

"I was totally buried inside my own body"

Until the age of 12, Martin Pistorius was a normal child, but then a neurological condition left him totally unable to move. Only his eyes seemed to be alive. This is Martin's story.

PILAR MANZANARES

"There is only one difference between children and myself: my mind leaps up and down, tumbles and somersaults, trying to free itself from its limits, providing flashes of glorious colour in a grey world. But nobody knows that, because I can't tell them. They think I am an empty shell. I'm 25 years old, but my memories of the past start at the moment when I began to come back to life from a place in which I wandered, lost," writes Martin Pistorius.

Today, married and with the independence which is provided by an automatic wheelchair and a special computer through which he can communicate with other people, Martin recalls how that terrible journey began, the one which left him "totally buried" in his own body.

Part of his life came to resemble that of journalist Jean Dominique Bauby, who also became trapped inside himself after an accident. Despite that, he managed to write a book by blinking his eyes, something portrayed on the big screen in the magnificent film "The Diving Bell and the Butterfly".

But for Martin, that tragedy did not come at the end of his life, but at the beginning. He was 12 years old when, due to a rare illness which no doctor was really able to diagnose, he became the "ghost boy", as he describes it.

"Over the years, I have listened attentively during so many meetings to the story of how in January 1988 I came home from school, complaining of a sore throat. I never went back to school after that. In the following weeks and months I stopped eating, started sleeping for many hours a day and kept complaining that it hurt me to walk. My body started to become weak because I wasn't using it enough, and so did my mind: first I forgot things that had happened in the past, then

everyday things and, in the end, I didn't recognise faces. The last words I said before closing in on myself were "When home?" when I was lying in bed in a hospital," explains Martin.

After that, nothing. He went into a type of wakeful coma that nobody understood. The only thing the doctors dared to say after carrying out numerous tests was that it was a degenerative neurological disorder, whose origin and diagnosis was unknown. "Then, politely but firmly, medicine washed its hands of my case, telling my parents, in very few words, that they should put me in a home until I died and ceased to be a problem for them," recalls Martin, painfully. But his parents weren't prepared to give up.

Back to life

Years passed and Martin remained the same, as if he were lost in another interior world. "In fact, my parents even put mattresses in the living room so they and my brothers, Kim and David, could live like I did, at ground level, in the hope they could forge strong links with me. But I just laid there, unconscious of what was going on around me. Then, one day, I came back to life," he explains.

That new stage was neither easy nor happy. Martin returned at the age of 16, or at least his mind began to wake up, although it wasn't properly intact until he was 19. He wasn't able to control the movements of his body or do anything for himself, so nobody understood what was happening to him or could even imagine that he was totally aware of what he could hear, see and feel. "I was the patient they couldn't do much about, as one doctor said to another in front of me. Everybody was so used to me not being there that they didn't even notice when



Above, Martin during a conference at an international meeting in Israel. Below, a family photo from 1987. "The last photo as a normal family," says Martin.

PHOTOS PROVIDED BY EDICIONES URANO

I started being present again," he says.

Fortunately, a carer called Virna, who worked at the day centre where Martin spent part of his days, did notice. "She realised that my eyes really were the windows of my soul and she became more and more convinced that I understood what she said to me," he explains. This woman managed to get Martin tested at the Centre for Augmentative and Alternative Communication at the University of Pretoria (South Africa). There, they discovered that Martin

"I would like everyone to stop and think about what it must be like not to be able to communicate. You can't tell anyone you're uncomfortable, or cold, or that something hurts"

could communicate, that he would have to start to learn again everything that his mind had unlearned, and they made communication easier for him by using sheets of paper with words and their corresponding drawings on them.

Talking through software

A laptop computer and communication software meant that Martin, the invisible boy who was abused and beaten by some of the people who were supposed to care for him at the centres for immobile people, was seen and admired by others. He looked for ways of making his computerised voice sound more natural and his story of overcoming adversity began to inspire those who listened to him. He was asked to give talks, to tell his story. "Somehow I became an accidental conference speaker," he says, adding that "I would like everyone to stop and think about what it is like not to have a voice or other means of com-

munication. You can't tell anyone you're uncomfortable, you're cold or that something hurts." But he has achieved something which few people can do, which is talk about what it was like to be in a centre for the physically and mentally disabled and then, 18 months later, be able to use more than a dozen computer programmes, read and write, have two jobs and numerous friends, some of them within what for Martin is the magical world of the Internet, a place where nobody could see his wheelchair or his physical limitations, only his real self.

That is what a social worker called Joanna did. In fact Martin, who is now 39, has dedicated his story to her: to his wife, with whom he is living a happy ending.

For further information: 'Cuando era invisible', by Martin Pistorius. Ediciones Urano, the Indicios collection.