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ghost boy

the miraculous
escape of a
misdiagnosed boy
trapped inside
his own body

MARTIN
PISTORIUS

GHOST BOY

The Miraculous Escape of a Misdiagnosed
Boy Trapped Inside His Own Body

MARTIN PISTORIUS



NELSON
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For my wife, Joanna, who listens to the whispers
of my soul and loves me for who I am.

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PROLOGUE

Barney the Dinosaur is on the TV again. I hate Barney—and his theme tune. It’s sung to the tune of “Yankee Doodle Dandy.”

I watch children hop, skip, and jump into the huge purple dinosaur’s open arms before I look around me at the room. The children here lie motionless on the floor or slumped in seats. A strap holds me upright in my wheelchair. My body, like theirs, is a prison that I can’t escape: when I try to speak, I’m silent; when I will my arm to move, it stays still.

There is just one difference between me and these children: my mind leaps and swoops, turns cartwheels, and somersaults as it tries to break free of its confines, conjuring a lightning flash of glorious color in a world of grey. But no one knows because I can’t tell them. They think I’m an empty shell, which is why I’ve been sitting here listening to *Barney* or *The Lion King* day in, day out for the past nine years, and just when I thought it couldn’t get any worse, *Teletubbies* came along.

I’m twenty-five years old, but my memories of the past only begin from the moment I started to come back to life from wherever I’d been lost. It was like seeing flashes of light in the darkness

as I heard people talking about my sixteenth birthday and wondering whether to shave the stubble on my chin. It scared me to listen to what was being said because, although I had no memories or sense of a past, I was sure I was a child and the voices were speaking about a soon-to-be man. Then I slowly realized it was me they were discussing, even as I began to understand that I had a mother and father, brother and sister I saw at the end of every day.

Have you ever seen one of those movies in which someone wakes up as a ghost but they don't know they've died? That's how it was, as I realized people were looking through and around me, and I didn't understand why. However much I tried to beg and plead, shout and scream, I couldn't make them notice me. My mind was trapped inside a useless body, my arms and legs weren't mine to control, and my voice was mute. I couldn't make a sign or a sound to let anyone know I'd become aware again. I was invisible—the ghost boy.

So I learned to carry my secret and became a silent witness to the world around me as my life passed by in a succession of identical days. Nine years have passed since I became aware once more, and during that time I've escaped using the only thing I have—my mind—and explored everything from the black abyss of despair to the psychedelic landscape of fantasy.

That's how things were until I met Virna, and now she alone suspects there's an active consciousness hidden inside me. Virna believes I understand more than anyone thinks possible. She wants me to prove it tomorrow when I'm tested at a clinic specializing in giving the silent a voice, helping everyone—from those with Down syndrome and autism to brain tumors or stroke damage—to communicate.

Part of me dares not believe this meeting might unlock the person inside the shell. It took so long to accept I was trapped inside my body—to come to terms with the unimaginable—that I'm afraid to think I might be able to change my fate. But, however fearful I am, when I contemplate the possibility that someone might finally realize I'm here, I can feel the wings of a bird called hope beginning to beat softly inside my chest.

1 | COUNTING TIME

I spend each day in a care home in the suburbs of a large South African city. Just a few hours away are hills covered in yellow scrub where lions roam looking for a kill. In their wake come hyenas that scavenge for leftovers and finally there are vultures hoping to peck the last shreds of flesh off the bones. Nothing is wasted. The animal kingdom is a perfect cycle of life and death, as endless as time itself.

I've come to understand the infinity of time so well that I've learned to lose myself in it. Days, if not weeks, can go by as I close myself down and become entirely black within—a nothingness that is washed and fed, lifted from wheelchair to bed—or as I immerse myself in the tiny specks of life I see around me. Ants crawling on the floor exist in a world of wars and skirmishes, battles being fought and lost, with me the only witness to a history as bloody and terrible as that of any people.

I've learned to master time instead of being its passive recipient. I rarely see a clock, but I've taught myself to tell the time from the way sunlight and shadows fall around me after realizing

I could memorize where the light fell whenever I heard someone ask the time. Then I used the fixed points that my days here give me so unrelentingly—morning drink at 10 a.m., lunch at 11:30, an afternoon drink at 3 p.m.—to perfect the technique. I've had plenty of opportunity to practice, after all.

It means that now I can face the days, look at them square on and count them down minute by minute, hour by hour, as I let the silent sounds of the numbers fill me—the soft sinuousness of sixes and sevens, the satisfying staccato of eights and ones. After losing a whole week like this, I give thanks that I live somewhere sunny. I might never have learned to conquer the clock if I'd been born in Iceland. Instead I'd have had to let time wash over me endlessly, eroding me bit by bit like a pebble on the beach.

How I know the things I do—that Iceland is a country of extreme darkness and light or that after lions come hyenas, then vultures—is a mystery to me. Apart from the information that I drink in whenever the TV or radio is switched on—the voices like a rainbow path to the pot of gold that is the world outside—I'm given no lessons nor am I read to from books. It makes me wonder if the things I know are what I learned before I fell ill. Sickness might have riddled my body, but it only took temporary hostage of my mind.

It's after midday now, which means there are less than five hours to go before my father comes to collect me. It's the brightest moment of any day because it means the care home can be left behind at last when Dad comes to pick me up at 5 p.m. I can't describe how excited I feel on the days my mother arrives after she finishes work at 2:00.

I will start counting now—seconds, then minutes, then hours—and hopefully it will make my father arrive a little quicker.

One, two, three, four, five . . .

I hope Dad will turn on the radio in the car so that we can listen to the cricket game together on the way home.

“Howzat?” he’ll sometimes cry when a wicket is bowled.

It’s the same if my brother David plays computer games when I’m in the room.

“I’m going up to the next level!” he’ll occasionally shriek as his fingers fly across the console.

Neither of them has any idea just how much I cherish these moments. As my father cheers when a six is hit or my brother’s brow knits in frustration as he tries to better his score, I silently imagine the jokes I would tell, the curses I would cry with them, if only I could, and for a few precious moments I don’t feel like a bystander any more.

I wish Dad would come.

Thirty-three, thirty-four, thirty-five . . .

My body feels heavy today, and the strap holding me up cuts through my clothes into my skin. My right hip aches. I wish someone would lie me down and relieve the pain. Sitting still for hours on end isn’t nearly as restful as you might imagine. You know those cartoons when someone falls off a cliff, hits the ground and smashes—kerpow!—into pieces? That’s how I feel—as if I’ve been shattered into a million pieces, and each one is hurting. Gravity is painful when it’s bearing down on a body that’s not fit for the purpose.

Fifty-seven, fifty-eight, fifty-nine. One minute.

Four hours, fifty-nine minutes to go.

One, two, three, four, five . . .

Try as I might, my mind keeps returning to the pain in my hip. I think of the broken cartoon man. Sometimes I wish I could hit the ground as he does and be smashed into smithereens. Because maybe then, just like him, I could jump up and miraculously become whole again before starting to run.