

A note from Jesse Ball, author of *Census* (ISBN: 9780062676139)

My brother Abram Ball died in 1998. He was twenty-four years old and had downs' syndrome. At the time of his death he had been on a ventilator for years, been quadriplegic for years, had had dozens of operations. His misfortune was complicated, yet his magnificent and beautiful nature never flagged. He was older than me, though smaller, and I spent many years at his bedside in the hospital.

But before that time, when we were both children together, when he could still walk and play, although I was young, I knew that I would one day have to take care of him, that one day I would be his caretaker, and that we would live together, could live together happily. As a child I assumed that duty in my mind and it became a part of me. I forecast the ways in which it might happen. I even worried (as a boy) about finding a partner willing to live with my brother and me.

It occurred to me last month that I would like to write a book about my brother. I felt, and feel, that people with downs' syndrome are not really understood. What is in my heart when I consider him and his life is something so tremendous, so full of light, that I thought I must write a book that helps people to see what it is like to know and love a downs' syndrome boy or girl. It is not like what you would expect, and it is not like it is ordinarily portrayed and explained. It is something else, different than that.

But it is not so easy to write a book about someone you know, much less someone long dead, when the memories you have of him are like some often trampled garden. I didn't see exactly how it could be done, until I realized I would make a book that was hollow. I would place him in the middle of it, and write around him for the most part. He would be there in his effect.

The relationship that I imagined as a child, that which I would have with my brother when he was grown, was very similar to that of a father and son, so I decided I would write a book about a father, on the point of death, who travels somewhere with his adult son, and that somehow, in the administration of those details, in and between the words, I could effect a portrait of Abram, as the son, and in doing so, would allow others to see what such a boy is like, or can be like.

In doing so, I was able, in some sense, to reenter the thoughts and ideas I had as a child—those I mentioned a moment ago, about how I would end up his caretaker, and what that would be like. A life is long, and we are many people, variously, in our guises, in our situations, but some part of us is the same, and what I felt as a boy I find myself able to feel now—a sad and powerful longing for a future that did not ever come, with all its attendant worries and fears.

I imagine some of you will recognize your own experience in these pages. I hope that others will find it a spur to new experience.