

Writing *Daniel Isn't Talking*

by Marti Leimbach

Creative writing teachers put enormous emphasis on the importance of a budding writer never allowing anything to distract him from his work. I can remember my early teachers demanding that I put away everything else in my life—boyfriends, alternative career ideas, hobbies, friends—you name it, in order to devote myself wholly and entirely to fiction. That is what it took, I was assured. Life would encroach with all of its demands and I was to resist anything that interfered with my writing. I don't think they were wrong. When I found myself in the enviable position of being a published author, I had to admit that it had taken exactly the kind of focus and determination my teachers had described.

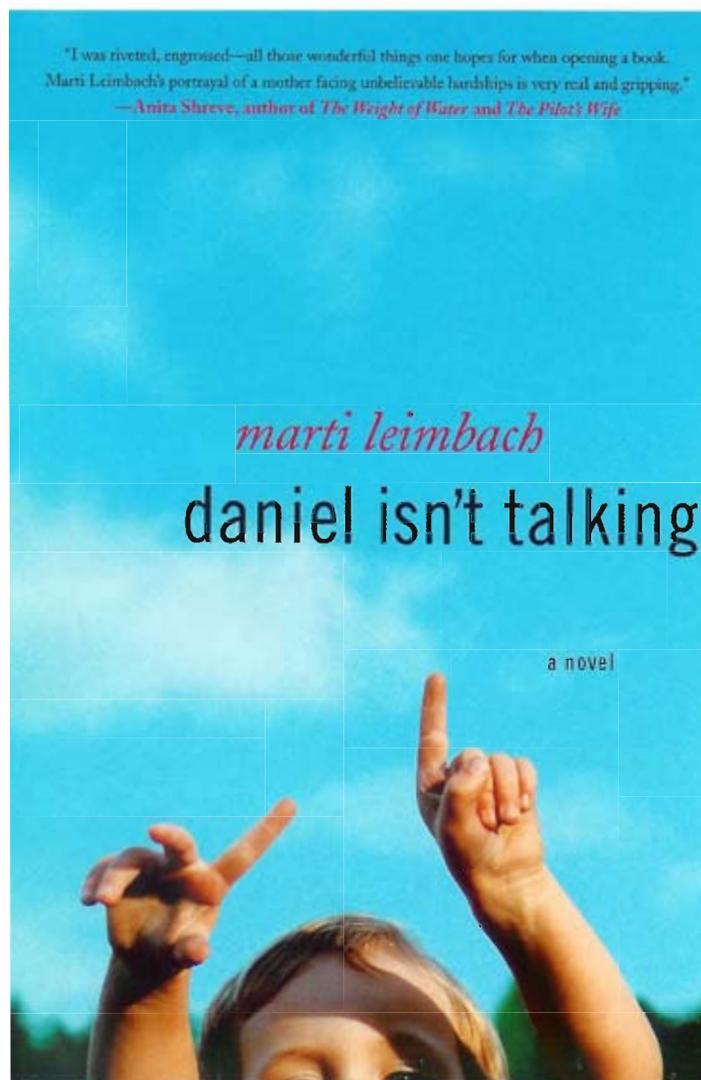
Imagine then, making a conscious decision to put writing aside after four published novels—which is exactly what I did when my son, Nicholas, was diagnosed with autism in December of 1999. You have to understand that I knew no other life than that of a writer. My walls were filled with books, my bed covered in paperbacks and proofs, my desk littered with manuscripts and articles I was working on and research I was conducting. I loved my work—but as anyone who has had a serious problem with one of their children will attest, work (and everything else) loses its meaning in the face of such a crisis.

When Nicholas was diagnosed with autism I made a decision much like the one I made as a very young writer: to let nothing get in the way of what I wanted to accomplish, of what Nicholas needed. Just as years ago I put away anything that interfered with my writing, now I discarded whole sections of my life in order to dedicate myself to my son. Writing was one of the first casualties. I pushed aside all my beloved fiction—the new titles, the old favourites—and brought in scores of texts about autism, about sensory integration, about language acquisition, about special diets and special programs. I was determined to do whatever I could to mitigate—even to remediate—Nicholas' autism.

This is the only way I could cope. By paring down my own personality, by using everything I had—my very life—as a kind of tool for helping Nicholas, I could just about make it through those excruciating early months after the diagnosis. All around me was discouragement. In 2000 there was very little available to give a parent of a child with autism any hope at all. I read books that told me things like autism is incurable; 80 percent of autistic people are functionally retarded; only three percent of autistic children grow up to lead independent lives; only 10 percent of people with Autism Spectrum Disorder have any sort of employment at all. Many adults with autism are wrongly diagnosed as schizophrenic and the patients are sectioned, drugged, and the parents of these individuals are helpless to have them released from confinement. That is what I read. This is part of what churned the misery inside me.

Another part was the boy in front of me who could not speak or point or play with toys. He regressed sometime after 19 months, a case of “late onset” autism, so I knew him when he was a normal baby, a normal toddler. I have pictures of him laughing and holding a ball up for me to see, of putting on a hat and dancing, of him smiling with shining eyes. And I have pictures of him as the light in those eyes faded and the ball lay motionless beside him.

At the time of Nicholas' diagnosis I had no thoughts of ever writing another novel. Even if I had not made the decision to stop writing, I doubt I could have mustered up a single paragraph.



The drama in my life was far more immediate and awful than anything I could make up, and novels—these things I loved and had dedicated myself to for so many years—suddenly seemed filled with stories of no real importance or, by contrast, were too sad for me to bear. There appeared to be no in-between and I was exhausted anyway, so I gave up and read nothing. Actually, that's not true. I occasionally dipped into *The English Patient*. I came to identify with the Canadian nurse, Hana, who had set it in her heart that she must look after the English patient, this burnt, unidentifiable man. Something about her idiosyncratic days, the bombed out building in which she lived, the manner in which she defended her right to choose this life of isolation and denial mirrored my own life, which I had now dedicated to saving my son.

"Save him from *what*?" you might ask. From those who believed there was no way to keep autism from consuming his life, that his diagnosis, this label—*autism*—meant he would likely remain mute, indifferent to other people, oblivious to the world? He used to scream in terror, charging for the door when a hand dryer sounded in a public restroom. If he saw a dog he panicked, crossing a street sometimes, his hand wrenching free of mine so that I could only rescue him by running faster. I have plucked him from wardrobes, where he has shut himself away in the dark, visited him at the edge of our garden where he paced until a path of bald earth formed at the fence line. I have seen the worst of him and I have had days when I thought that the worst was all that would ever be. Sometimes I envied Hana in *The English Patient*. However, dedicated she was to her patient, she was not his mother. He was not a child. She could live with failure, while I could not.

No, I could not live with failure. To stand by as your child fails to gain basic developmental milestones, fails to speak or play or even to look at other people, all the while taking on all sorts of bizarre, nonsensical behaviour—squeaking and throwing things and jumping in circles—all this required a presence of mind that I simply did not possess. In public, whenever I happened to see a caregiver with a child bound in a wheelchair, profoundly retarded and incapacitated, I began to imagine that child's parents. I wondered who they were, how they coped.

Once, during a stay in hospital I got to know a mother whose boy had been perfectly normal until he contracted meningitis at the age of two. He was now 15, an emaciated figure in a wheelchair who could not speak or move. We talked about how she had travelled the world in search of help for him, and how she had given up now, knowing that there are no answers for him, and nothing certain except his further deterioration. When I said I admired her she replied, "What you mean is that you are glad you are not me."

That was true. I stared at the floor. Then I told her that sometimes, although this might sound absurd to her given how much worse the situation was with her own child, I felt I could not cope. I could not stand to watch what might happen to my son.

"You have no choice," she said. She was right, of course.

So I looked for answers. I held out hopes as teams of educational psychiatrists, speech therapists, occupational therapists, dietary consultants, educators of all descriptions and every alternative practitioner known to Britain, evaluated my son and his condition. I marched Nicholas in and out of offices, and opened our home to a whole parade of professionals who came with their clipboards and their notebooks, their business cards and their fees.

At night I read accounts of children who had progressed, stories about one or the other autistic child who had started with no language and then began to speak, children who could not understand the purpose of a toy and then, after much behavioural intervention, learned to love to play. I dreamed of the story I would one day tell about my own son; not a novel but a true story I would tell before an audience of people, about his "recovery," about how he'd managed to overcome this dreadful thing called autism.

That was the story I wanted to tell. For a while I thought perhaps it would be realized, for amazingly Nicholas did get better. Just like the boy in *Daniel Isn't Talking*, he gradually began to use language, to engage with his family and his therapists. Interestingly, however, it was after Nicholas started to be "less autistic" and more like any other child that my desire to see him become completely "normal" started to fade. As he developed I got a clearer idea of "who" Nicholas is and it was evident that he was many things, and one of them was definitely autistic. It wasn't that he was "locked into" autism or that the autism was a separate thing like a tumour that needed removal, but rather it was a kind of membrane through which his understanding of the world was filtered.

But he had started to talk. And with talking came story-telling and games and mischief and fun. As time went by, I found I could read a book that wasn't about autism. I could sleep for hours and hours, just like a normal person. Yes, it did take years and I did work very hard for all that time and always in complete obscurity and as though my life depended on it – but things got better. He got better. And I found myself able to risk diverting my attention a little and writing fiction once more. *Daniel Isn't Talking* is very much "my" book, and perhaps is one way of coming back into "the world"—even the literary world, which I thought was gone from me forever. And it feels good to be back.



Available at bookstores everywhere, Marti Leimbach's acclaimed novel, *Daniel Isn't Talking*, (published by McClelland & Stewart, ISBN 0771052022) is a remarkable story about a mother who discovers that her three-year-old son is autistic. Desperate to help him and frustrated by the seeming limits of the conventional medical system, she takes Daniel's care into her own hands. Passionate, moving and heartbreakingly real. Visit www.martileimbach.com.