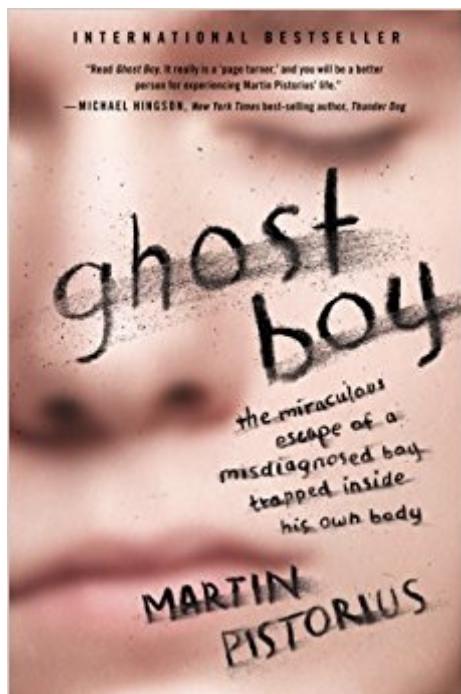


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# Ghost Boy: The Miraculous Escape Of A Misdiagnosed Boy Trapped Inside His Own Body



## Synopsis

They all thought he was gone. But he was alive and trapped inside his own body for ten years. In January 1988 Martin Pistorius, aged twelve, fell inexplicably sick. First he lost his voice and stopped eating. Then he slept constantly and shunned human contact. Doctors were mystified. Within eighteen months he was mute and wheelchair-bound. Martin's parents were told an unknown degenerative disease left him with the mind of a baby and less than two years to live. Martin was moved to care centers for severely disabled children. The stress and heartache shook his parents' marriage and their family to the core. Their boy was gone. Or so they thought. Ghost Boy is the heart-wrenching story of one boy's return to life through the power of love and faith. In these pages, readers see a parent's resilience, the consequences of misdiagnosis, abuse at the hands of cruel caretakers, and the unthinkable duration of Martin's mental alertness betrayed by his lifeless body. We also see a life reclaimed—a business created, a new love kindled—all from a wheelchair. Martin's emergence from his own darkness invites us to celebrate our own lives and fight for a better life for others.

## Book Information

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## Customer Reviews

'It is a deeply affecting and at times shocking book... The Diving-Bell and the butterfly but with a happy ending' Sunday Times 17/7 'Deeply moving' Mail on Sunday ']Pistorius] is almost fearless in the way he confronts emotional reality' Catherine Deveney, Scotland on Sunday --Catherine Deveney, Scotland on Sunday

Martin Pistorius was born in Johannesburg, South Africa in 1975. An unknown illness at the age of twelve left him wheelchair bound and unable to speak, and he spent fourteen years in institutions. In 2001 he learned to communicate via computer, make friends and change his life. In 2008 he met the love of his life, Joanna, and immigrated to the UK. In 2009 they married and in 2010 he started his own business. He describes himself a Geek with a wicked sense of humour and a love of technology. He loves animals, is a keen photographer, enjoys watching cricket, Formula 1 Grand Prix and films, listening to music, spending time with friends and, most of all, being with his wife.

So many books are so poorly written that reading them is drudgery for me. I'm an avid reader, but I find myself putting quite a few books back on the shelf after the first few chapters. Mr. Pistorius grabbed my attention on page one and kept it through the acknowledgements at the end. I still can't stop thinking about him. I've been an RN for many years. This book made me question my attitude toward many patients who've been in my care. I'm kind and compassionate, for sure, but could I have missed something with some of my most debilitated patients? For at least one of them was there a keen intellect, hidden by a silent, twisted body? This book makes me wonder.

When Martin Pistorius was 12 years old, he came home from school with a sore throat. Over the next two years, his mind and body shut down, until he was left a quadriplegic who could not speak. Then, around the time he was 16, his mind started coming back to life. He tells his story in the book, *Ghost Boy*. As Martin becomes more aware, he realizes that he has little to no control over his limbs and that he has no voice. All he can do is smile and move his eyes and head. He tries to use these signals to let everyone around him know that he is conscious and aware, but, as he states in the book, "They'd been told long ago that I was severely brain damaged, so when the young man with stick-like limbs, empty eyes, and drool running down his chin occasionally lifted his head, that's what they saw." Martin spends the next decade in his unresponsive body, without a working voice. His days are spent at a day care facility while his parents work, but his father picks him up every evening to take him home to the family. His mind is active, and he spends much of his time developing elaborate fantasies to escape the horror of being trapped inside his own body; it's the only way he keeps from going mad. Then a new caretaker enters his life and has a hunch that Martin is aware. She convinces others around her, and they take him to be evaluated for an alternative communication device. He passes the evaluation, and a new life is opened for him. Martin speaks of his faith in God; that while he couldn't explain it, he knew that God was with him and he wasn't

alone. His courage and strength is inspiring, as is the love of his father and mother and the woman he ends up marrying. I couldn't put the book down. Ghost Boy is an book of amazing perseverance through the most horrific trials one could imagine, and it's definitely worth your time to check out this true story. Disclosure of Material Connection: I received this book free from the publisher through the BookSneeze.com® book review bloggers program. I was not required to write a positive review. The opinions I have expressed are my own. I am disclosing this in accordance with the Federal Trade Commission's 16 CFR, Part 255 [...] : "Guides Concerning the Use of Endorsements and Testimonials in Advertising."

A Review of: Ghost Boy, by Martin Pistorius The author of this book, Martin Pistorius, spent many years unable to share any thoughts or feelings he had. The book is addressed to any people surrounding or interacting with individuals who are using an AAC device, or who may need to use an AAC device in the future. Martin gives a firsthand view of what it was like to spend years locked inside his own mind, as well as his journey through discovering AAC and progressing using his device. Can you imagine spending years understanding everything going on, yet unable to give any indication that you're aware? Martin's life changed drastically when he was given the ability to speak again. Martin Pistorius was 12 years old when he went home sick from school, never to return. What started as a sore throat became Martin's gradual decline to what seemed like an almost lifeless being. His parents exhausted all efforts to uncover the source of his illness and get him the help needed. There was a period of time in which Martin was completely unaware of everything around him, until one day he started becoming aware again. His body wasn't progressing with his mind. Martin was unable to control his body or voice; however, his mind was slowly progressing, and continued to do so until he reached full cognitive abilities. He had no way to inform those surrounding him that his mind had returned. The woman who made the life-changing difference for Martin was Virna, the relief caregiver at the care home Martin spent time most days. Many people talked around Martin, but Virna talked to him as if he could understand. She had suspicions Martin could understand the world around him, so she advocated for him to get an evaluation. He proved to others he might have receptive abilities. It was a slow process to get Martin means of communication, but his mother worked tirelessly to find the perfect device. She learned Martin could help her choose what he wanted, rather than making the decision for him. Once Martin had an AAC device, life slowly, but surely began to change for him, as well as for everyone interacting with him. Martin's mom worked with him to program it, and for the first time since he became ill, he could make requests and share thoughts. It

was time consuming to practice with his new computer and program. Scanning on the device takes extensive amounts of time. If he missed the message he intended to select, he had to wait another long period of time until it came across the message again. It would take a large amount of patience to communicate this way. Martin was robbed of many things in life, for reasons beyond his control. For the first time he experienced the feeling of love, as well as heartbreak. The first time he realized he could indicate something was hurting, he bit his dad. Life was an emotional roller coaster, most of which was on the downhill. He couldn't share feelings of frustration, fear, and loneliness, but had to cope with everything on his own. Physical improvements such as walking again were the least of Martin's worries in comparison to his desire to be able to feed and wash himself, indicate when full, or express feelings. Having everything bottled up inside and feeling powerless over everything that happened to him each day left him feeling like there was no choice but to end his life. Given a failed attempt, Martin found comfort in the following days in realizing that his father defeated loneliness with him as he cared for Martin. Martin slowly became more capable of using his new program to communicate and was able to make his first phone call with it: a surprise for his sister. Another first that came with his progression was fixing a computer at the health center he attended, which led to a first time feeling of pride. One thing led to another and Martin began working one day a week. He was gaining more control of his right hand, which was used for all of his communication. As Martin landed his first more permanent job, he had to become used to giving opinions, as well as obtain and learn to use an electric wheelchair. An electric wheelchair opened up a whole new level of independence for Martin. He was now working, and speaking to large groups of people. Although positive things were happening for Martin, it's critical to acknowledge the most painful parts of his life. Not only did he struggle through being locked inside his own body and mind, he also experienced extreme abuse by people who should have been there as helpers. A near death experience with pneumonia led Martin to finding his lifelong partner, supporter, and encourager. Something Martin assumed he might never experience became the rest of his life. Martin fell in love with someone who felt the same in return; someone not only willing, but also wanting to take part in the lifestyle and challenges that Martin presented. This book is a wonderful story from the viewpoint of someone who lived through the unimaginable and came out of the years-long experience to go far in his life. Some information about why any assessment to test Martin's receptive abilities was never attempted would be interesting. Hearing direct viewpoints of people surrounding Martin closely would also provide an interesting addition. The list of people who would benefit from reading this book is endless, as any person can gain understanding and compassion for those who communicate in

ways we are not as familiar. We go through our lives likely communicating with our speech and other non-verbals. Having acceptance for individuals who communicate in more time-consuming and frustrating ways is critical. This book benefits those working with individuals with limited or no communication so no person “slip through the cracks” the way Martin did for years under the impression he couldn’t understand anything.

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