood went smoothly. Once I had

my diploma, I found a job at a newspaper. Then I met Loïc, the love of my life. We got married, we had a son, and then a daughter—a pigeon pair. We bought an apartment and a car. We both had jobs that guaranteed us personal fulfillment and a degree of recognition. That's a rough outline of thirty-two years of happiness: happy childhood, check; well-balanced adolescence, check; successful studies, check; interesting job, check; husband and perfect children, check; apartment, car, holidays, check. Life of bliss, check! How great, how wonderful, how perfect.

In all these lists of the codes that make up happiness, there is no place for sickness, pain, and suffering, not even in the margins. So where did my daughter's unusual way of walking fit into all this? Because, at the grand old age of eighteen months, Thaïs didn't have an entirely normal gait. Her feet tilted outward slightly as they touched the ground. I noticed it one late summer's day when I saw her footprints in the wet sand on a beach in Brittany. Loïc and I were just smugly counting all those ticked boxes and contemplating having a third child to ice the cake of our lovely family. I watched Thaïs walk toward me, and looked along the line of footprints she'd left in the sand, thinking I'd feel a surge of maternal pride. I noticed that a bulge of sand had formed on the outside of each footprint. And I didn't like it. Even before anxiety set in, I instantly hated that flawed walk. I saw it as the grain of sand that would jam the cogs of our unimpeachable happiness. I wanted Thaïs to keep her promise of perfection, not to hobble like that. Those awkward little footsteps threw a pebble into our idyllic pond, and went on to whip up a terrible storm.

Sometimes it takes only a moment, just one word to turn a life upside down. The word: "leukodystrophy." The moment: when we were told. Our peaceful existence was blown apart the day Thaïs turned two. Sheltered from prying eyes, in a consulting room at the end of a long corridor in a neuropsychiatric unit, doctors told us that our daughter had a degenerative neurological condition called metachromatic leukodystrophy. Too many unpronounceable words in one sentence. . . . Her life expectancy would be short and her existence painful. Over the coming months Thaïs would gradually lose all her faculties: the ability to walk, and to move at all, but also the power of speech, her sight, her hearing. . . . Then she would lose her life. And the last sentence was the cruelest: there is no cure, no form of treatment. No hope. The end of happiness. Or at least of the concept I'd had of it until then.

The phosphorescent numbers on the alarm clock bring me back to the present. It's definitely time I get up if I don't want the whole household to be late. I wistfully climb out of the warm covers, slip on a robe, and walk out of the bedroom. A crack of yellow light filters under Gaspard's door. I go in and, among a scrambled-up comforter, I spy a thick mop of hair, a hand gripping an open book, and, behind dark-rimmed glasses, two big brown eyes speeding over the words. Gaspard's already reading at this time in the morning. I tilt my head to make out the title on the cover. Having devoured the whole "Petit Nicolas" series of children's books, Gaspard is now chomping his way through spy novels.

I rumple his hair and tell him it's time to get up. He heaves a sigh.

"Already? I'm on a real cliffhanger."

"Yes, already and quickly. You're going to be late for school."

I always get the same refrain, and it makes me smile every morning. I like his daily protests because it's so fitting for a ten-year-old. For any ten-year-old. I've often worried that Gaspard would grow up too quickly over these ten years. Our family circumstances mean that he was confronted with sickness, suffering, and death at a young age. His image of life has been altered. But he's still developing like most boys his age. He doesn't like school or girls—at least not for now. He'd rather be playing with his friends or letting off steam on the rugby pitch. The difficulties of life haven't robbed Gaspard of his childhood. He's lived it to the full, although he now feels he's turned a corner: on his tenth birthday, he announced that he would now be a preteen until he

was thirteen. From then until he was eighteen he'd be experiencing "teenage angst." . . . There we are, the schedule is all set out. We know what to expect over the next few years. Like any mother, I'm not relishing being confronted with a son in full-blown adolescence, but I'm happy to see that Gaspard is planning on going through these natural stages. It means he's well balanced.

When he's dressed, Gaspard comes to join me in the kitchen. Loïc comes in next, also ready to face the day. We each sit down at our places. My men aren't very talkative at breakfast time. Gaspard helps himself to some orange juice and pours cold milk over his cereal, then disappears behind the cardboard packaging, absorbed in the game that this particular brand prints on the back. Loïc stirs his coffee, without a word. Then he breaks the silence, which until then was interrupted only by chocolate-coated cornflakes crunching between Gaspard's teeth.

"Gaspard, do you know what today is?"

"A school day, like all the rest," he replies glibly.

"Yes, but it's February 29. That's a special date."

"I know; it only happens every four years. Actually, I don't think it's fair we have school today. This should be a holiday. I can't see why they give us an extra day at school like that."

"What really matters," Loïc persists, "is today is Thaïs's birthday."

"Oh yes, it is . . . how old would she be?"

"Eight. A big girl, wouldn't you say?"

Gaspard's spoon hovers midway between his bowl and his mouth. His eyes blur into the middle distance as he analyzes the information. He doesn't have an eight-year-

old sister. He tries to imagine it, to project himself into a hypothetical present. The spoon continues on its way, and Gaspard speaks through his mouthful: "Do you remember Thaïs well, Mommy? I feel like I'm forgetting her face. Do you get that, too?"

"Yes, sweetheart, I get that a lot. Memories fade with time, but feelings stay the same."

This all seems clear to me now, but I would never dare tell him how terribly I've struggled against the natural failings of the human memory. Yes, you can even forget what you thought was unforgettable. Even your own child's features, the smell of her hair, the feel of her skin. You forget, and there's nothing you can do about it. I felt such panic the first time I asked myself, "Actually, what *were* her eyes like, and her voice, and the warmth of her body?" I felt guilty. I felt I had to do everything in my power to stop time from obscuring my memory with its opaque veils, until I realized that Thaïs was fading in my mind's eye but not in my heart. The heart's memory is our feelings, and it doesn't suffer any erosion with the passage of time. It is fresh, timeless, unchanging. When I call on my heart's memory, I can conjure impressions inscribed in the very depths of my being. The feelings I had with Thaïs and for her come back to me intact. And I can savor magical moments in which my memory faithfully restores the way Thaïs smelt, the twinkle in her dark eyes, the depth of her sigh. I cry like a baby every time my feelings bring my memories back to life.

“Time to go!” Loïc announces. He’s dropping Gaspard at school this morning on his way to work. He takes me gently in his arms and whispers, “I hope you’re going to be okay today, my darling. I’ll be thinking of you, and her. Eight years ago we brought a wonderful little girl into the world.” I cling to him, burying my head in the crook of his neck, dampening his collar with my tears. Yes, a wonderful little girl. . . .

Gaspard slips out to brush his teeth and wash his face and hands, puts on his coat, heaves his heavy satchel onto his back, and leaves the apartment with a “Have a nice day, Mommy. See you later.” I rush over and jam my foot in the door just before it slams shut.

“Wait, Gaspard; you didn’t give me a kiss.”

“Mom!” he sighs sulkily. “I’m ten years old. I’m not going to kiss you every time I go out. Kisses are for babies.”

My boy wants to be all grown-up already. Still, he doesn’t pull away when I plant a long, noisy kiss on each of his cheeks. I hold him to me for a moment before giving him back his freedom. I too wish this could be a holiday, so that we could stay together as a family today.

I step back into the now-silent apartment. Everything feels strangely still. I take refuge under the shower and let the hot water stream over my shoulders for a long time, hoping that I can finally release this recalcitrant muscular tension. Then I wrap

myself in a thick towel and leave the steamy bathroom. In my bedroom I stand in front of the open wardrobe, gazing in bewilderment at my carefully folded clothes.

“I don’t have anything to wear,” I say with a sigh.

This might seem like an incongruous comment to anyone looking at the dizzying piles of clothes in my closet. But I really mean it. I have more clothes than I need, but I don’t have anything to wear today, because I can’t see what sort of outfit would suit my mood. That’s right—my moods have their own sartorial codes; the way I dress depends on how I feel that day. Today nothing in my wardrobe seems to reflect my state of mind. My mood is shaky. Ever since first light it’s been hovering between happiness and pain. And it will stay like that ’til after dark.

I knew, even before Thaïs died, that her birthday would be more painful to get through than the anniversary of her death. Of course, memories of the day she died and, even more so, of her funeral are always with me. I can picture that overcast Brittany sky, the hostile darkness feebly illuminated by flickering torches. I can feel the drizzly December chill seeping through our clothes so that our bodies are wrapped in a straightjacket of ice. I see myself kneeling in the cloying wet mud at one end of the gaping hole that will swallow up a part of my very flesh, reeling drunkenly from my tears and the cup of sorrow I’ve drunk. It’s always an ordeal remembering that time.

Memories of Thaïs’s birth are perhaps crueler still when you see them through the prism of the rest of her life. I always dreamed of having a daughter. Thaïs’s arrival was all I could have wished for. That tiny little baby represented so much promise of happiness to my mother’s heart. I now feel contradictory emotions when I remember that day. Every year, between February 28 and March 1, I cry and smile at the same

time. I cry for the broken dreams and that terrible absence, and I smile to think of the time I spent with Thaïs. Obviously I wish she could have been healthy, and could live many long years to come, but I don't regret a minute we shared together, those heart-to-heart moments, that precious lifespan. And I'm grateful when I remember everything my daughter taught me. The minute I held Thaïs in my arms for the first time, I felt that I knew I had an ally for life. Not for my life, no; for her life, her three-and-three-quarters-year life. And beyond that, too, because Thaïs is still a precious ally to me.

I decide to leave it to chance. I close my eyes and rummage blindly through the piles of clothes. My hands settle for textures rather than shapes. They plump for a very simple silk top and a comfortingly soft sweater. I open my eyes; chance did a good job: the sweater is purple—Thaïs's favorite color. I complete the outfit with a pair of jeans, high-heeled boots, and matching earrings. Now I'm finally ready to get through today!

I've only just finished getting dressed when a voice calls from behind me. I can hear his little footsteps sliding over the wooden floor; I can smell his sleepy-child smell. From the lilt in his voice, I can tell that his face is lit up with a smile. I crouch down and draw him to me, wrapping my arms around him as tightly as I love him. My little treasure. . . .

“Good morning, Mommy.”

“Good morning, my little Arthur. You slept well. It’s late, you know.”

“I slept well,” he agrees, “but I had a ‘fog.’”

“A fog? What’s that?”

“It’s a horrible dream with monsters and wolves. Do you want me to tell you about it?”

“Of course I do. You tell me about your fog.”

Arthur launches into one of those breathtaking accounts that he alone has mastered. I can tell by the way his eyes dart around that he’s embellishing things as he goes along. The story is a total jumble, but it bristles with terrifying creatures. When he stops, he’s almost out of breath from this endless tirade.

“You see what I mean? Scary, huh?”

“Yes very. Much more frightening than a nightmare.”

“What’s a nightmare?” he asks.

“It’s like a fog. . . .”

“Like a ‘ninemare’ then?”

“Very nearly like a ‘ninemare.’”

I’m weak. I can’t bring myself to correct his mispronunciations, his ‘tooshpaste’ and ‘radigator’ and ‘soap duds,’ all the words he gets wrong, distorts, or appropriates in his own original way. All the words that remind me that my little boy is three and a

quarter, that he can walk and talk and is in perfect health. That he's my obsession. Yes, Arthur is my greatest obsession.

Sometimes it's good to love to distraction. To lose your mind over someone, but not your head, just putting aside rational thoughts and listening only to your heart. Loïc and I had been tormented by a longing for another child for some time. We weren't trying to replace Thaïs—the irreplaceable Thaïs! We just wanted to have a baby, like any other couple, that was all. It was a longing that drained me and saddened me because I thought it couldn't be fulfilled. Metachromatic leukodystrophy is inscribed in our genes. We could pass it on to any child of ours from the moment of conception. The terror of suffering all over again locked down my womb; I didn't feel that I could possibly carry another baby. I was terrified and unhappy. One morning Loïc managed to find the words to break down the prison of my fears.

"Okay," he said. "What if we tried to look at the situation differently. Do you feel you could love another child? Do you think you could love that child just as it is, and you could do everything in your power to make it happy?"

"Yes!" I almost shouted. "Yes, I could. That's all I want. To love a baby and make it happy."

"Well, what are we afraid of, then?"

Nine months later, almost a year to the day since Thaïs died, Arthur was born, in perfect health. We overcame our fears; we took a chance on life. Our families congratulated us, welcoming the news with touching enthusiasm. On the other hand,

others, some of them close to us, couldn't understand our decision. When people asked us, "But how could you have another baby?" we replied simply, "The way most people do, in private!" This answer wasn't meant to be just a humorous riposte; it really was the truth. The decision to have a baby belongs to us. It is integral to our relationship. It is in no way open to public debate or a referendum. We will never justify our choice to have Arthur to anyone. We can't even explain it. It's a sort of madness, a wonderful madness, the madness of love. And, to quote Blaise Pascale, "the heart has its reasons, of which reason knows nothing."