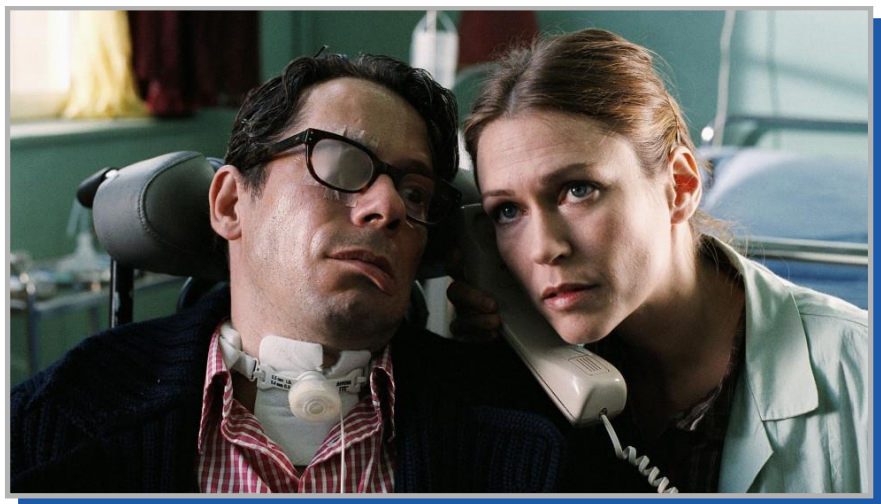


THE DIVING BELL AND THE BUTTERFLY: A BOOK REVIEW

BY JACQUI PICH



Jean-Dominique Bauby was at the height of his career – a successful and handsome editor-in-chief of the French *Elle* magazine. Suddenly and irrevocably, at the age of 43 years his world changed as a result of a catastrophic stroke. When he finally awoke from a coma he was diagnosed with ‘locked-in’ syndrome. Jean-Dominique was cognitively intact and could hear and see but was totally paralysed, unable to move or speak, except for the ability to blink his left eyelid. Over a period of time, he used this one vestige of his former self to communicate with the outside world. He developed an alphabet code which was painstakingly translated to word by his speech pathologist, Sandrine. This process led to his memoir, titled *The Diving Bell and the Butterfly*.

In this memoir, the diving bell symbolises Bauby’s physical immobility, and the sense that he is submerged in one; while the butterfly is a metaphor for the fluttering of his eyelid and the joyful freedom of his mind escaping his captured body. Bauby is a vulnerable patient, dependent on care providers for all of his activities of daily living. Where once he had been providing personal care such as shaving, to his ageing father, he is now completely dependent on others. As the memoir progresses, healthcare professionals become central figures in Bauby’s life. However, while most of his friends adopt his communication system, at the hospital, it is only Sandrine and a female psychologist that utilise it.

Poor communication and dehumanisation are central themes in this memoir, as Bauby becomes a ‘task’ to be dealt with rather than a person in need of care. He describes one encounter with an ophthalmologist, who he wakes to find sewing his right eyelid shut: “*as if he were darning a sock*”. Bauby tries desperately but unsuccessfully to communicate with him:

‘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.

¹ *The Diving Bell and the Butterfly* [online image]. Retrieved August 24, 2018 from: https://images.amcnetworks.com/ifc.com/wp-content/uploads/2007/11/11262007_amalric_article.jpg

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'.

Bauby counteracts his descriptions of thoughtless healthcare workers with empathic reflections of how difficult and busy their jobs must be. He describes how some turn on the television, close the door and exit with great haste to avoid having to engage with him. Others talk to him outside of his field of vision and some leave the TV on without consideration or turn it off mid-soccer game without asking. There is also a nurse who adjusts the curtain seemingly on purpose so the sunlight shines in to his good eye, causing him discomfort. The lack of person-centred care and the sense that Bauby represents a series of tasks to be completed is illustrated in the following narrative: ‘

'...for half an hour, the alarm on the machine that regulates my feeding tube has been beeping out into the void. I cannot imagine anything so inane or nerve-racking as this piercing beep beep beep pecking away at my brain. As a bonus, my sweat has unglued the tape that keeps my right eyelid closed, and the stuck-together lashes are tickling my pupil unbearably. And to crown it all, the end of my urinary catheter has become detached and I am drenched. Awaiting rescue, I hum an old song by Henri Salvador: "Don't you fret, baby, it'll be all right." And here comes the nurse. Automatically, she turns on the TV. A commercial, with a personal computer spelling out the question: "Were you born lucky?"

The monotony and loneliness of the hospital existence is also made apparent in the book:

'...Sunday. I dread Sunday, for if I am unlucky enough to have no visitors, there will be nothing at all to break the dreary passage of the hours. No physical therapist, no speech pathologist, no shrink. Sunday is a long stretch of desert, its only oasis a sponge bath even more perfunctory than usual'.

Bauby reflected on how his appearance could be a source of revulsion to some:

'... reflected in the glass I saw the head of a man who seemed to have emerged from a vat of formaldehyde. His mouth was twisted, his nose damaged, his hair tousled, his gaze full of fear. One eye was sewn shut, the other goggled like the doomed eye of Cain'.

Poignantly, the memoir was published just two days before Bauby's death in 1996.

Artist/director Julian Schnabel's feature-film adaptation of the book was released in 2007, starring Mathieu Amalric as Bauby. The film was nominated for several international awards and won best director at the Cannes Film Festival.

DISCUSSION/REFLECTION QUESTIONS

1. The experiences described in *The Diving Bell and the Butterfly* allow learners to view Bauby's care through his eyes. Reflect on and discuss your understanding of Bauby's feelings, concerns and needs.
2. Evidence shows that poor communication is one of the main reasons for patient complaints about healthcare staff and for the occurrence of adverse events. Certain groups are especially vulnerable, for example the elderly, cognitively impaired, those with sensory deficits and from non-English speaking backgrounds.
 - How could the communication – verbal and non-verbal - between the healthcare professionals and Bauby have been improved?

- With reference to *The Diving Bell and the Butterfly*, discuss how effective communication can improve people's healthcare experiences and enhance patient safety (physical and psychological), particularly for those who have a communication impairment.
 - Despite a communication method being available, only two of the hospital staff use this approach? Why do you think this was the case?
3. Discuss how the lack of person-centred care described in *The Diving Bell and the Butterfly* presented a risk for Bauby's clinical safety.
- Bauby's care was not person-centred on a number of occasions and he was often treated as a series of tasks to be completed. How did this make him feel?
 - Bauby described the feeling of being trapped in a diving bell – what impact did this have on his psychological and spiritual health?
 - Bauby spent most of his time in his hospital room. What could the staff have done to improve his physical environment and how might this have impacted his wellbeing?
4. The catastrophic physical impact of locked-in syndrome on Bauby and his subsequent vulnerability demonstrate how easily empathy can be compromised when we enter the hospital environment and entrust all of our personal care to strangers.
- Discuss strategies that can be used to protect the dignity of people in need of healthcare.

LINKS

The Diving Bell and the Butterfly trailer: <https://youtu.be/t4Ek4ZBpshs>

REFERENCE

Bauby, J. (1998). *The Diving Bell and the Butterfly*. New York: Vintage

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