

“A very black fly settles on my nose. I waggle my head to unseat him. He digs in. Olympic wrestling is child’s play compared to this.”

The Diving Bell and the Butterfly by Jean-Dominique Bauby is a window into the mind of a person afflicted with locked-in syndrome. The form of assistive technology discussed in the book is the use of wheelchairs and a communication system using the alphabet ordered by most-used letters rather than being ordered alphabetically. “It is a simple enough system. You read off the alphabet (ESA version, not ABC) until, with a blink of my eye, I stop you at the letter to be noted.” This tedious and time consuming process is the only means with which Bauby has to communicate. I was surprised to see that this was the only system available, even in 1996. Modern technology has progressed in many ways in the past 15 years however I would have expected a better system for this patient.

Before reading this book, I was unfamiliar with locked-in syndrome. Upon reading the synopsis on the back of the book I was fascinated by this torturous hell of an illness. Bauby becomes a prisoner in his own body, merely able to move his head 90 degrees and blink his left eye. As he mentions in his book, simple actions such as getting dressed, shaving, and drinking hot chocolate become amazing, wondrous feats.

The most striking element of the book was the random train-of-thought mentality featured throughout. Some chapters were seemingly random samples of the mind wandering which, in a way, demonstrates the experience of locked-in syndrome better than any literal description ever could. It only makes sense that, trapped inside one’s own body, the mind would need to wander in order to remain sane. Days were spent dreaming about trips to far away destinations, vacationing in memories, and mentally feasting on fantasy foods. By the end of the

book, the reader cannot help but realize that this random collection of thoughts offers a clearer example of the experience of being locked-in, than a straightforward account ever could.

This book affects the reader in a way that makes them appreciate what they have. Throughout the pages of The Diving Bell and the Butterfly, I found myself reading the book like a passerby of an accident on the highway. As uncomfortable as it was, I could not look away or stop picturing myself in the circumstances presented to me. I found myself appreciating the taste of my dinner or the ability to put my arm around my girlfriend. Simple everyday things become treasures locked away to patients suffering locked-in syndrome.

Jean-Dominique Bauby was the editor of Elle, a French fashion magazine. With the knowledge and experience of a professional writer, his identity certainly affected the tone of the book. As a higher-up for a chic magazine, Bauby's past pretentiousness and highfalutin characteristics transform into humbled writing. One can see from the book how Bauby changed after being affected by locked-in syndrome. Moreover, the colorful language and elegant writing style offer a glimpse into a beautiful mind still trying to keep itself fit. Bauby offers cynicism, humor, happiness, and depression in ways that are hard to express through words. Reading his impressions on spending time with his children or accompanying him on a trip to the beach to smell French fries is an experience that can only be created by a truly talented writer.

The Diving Bell and the Butterfly is a fascinating read that offers a glimpse into an unimaginable prison in which those held captive by illness must fight to remain sane. Amazingly enough, Jean-Dominique Bauby manages to retain his fierce wit while pining for a lost life by detailing the experience of having one's life irreparably altered.