

Excerpts from the memoir *The Diving Bell and the Butterfly*, by Jean-Dominique Bauby.

No need to wonder very long where I am, or to recall that the life I once knew was snuffed out Friday, the eighth of 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 cerebrovascular accident took 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." Paralyzed from head to toe, the patient, his mind intact, is imprisoned inside his own body, unable to speak or move. In my case, blinking my left eyelid is my only means of communication.

Eventually, perhaps I will be able to breathe naturally, without a respirator, and muster enough breath to make my vocal cords vibrate.

I am fond of my alphabet letters. At night...vowels and consonants dance for me. Hand in hand, the letters cross the room, whirl around the bed, sweep past the window, wriggle across the wall, swoop to the door, and return to begin again.

ESARINTULOMDPCFBVHJQZYXKW

The jumbled appearance of my chorus line stems not from chance but from cunning calculation. More than an alphabet, it is a hit parade in which each letter is placed according to the frequency of its use in the French language. That is why E dances proudly out in front, while W labors to hold on to last place. B resents being pushed back next to V, and haughty J—which begins so many sentences in French—is amazed to find itself so near the rear of the pack. Rolypoly G is annoyed to have to trade places with H, while T and U, the tender components of *tu*, rejoice that they have not been separated. All this reshuffling has a purpose: to make it easier for those who wish to communicate with me.

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. The maneuver is repeated for the letters that follow, so that fairly soon you have a whole word, and then fragments of more or less intelligible sentences. That, at least, is the theory. In reality, all does not go well for some visitors. Because of nervousness, impatience, or obtuseness, performances vary in the handling of the code (which is what we call this method of transcribing my thoughts). Crossword fans and Scrabble players have a head start. Girls manage better than boys. By dint of practice, some of them know the code by heart and no longer even turn to our special notebook—the one containing the order of the letters and in which all my words are set down like the Delphic oracle's.

The identity badge pinned to Sandrine's white tunic says "Speech Therapist," but it should read "Guardian Angel." She is the one who set up the communication code without which I would be cut off from the world. But alas! while most of my friends have adopted the system, here at the hospital only Sandrine and a female psychologist use it. So I usually have the skimpiest arsenal of facial expressions, winks, and nods to ask people to shut the door, loosen a faucet, lower the volume on the TV, or fluff up a pillow. I do not succeed every time.

Speech therapy is an art that deserves to be more widely known. You cannot imagine the acrobatics your tongue mechanically performs in order to produce all the sounds of a language.

Just now I am struggling with the letter **I**, a pitiful admission for an editor in chief who cannot even pronounce the name of his own magazine! On good days, between coughing fits, I muster enough energy and wind to be able to puff out one or two phonemes. On my birthday, Sandrine managed to get me to pronounce the whole alphabet more or less intelligibly. I could not have had a better present. It was as if those twenty-six letters had been wrenched from the void; my own hoarse voice seemed to emanate from a far-off country. The exhausting exercise left me feeling like a caveman discovering language for the first time.

On top of the various discomforts that accompany locked-in syndrome, I suffer from a serious hearing disorder. My right ear is completely blocked, and my left ear amplifies and distorts all sounds farther than ten feet away.

September means the end of vacations, it means back to school and to work, and here at the hospital it's time to start a new season. I've made some progress. I can now grunt the little song about the kangaroo, musical testimony to my progress in speech therapy:

The Kangaroo escaped the zoo.

"Goodbye zoo!" cried Kangaroo...

Cleared the wall with one clean jump,

Leaped across with a great big thump

Her elbows on the small mobile Formica table that serves as her desk, Claude is reading out these pages we have patiently extracted from the void every afternoon for the last two months. Some pages I am pleased to see again. Others are disappointing. Do they add up to a book?