Jean-Dominique Bauby

from THE DIVING BELL AND

THE BUTTERFLY

A patient in a French hospital, completely stripped of any ability to move or speak, offers an extraordinary perspective on the skillfulness of the doctors who attend to him, and on the world of the hospital, giving the reader of this excerpt a full measure of an utterly helpless patient's resentment and anger in the face of indifferent, "ungracious" care.

JEAN-DOMINIQUE BAUBY was the forty-three-year-old editor-in-chief of *Elle* when he suffered a stroke that decimated his brain stem. After weeks in a coma, he awoke to find that he suffered from a rare condition known as "locked-in syndrome," which left his mind intact but his body almost completely paralyzed. Bauby "dictated" this story by blinking his one still-functioning eye, one letter at a time. He died two days after *The Diving Bell and the Butterfly* was published in France.

Thave known gentler awakenings. When I came to that late-January morning, the hospital ophthalmologist was leaning over me and sewing my right eyelid shut with a needle and thread, just as if he were darning a sock. Irrational terror swept over me. What if this man got carried away and sewed up my left

eye as well, my only link to the outside world, the only window to my cell, the one tiny opening of my diving bell? Luckily, as it turned out, I wasn't plunged into darkness. He carefully packed away his sewing kit in padded tin boxes. Then, in the tones of a prosecutor demanding a maximum sentence for a repeat offender, he barked out: "Six months!" I fired off a series of questioning signals with my working eye, but this man-who spent his days peering into people's pupils—was apparently unable to interpret a simple look. With a big round head, a short body, and a fidgety manner, he was the very model of the couldn't-care-less doctor: arrogant, brusque, sarcastic—the kind who summons his patients for 8:00 A.M., arrives at 9:00, and departs at 9:05, after giving each of them forty-five seconds of his precious time. Disinclined to chat with normal patients, he turned thoroughly evasive in dealing with ghosts of my ilk, apparently incapable of finding words to offer the slightest explanation. But I finally discovered why he had put a six-month seal on my eye: the lid was no longer fulfilling its function as a protective cover, and I ran the risk of an ulcerated cornea.

As the weeks went by, I wondered whether the hospital employed such an ungracious character deliberately—to serve as a focal point for the veiled mistrust the medical profession always arouses in long-term patients. A kind of scapegoat, in other words. If he leaves Berck, which seems likely, who will be left for me to sneer at? I shall no longer have the solitary, innocent pleasure of hearing his eternal question: "Do you see double?" and replying—deep inside—"Yes, I see two assholes, not one."

I need to feel strongly, to love and to admire, just as desperately as I need to breathe. A letter from a friend, a Balthus painting on a postcard, a page of Saint-Simon, give meaning to the passing hours. But to keep my mind sharp, to avoid descending into resigned indifference, I maintain a level of resentment and anger, neither too much nor too little, just as a pressure cooker has a safety valve to keep it from exploding.

And while we're on the subject, *The Pressure Cooker* could be a title for the play I may write one day, based on my experiences here. I've also thought of calling it *The Eye* and, of course, *The Diving Bell*. You already know the plot and the setting. A hospital room in which Mr. L., a family man in the prime of life, is learning to live with locked-in syndrome brought on by a serious cerebrovascular accident. The play follows Mr. L.'s adventures in the medical world and his shifting relationships with his wife, his children, his friends, and

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his associates from the leading advertising agency he helped to found. Ambitious, somewhat cynical, heretofore a stranger to failure, Mr. L. takes his first steps into distress, sees all the certainties that buttressed him collapse, and discovers that his nearest and dearest are strangers. We could carry this slow transformation to the front seats of the balcony: a voice offstage would reproduce Mr. L.'s unspoken inner monologue as he faces each new situation. All that is left is to write the play. I have the final scene already: The stage is in darkness, except for a halo of light around the bed in center stage. Nighttime. Everyone is asleep. Suddenly Mr. L., inert since the curtain first rose, throws aside sheets and blankets, jumps from the bed, and walks around the eerily lit stage. Then it grows dark again, and you hear the voice offstage—Mr. L.'s inner voice—one last time:

"Damn! It was only a dream!"