

Ghost Boy

The miraculous escape... trapped inside his own body (a summary by Pat Evert)

- Prologue

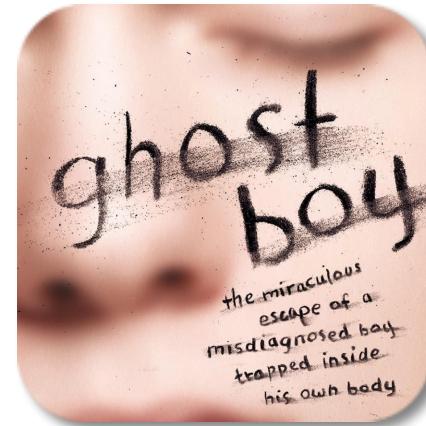
My mind was trapped inside a useless body, my arms and legs weren't mine to control, and my voice was mute. I couldn't make a sign or a sound to let anyone know I'd become aware again. **I was invisible —the ghost boy.** Nine years have passed since I became aware once more, and during that time I've escaped using the only thing I have—my mind.

• The deep

Until the age of twelve, I was a normal little boy. The last words I ever spoke were about a year after I first became ill as I lay in a hospital bed. I was completely unresponsive. I was in a kind of waking coma. Years passed with me lost in my dark, unseeing world. My parents even tried putting mattresses on the living-room floor so that they, Kim, and David could all live as I did—at floor level—in the hope of reaching me. But I lay like an empty shell, unaware of anything around me. Then one day, I started coming back to life.

• The box

I wasn't paralyzed: my body moved but it did so independently of me. My limbs had become spastic. They felt distant, as if they were encased in concrete, and completely deaf to my command. People were always trying to make me use my legs—physical therapists bent them in painful contortions as they tried to keep the muscles working—but I couldn't move unaided. I think my mind started to awaken at about the age of sixteen, and by nineteen it was fully intact once more. **The only person who knew there was a boy within the useless shell was God, and I had no idea why I felt His presence so strongly.** I'd been put into a box long before, after all. Each of us has. Are you the "difficult" child or the "histrionic" lover, the "argumentative" sibling or the "long-suffering" spouse? Boxes make us easier to understand, but they also imprison us because people don't see past them. **We all have fixed ideas of each other even though the truth can be far removed from what we think we see.** So that's why I stayed inside the box I'd been put into so long before. It was the one marked with a single word: "imbecile."



• **My parents**

I realized that my illness had driven a deep wedge into the heart of a family I somehow instinctively knew had once been so happy.

• **Changes**

The changes are so small that my parents might not even be aware of them, but I can sense hope in the air for the first time in years. I'll use symbols because I can't read or write. Letters have held no meaning for me since I came back to life.

• **The beginning and the end**

My greatest fear is that I will be left in one of those places where children like me sit all day with no interaction or stimulation. That would be the worst kind of living death. Humping you like a sack of potatoes, they wash you briskly with freezing water and always get soap in your eyes, however hard you squeeze them shut, before thoughtlessly feeding you food that is either too cold or too hot. All the while they don't speak a word or smile for fear of seeing a person staring back. Do they really think that a limited intellect means a child can't feel viciousness in a person's touch or hear anger in the tone of their voice? There are three topics women will return to again and again in conversation: their husbands, who are often a disappointment; their children, who are usually wonderful; and their weight, which is always too high.

• **Day by day**

Each emotion is different: excitement makes my stomach shiver, guilt brings a soft swell of nausea deep inside, and remorse makes my heart feel heavy. These emotions are so different to what I've known for so long—feelings that I muted to gray to save myself from being driven mad by the monotony of my existence and my powerlessness over every identical day.

• **The wretch**

Virna is the only one who sees me. More importantly, she believes in me. When I catch sight of my reflection in the mirror, I quickly look away because staring back at me is a man with glazed eyes, a bib to catch his drool, and arms that are drawn up to his chest like a dog begging for bones. I hardly recognize this stranger, so I understand if other people find him hard to stomach.

• **Life and death**

The symbol I return to perhaps more than any other because **I am so unsure of what to say after those two small words. I am . . . What? Who? I don't know.** I've never been given a chance to find out. The ghost boy was finally coming back to life.

• **I tell a secret**

All I know in this moment, as I look at Virna, is that I love her. I've never told anyone anything like this before, **never dared imagine that it might be possible for someone to love me.** "We can only ever be friends," Virna says slowly. "You must understand that. There never can be anything between us, Martin. I'm sorry." I can feel a pain in my

chest. I've never known anything like it before, but I know what it is. I've heard it talked about in movies and listened to people describe it in songs. I understand what it is now even as it pierces me: heartbreak.

• **The furies**

If there were three furies in my story, their names were Frustration, Fear, and Loneliness. These were the phantoms that trod their blackened path through my mind for nine long years. Frustration came first, every molecule vibrated with anger as she infected me. It constantly reminded that I couldn't determine my own fate in even the smallest of ways. Not being able to walk always felt almost insignificant to me compared to my other limitations. Next came fear, the fear of being powerless over what happened to me, the fear that I was growing up and would be put into permanent residential care because my parents couldn't cope with me as they got older. **Loneliness was perhaps the most terrifying of all.** I was hopeful for a moment of connection that would defeat the feeling of being completely alone... I lay squirming with shame, thinking how repulsive I must be.

• **Daring to dream**

"Oh no!" Dr. Bryen exclaims. "I don't agree with you at all. Don't you see, Martin? You can't ask other people to give you permission to dream. You just have to do it." I've never been asked to think about what I want. **I don't know what it's like to make decisions for myself, let alone dare to dream.** I look at her. I know so much about other people's expectations and so little about my own.

• **Standing in the sea**

I went on holiday with my family for the first time when I was twenty-five. Usually I went into residential care when they went away, but this time I was taken on the trip to the sea. And it was only in that moment, as I felt my father's arms holding me upright and his strength keeping me steady, that **I knew his love was strong enough** to protect me from an ocean.

• **The speech**

The room is quiet as I talk about meeting Virna and my assessment, the hunt for a communication device. Then I tell them about the months of research into computer software, and the work I've done learning to communicate. "In 2001 I was at a day center for the profoundly mentally and physically disabled," I say. "Eighteen months ago, I didn't know anything about computers, was completely illiterate, and had no friends. "Now I can operate more than a dozen software programs, I've taught myself to read and write, and I have good friends and colleagues at both of my two jobs."

• **The laptop**

I must spend the rest of my life relying on a hunk of metal that might give up suddenly without a hint of warning. I can hardly breathe. My life is so fragile. I've spent all this time thinking that I'd left the ghost boy behind forever. It's only now that I realize how closely he still shadows me.

- **Lurking in plain sight**

People don't hear what they don't want to, and I have no way of making them listen. What happened to me is a darkness that is always with me, and I fear I will be tormented forever if I don't try to speak of it. I learned that the people who play out their darkest desires on us, however fleetingly, aren't always the most easily recognizable. They aren't bogey men or women; they are ordinary, forgettable people. Maybe they are even entirely blameless until the chance to use a seemingly empty vessel encourages them to cross a line they might otherwise never have dared breach.

- **Strangers**

It was 1998, and I was twenty-two years old. I'd started to become aware six long years before and was **convinced by then that no one would ever know I was whole inside.** I became seriously ill with pneumonia. Sadness created a chasm inside me. I was tired of living. I didn't want to fight any more. Tiny gestures from strangers were what started to tether me to the world again. I didn't know what each of those strangers had given me until one of them **touched my broken, twisted, useless body and made me realize that I wasn't completely abhorrent.** And it was then that I realized that families might be the ones who pick us up time and again but strangers can also rescue us—even if they don't know they're doing so.

- **Everything changes**

We talk about the tiny details of our days and our hopes for the future, we joke together and laugh, and talk more honestly about our innermost feelings than I've ever done before. There is no need to hide. I feel I can trust her. If I want to be loved for who I am, then Joanna must know all of me, so I tell her all my physical limitations. I've lived my whole life as a burden. She makes me feel weightless. I'm usually so careful and considered, but Joanna is making me reckless. She doesn't see barriers but possibilities; she is utterly unafraid, and I'm beginning to feel that way too.

- **Falling**



Love might be irrational, but we make **the choice to risk everything.** The greatest lesson I'm learning with her, though, is that living life is about taking chances, even if they make you feel afraid. The prize at stake was the one I wanted most. Life can't be experienced at arm's length like an academic project. It must be lived, **gradually I've learned to trust my own judgement**—even if it is sometimes wrong—as I've realized that life is about shades of gray, instead of black and white. And the most important thing I've

learned is how to take risks. Although I found it disorienting when it started to happen each day, week or month, I learned that this is what life is like—unpredictable, uncontrollable, and exciting. Then I met Joanna, and now I'm prepared to take the greatest chance with her. For the first time in my life, **I don't care what others think or worry about keeping up appearances** and creating a good impression.

• **Together**

I am drunk, intoxicated by everything that is happening to me for the first time: seeing her smile when she looks up at me sitting opposite her and losing myself in her kiss. I've never known a person who accepts me so completely and has so much peace inside them. **I've never had someone take pleasure in me before.** It is the simplest but most perfect of feelings. What surprises me most, though, is that she seems almost uninterested in my rehabilitation.

• **I can't choose**

But I can't do it. I don't know how. It's a secret I've kept for all the months that we've known each other. I've hidden it so well that I've prevented it from being brought out into the open. I'm lost in Joanna's world, where there are constant decisions to be made—what to eat, where to go, and when to do things. As soon as one decision is made, it feels as if another is snapping at its heels, and I feel **overwhelmed by choices** I'm not used to making. My fear of the world feels like a boulder that weighs heavy inside me, a shadow that is threatening to blot out all of her light. I'm not what she thinks I am. I'm a fraud.

• **Confessions**

I remembered all the times I'd asked myself what **I dared to dream** since meeting Diane. All I wanted when I first asked myself the question was to be able to communicate more and go out into the world. Once I'd achieved that and started working, I dreamed of living a more independent life and finding someone to share it with. Now I've met Joanna and her dream is mine too—a wedding and a house together.

• **Up, up and away**

"You are my soulmate, my best friend, my companion, my lover, my rock and strength, my soft place to fall in this crazy world. And that is why I want to hold you, cherish you, take care of you, protect you, and love you with everything I have. So will you do me the honor, the enormous privilege, of sharing the rest of my life with me and becoming my wife?" I push my hand into my pocket and pull out the ring. There are tears in Joanna's eyes as I hold it up to her—a pool of gold hanging by a thread that glints in the early morning light. She bends towards me. "Yes, my liefie," she says. "I will be proud to be your wife."



Martin and Joana married in 2008 and had a baby boy in 2018.