The Diving-Bell and the Butterfly

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Translated from the French, The Diving-Bell and the Butterfly is a beautiful and poignant account of a 45 year old father of two failing victim to a catastrophic stroke. The resulting "locked-in syndrome" means he is unable to speak or move—his only means of interaction is through blinking his left eye.

The book focuses on his room in a naval hospital on the north coast of France. He discusses scabrous orderlies, "arrogant, brusque, sarcastic" doctors, and a fear of losing the use of the "only window to his cell," his left eye. Only Sandrine, his speech therapist, reaches out with kindness, patience, and empathy. Using an intuitive alphabet, through blinking, he learns to communicate, and painstakingly dictates this book.

Likening this suspended animation to "a giant invisible diving-bell holding my whole body prisoner" he describes the unforgiving reality of disability and the banality of complete dependence for communication, ablutions, or even changing the television channel—something many doctors, patients, and carers can identify with.

To escape, his "mind takes flight like a butterfly" and he finds solace in fantasies of wine, women, and song. He also takes us on a vivid voyage through his memories of his work, holidays, and family.

In Alexandre Dumas' The Count of Monte-Cristo, the character Noirtier de Villeforte also suffered this "monstrous, iniquitous, revolting, horrible" condition. "His inner life was like the distant gleam of a candle which a traveller sees by night across some desert place, and knows that a living being dwells beyond the silence and obscurity," writes Dumas. Akin to Noirtier, Dauby feels a "zombie father" and "unpredictable animal" to his children, unable to embrace, school, or counsel them.

Sharing his decline is his 93 year old, decrepit father who, unable to visit, telephones the son "who can never reply." Both are trapped in failing bodies, unable to care for their children; only his father's fate is timely and just.

Mourning for what was and what will never be, Bauby poetically describes his life as a string of missed opportunities: "the women we were unable to love, the chances we failed to seize, and the moments of happiness we allowed to drift away."

This book is undoubtedly a medical masterpiece because of its uncompromising account of human nature; how it wilts under sufferance and pain but blossoms with even a trace of kindness and love. It is pertinent to our professional and personal lives, reminding us to treat patients (or indeed anyone) as we would wish to be treated ourselves. Finally, it shows how fragile and transient our health and lives are and how much we take for granted.

By Jean-Dominique Bauby
First published in 1997

See also BMJ 2005;331:94-7 doi: 10.1136/bmj.331.7508.94
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