

The Diving-Bell and the Butterfly

Jean-Dominique Bauby

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Extract

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Prologue

THROUGH THE FRAYED curtain at my window a wan glow announces the break of day. My heels hurt, my head weighs a ton, and something like a giant invisible diving-bell holds my whole body prisoner. My room emerges slowly from the gloom. I linger over every item: photos of loved ones, my children's drawings, posters, the little tin cyclist sent by a friend the day before the Paris-Roubaix bike race, and the IV pole overhanging the bed where I have been confined these past six months like a hermit crab dug into his rock.

No need to wonder very long where I am, or to recall that the life I once knew was snuffed out on Friday, 8 December, last year.

Up until then I had never even heard of the brain-stem. I've since learned that it is an essential component of our internal computer, the inseparable link between the brain and the

spinal cord. I was brutally introduced to this vital piece of anatomy when a cerebro-vascular accident put my brain-stem out of action. In the past it was known as a 'massive stroke', and you simply died. But improved resuscitation techniques have now prolonged and refined the agony. You survive, but you survive with what is so aptly known as 'locked-in syndrome'. Paralysed from head to toe, the patient, his mind intact, is imprisoned inside his own body, but unable to speak or move. In my case, blinking my left eyelid is my only means of communication.

Of course the sufferer is the last to hear the good news. I myself had twenty days of deep coma and several weeks of grogginess and somnolence before I fully appreciated the extent of the damage. I did not fully awake until the end of January. When I finally surfaced, I was in Room 119 of the Naval Hospital at Berck-sur-Mer on the French Channel coast – the same Room 119, infused now with the first light of day.

An ordinary day. At seven the chapel bells begin again to punctuate the passage of time, quarter-hour by quarter-hour. After their

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night's respite, my congested bronchial tubes once more begin their noisy rattle. My hands, lying curled on the yellow sheets, are hurting, although I can't tell if they are burning hot or ice cold. To fight off stiffness I instinctively stretch, my arms and legs moving only a fraction of an inch. It is often enough to bring relief to a painful limb.

My cocoon becomes less oppressive, and my mind takes flight like a butterfly. There is so much to do. You can wander off in space or in time, set out for Tierra del Fuego or for King Midas's court.

You can visit the woman you love, slide down beside her and stroke her still-sleeping face. You can build castles in Spain, steal the Golden Fleece, discover Atlantis, realize your childhood dreams and adult ambitions.

Enough rambling. My main task now is to compose the first of these bedridden travel notes so that I shall be ready when my publisher's emissary arrives to take my dictation, letter by letter. In my head I churn over every sentence ten times, delete a word, add an adjective, and learn my text by heart, paragraph by paragraph.

THE DIVING-BELL AND THE BUTTERFLY

Seven thirty. The duty nurse interrupts the flow of my thoughts. Following a well-established ritual, she draws the curtain, checks tracheostomy and drip-feed, and turns on the TV so I can watch the news. Right now a cartoon celebrates the adventures of the fastest frog in the West. And what if I asked to be changed into a frog? What then?

The Wheelchair

I HAD NEVER SEEN SO many white coats in my little room. Nurses, orderlies, physiotherapist, occupational therapist, psychologist, neurologist, interns and even the department head – the whole hospital had turned out for the event. When they first burst in, pushing the device ahead of them, I thought it meant that I was being ejected to make room for a new patient. I had already been at Berck a few weeks, and was daily drawing nearer to the shores of awareness, but I still could not imagine any connection between a wheelchair and me.

No one had yet given me an accurate picture of my situation, and I clung to the certainty, based on bits and pieces I had overheard, that I would very quickly recover movement and speech.

Indeed, my roving mind was busy with a thousand projects: a novel, travel, a play, marketing a fruit cocktail of my own invention.

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(Don't ask for the recipe; I have forgotten it.) They immediately dressed me. 'Good for the morale,' pronounced the neurologist in sententious tones. And in truth I would have been pleased to trade my yellow nylon hospital gown for a checked shirt, old trousers and a shapeless sweater – except that it was a nightmare to put them on. Or rather to watch the clothes manipulated, after endless contortions, over these uncooperative deadweight limbs, which serve me only as a source of pain.

When I was finally dressed the ritual could begin. Two attendants seized me by the shoulders and feet, lifted me off the bed and dumped me unceremoniously into the wheelchair. I had graduated from being a patient whose prognosis was uncertain to an official quadriplegic. They didn't quite applaud, but they came close. My caretakers made me travel the length and breadth of the hospital floor to make certain that the seated position did not trigger uncontrollable spasms, but I was too devastated by this brutal downgrading of my future hopes to take much notice. They had to place a special cushion behind my head: it was wobbling about like the

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head of one of those African women upon removal of the stack of rings that has been stretching her neck for years. 'You can handle the wheelchair,' said the occupational therapist with a smile intended to make the remark sound like good news, whereas to my ears it had the ring of a life-sentence. In one flash I saw the frightening truth: It was as blinding as an atomic explosion and keener than a guillotine blade. They all left.

As three orderlies laid me back down, I thought of movie gangsters struggling to fit the slain informer's body into the boot of their car. The wheelchair sat abandoned in a corner, with my clothes tossed over its dark-blue plastic back-rest. Before the last white coat left the room I signalled my wish to have the TV turned on low. On screen was my father's favourite quiz show, *Letters and Numbers*. Since daybreak an unremitting drizzle had been streaking the windows.