

Editorial: A Butterfly Locked-In A Diving-Bell – Is Freedom Possible?

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Abstract

“I am locked in. I am as good as dead” [1].

Name: Jean-Dominique Bauby (Jean-Do)

Age: 43

Profession: Journalist, Editor-in-Chief of the French Elle magazine

Diagnosis: Brainstem stroke – Locked-in syndrome (LIS)

Date: December 8th, 1995

In 2007, the film *Le Scaphandre et Le Papillon* (The Diving Bell and the Butterfly) directed by Julian Schnabel and written by Ronald Harwood was released. This was the movie version of the best-selling Bauby’s autobiography previously published in 1997 [1].

The film describes the true life story of Bauby, a man who had everything and consequently lost everything after a brainstem stroke. A man bed-bound with no ability to speak or move anything but his left eyelid [2,3,4,5]. By blinking not only was he able eventually to communicate with his physicians, nurses, speech therapists and family members, but also to write his own memoir via a code of alphabet letters [4,5,6,7]. He was locked-in [5].

The locked-in syndrome (LIS) or *maladie de l’emmuré vivant* or *cerebromedullospinal disconnection* can be defined as the presence of sustained eye opening, preserved cognitive abilities, aphonia or severe hypophonia, quadriplegia/paresis and a mode of communication with vertical or lateral eye movement or blinking of the upper eyelid [2]. The most common etiology is damage of the basis pontis through vertebralbasilar artery occlusion [2,7].

Bauby remained comatose for almost three weeks. He woke

up paralyzed [6], “reduced to the existence of a jellyfish”, “rigid”, “mute”, “deprived of all pleasures” and in despair:

“I am plunged into despair.”

“The feeling of doom wouldn't leave.”

“Is this life? ... a constant repetition.”

“This is hell.”

“This is a nightmare.”

“I do want to die. I really do.”

His body became a prison [5]; a diving bell [6]. “My heels hurt, my head weighs a ton, and something like a giant invisible diving-bell holds my whole body prisoner.” He just wanted to be the cartoon of a frog he was watching on the TV; a frog swimming and hopping insanely (“If I could only be that frog”).

Slowly, his past dissolved... [3] “Like a sailor who watches the shore gradually disappear, I watch my past recede. But more and more of it is reduced to the ashes of memory.” A memory considered as “a jigsaw puzzle with pieces missing.” Bauby felt alone (“Sunday. I dread Sunday. No therapists, no visitors, a skeleton staff. Sunday is a long stretch of desert”). He needed protection (“But my favorite sight of all is the lighthouse, tall, robust, reassuring in red and white stripes. I place myself under the protection of this brotherly symbol, guardian not just of sailors but of the sick whom fate has cast to the far edge of life”). He needed approval as well (“What children we all are, we all need approval”).

Admitted in the Naval Hospital, at Berck-sur-Mer (Normandy), where “wheelchairs are as commonplace as

Ferraris at Monte Carlo,” Bauby was thinking about his children [8]: “There are no words to express the grief that surges over me. I, their father, have lost the simple right to ruffle their hair, clasp their downy necks, hug their small, little, warm bodies tight against me.” Yet, “I guess that even a rough sketch, a shadow, a tiny fragment of a dad is still a dad.” For the celebration of the Father's Day his children paid him a visit that filled him with happiness: “We have never before fitted this made-up holiday into our emotional calendar. But I suppose there's a first time for everything. Locked-in syndrome. Yet, I'm filled with joy seeing them living, moving, laughing.”

Amazingly, Bauby moved on with liveliness and hope for the future [3]. “It took what I can only describe as a miracle to lift my spirits. It's dangerous to believe in personal miracles. They tend to make one feel self-important.” But he kept on going [9]. He made a rule, never to feel sorry for himself again. “Sometimes I think I hear my heart beating but I tell myself it's the sound of butterfly's wings. Yes, I am making indomitable progress and I may even have butterfly hearing. I can look forward to the future.” He soon found the keys to freedom: “I've only just realized that there are only two things apart from my eye that aren't paralyzed... Imagination and memory are the only way I can escape my diving bell” [5,6].

Moreover, he maintained and exhibited an enhanced sense of (ironic) humor [3] which sometimes alleviated depression [4]. When he heard that old friends called him “vegetable” [6], he asked: “Did they say what sort of vegetable?” In another occasion, when his son Théophile asked him if he wanted to play Hangman, Bauby thought: “I'd like to tell him I have enough trouble playing quadriplegic.” Even when a nurse told him “Bon Appétit”, regardless the fact that Bauby could not even swallow, he remained calm and commented: “Saying that to me is like saying Merry Christmas to someone on August 15th.”

Bauby's book includes all the humanistic qualities important in caring for the severely disabled [10]. Clinicians seem to

forget that quality of life often equates with social rather than physical interaction. Even LIS patients without motor recovery typically have a wish to live and rarely have suicidal thoughts. Thus, medical treatment should be as aggressive as it would be for other people with potential survival of a decade or more [7]. Locked-in syndrome (LIS) is not synonymous with death. And Bauby has made this more than clear. He chose the option of imagination. He chose the option of the butterfly. He chose freedom. In his memoir the butterfly signifies freedom. The dedication to his two children found in the first page of his book (published two days before he died) [6] couldn't be more meaningful:

“Pour Théophile et Céleste en leur souhaitant beaucoup de papillons” (For Théophile and Céleste wishing them many butterflies) [1].

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