

Exploring *The Diving Bell and the Butterfly*: Locked In but not Out.

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The Main character is Jean-Dominique Bauby who was 43 and the editor in chief for the French magazine *Elle*. Bauby was successful, some say at the height of his career and described by many as an enigmatic, vivacious, charismatic, talented, handsome and a charmer who had the world at his fingertips and an impassioned approach to life. He led a privileged life, with a lot of it spent globetrotting and undertaking exciting adventures and activities (Glenn, 2009). Spending his time between work, social events, his mistress and his two young children.

The Day it all Changed

In December 1995, Bauby was driving his BMW, taking his son to a night out at the theatre. His memory of the initial event is blurred with the impact of his cerebral event swift in rendering him unconscious. Bauby was unconscious for 20 days after having experienced a catastrophic brain stem stroke (Caston). His plight begins to emerge as he regains consciousness and there is a frightening realisation that he is unable to move (Glenn, 2009).

Over time he regained a little movement of his head and was able to blink his left eyelid, but that was it, his one vestige of his former self. Bauby was completely vulnerable and was dependent on others for every aspect of his care. Bauby's plight perhaps represents the most desperate of illness associated with the retention of consciousness (Kearney, 2006). He has become a prisoner in his body and was no longer able to communicate verbally or through expression, and throughout the book his desperation is clear.

Locked in Syndrome

It is difficult to think of a physical disability that is more cruel than Locked in Syndrome. (Laureys et al., 2005). Locked in Syndrome occurs when there is damage (spontaneous or traumatic) to the ventral pons and caudal midbrain (Halan et al., 2021; Schjolberg & Sunnerhagen, 2012). This damage can occur secondary to a lesion, hemorrhage or traumatic injury (Sorenson et al., 2013). It is the most dramatic presentation and outcome of a brainstem infarct in the pons (de Mendivil, Alcalá-Galiano, Ochoa, Salvador, & Millán, 2013).

Cerebrovascular disease is the most common cause of Locked in Syndrome usually occurring as the result of ventral pontine infarction after basilar artery occlusion (Casanova, Lazari, Lotta, & Mazzucchi, 2003).

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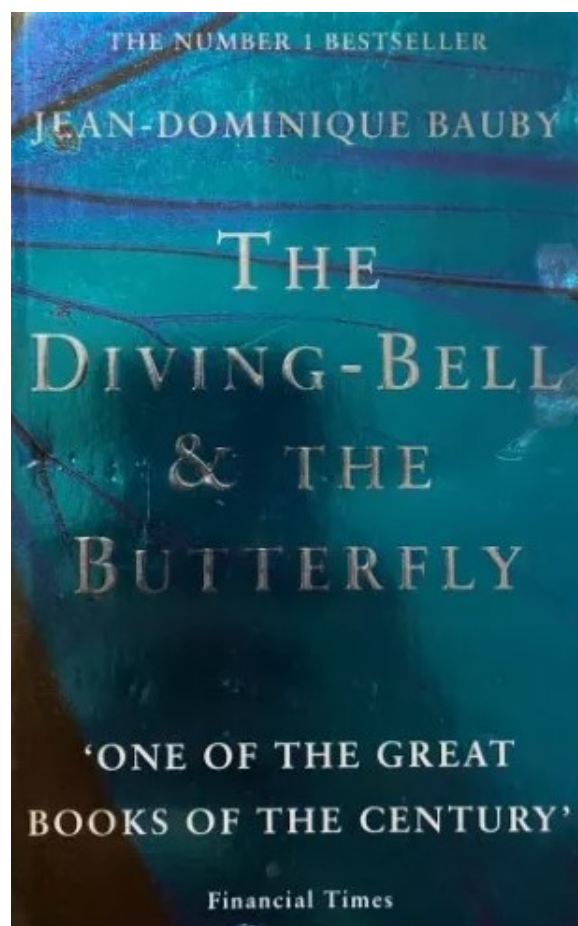
DOI: 10.21307/ajon-2024-011

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The characteristics that differentiate Locked in Syndrome from a persistent vegetative state is the preservation of consciousness and cognitive function (Sorenson et al., 2013). Locked in Syndrome presents with upper neurone quadriplegia, bilateral horizontal gaze and anarthria, paralysis of the lower cranial nerves but with preserved cognitive capacity and in some cases vertical eye movement and or the ability to blink (Schjolberg & Sunnerhagen, 2012). For Bauby, the expected trajectory of his illness is one of no recovery (Kearney, 2006). Additional to the inability to move and communicate, individuals generally present with decreased vital capacity in breathing, dysphagia, vertigo, insomnia and sleep apnoea (Casanova et al., 2003).

Following his cerebrovascular event Bauby was locked in and trapped with a conscious and active mind inside a motionless body. The book provides insight into Bauby's situation over the last few months of his life and has sparked debate regarding Right to Life as well as the quality of life for individuals in the same situation (Wiltshire, 1999). The book presents a mostly positive story demonstrating that Bauby did have a rich, imaginative and worthwhile life despite his extreme physical restrictions (Glenn, 2009). However, it may be argued that there is little quality of life in a situation like that. For Bauby, the gamechanger in regard to quality of life was being calm and composed enough to explore his imagination and memories, and importantly establishing the ability to communicate.

Telling his story was the one aspect of his life that he remained somewhat in control of. His only means of communicating was blinking his left eye as each letter of the alphabet was read out to him. Bauby refers to his physical



inertia as the 'diving bell' that at times is floating into the depths of the sea and the 'butterfly' is his mind that is free to wander from the past to the present and beyond into imagination. The butterfly is his escape from his body that is now a prison (Laine, 2010). Despite the situation following his stroke Bauby chose to live on in his mind, recreating a life rich in lovers, friends, children, travels, fancy meals and books (Mathiasen, 2008). This inner freedom was limitless, regardless of the boundaries his body placed on him.

Bauby's Strength in Communication

The Diving Bell and the Butterfly far exceeds all of Bauby's previous journalistic work in importance. Bauby draws from his vast journalist experience and importantly his imagination. The book was written whilst in hospital on the

windswept coast of Northern France where he was hours away from those he loved and from those that loved him, and where he would spend the rest of his life. Despite this separation he was able to reconnect with his elderly father, and estranged partner and mother of his two children (Church, 2008). Bauby was trapped in his now motionless body, with only had his thoughts, observations, and memories to keep him company for long hours. In his previous occupation, he had built his career around sharing information, so it was perhaps a natural course that he began to dictate his story.

It was his memories and imagination that could take him away from the confines of his current state and the hospital confines (Church, 2008). During the time he was not dictating his story, he was undertaking the rigours of physical, speech and occupational therapy. His nights were his time to compose, starting word by word then sentence by sentence, rethinking and rearranging until he had a plan of what to dictate the following day.

Communication has a profound impact on quality of life and establishing a functional means of communication with every individual that we care for needs to be a high priority. Communication is the key to breaking down the often-isolating wall of an illness. Deficits in communication drastically affect individual autonomy (Sorenson et al., 2013). For those with Locked in Syndrome the ability to communicate is significantly impacted, although modern technology is changing this and opening more opportunities.

We cannot underestimate the importance for us as nurses to communicate with our patients and those we care for. It is easy to be

complacent and forget to speak to the individuals we are caring for (Woodward, 2008), or worse speak over them and between ourselves, or in some instance engage in communication in a native language, leaving a patient unable to understand, or contribute to the conversation, and wondering if the care providers are talking about them or even making fun of them. In this situation small cues of distress that a patient might be expressing can be easily missed. Engaging patients and enabling them to communicate their thoughts, questions, fears and experiences can have a profound impact on quality of life.

Communication is fundamental to human nature and key to our existence and interactions with others. (Ingram, 2015). Bauby could be described as lost or a castaway until that magical moment when a means of communication was established. His inaudible voice has reached so many readers around the globe despite the insurmountable obstacles in his path. As Raoul et al. (2001) notes '*a man bereft of almost all that previously defined him, including his ability to communicate, manages to convey the unspeakable*'. This really highlights the importance of establishing a means of communication.

There is no cure for Locked in Syndrome so rehabilitation with a focus on the goals of communication is fundamental to promoting autonomy (Sorenson et al., 2013). One aspect that is important to remember is that during his time in hospital Bauby was not just writing a book, he was also communicating his likes and dislikes, his everyday needs and thoughts, and experiences to be shared with friends and family.

What is important to patients is not always recognised by staff, with poor communication and dehumanisation themes touched on in the book. One example is Bauby awakening to find an ophthalmologist sewing his right eyelid shut. He tries frantically to get the man's attention 'but this man – who spent his days peering into people's pupils – was apparently unable to interpret a simple look' (Bauby, 1997). Whilst Bauby might complain about the staff or incidents, there is no anger (Kearney, 2006) and he is empathetic to how busy the staff are and how difficult their jobs must be, but he still craves that sliver of humanity, that small gesture of person-centred care and most of all communication.

Reconciliation and Acceptance

Bauby's ability to reconcile and accept of his new life is an interesting theme. It leads me to consider the stages of grief following a life changing incident or injury. What is more incredible is that Bauby had little neuroanatomical knowledge and writes of being brutally introduced to the brainstem and its function

when he woke from his own cerebrovascular accident. There is often a focus on cognitive and physical outcomes following a cerebrovascular accident, but it is important to acknowledge that individuals also face emotional and mental health challenges (Hughes & Cummings, 2020). There are many stages of grief following a cerebrovascular event, including depression, grief, anger, denial, mourning and acceptance (Alaszewski, Alaszewski, & Potter, 2004). These stages are not static, nor do they occur in a prescribed order.

Bauby explores the undertaking of personal hygiene and how tasks such as having his bottom wiped was one day accepted with the lapse into infancy almost amusing, only to be unbearable the next day resulting in physical distress. Mathiasen (2008) notes that it is Bauby's sense of humour that sometimes alleviates his depression. The book presents the full extent of emotions that an individual will experience when faced with a devastating diagnosis. Raw anger is followed by frustration, then we begin to see glimpses of humour



and determination. For nurses it is fundamental to hold fast to the fact that caring is at the centre of nursing, and this involves preserving the dignity of those whom we care for (Sorenson et al., 2013). Individuals like Bauby are at risk of having their autonomy violated, and this can occur even unintentionally, highlighting the importance of maintaining awareness. The preservation of patient dignity is an effective way of protecting patient autonomy (Sorenson et al., 2013). It is quite surprising that even following some pretty inhumane treatment, Bauby still expresses a fondness for the staff even if they are also, as he describes 'his torturers'.

Bauby describes and shares the challenges and frustrations of being trapped in his now motionless body. He lets the reader in to his body, that he has no control over, and importantly his memory, the one part of his life that he can control. Bauby describes his experiences that are for many of us are everyday occurrences on a busy ward. His feeding tube is alarming and he '*cannot imagine anything so insane or nerve-racking as this piecing beep beep beep*' (Bauby, 1997). *At the same time the tape holding his right eye unstuck, and his catheter has detached, and he is drenched. There is little he can do but await rescue, he is at the mercy of his own changed body and those assigned to care for him. This really brings home the vulnerability of some of our patients, particularly those who are unable to express their own needs. Bauby writes further of all the ward's noises we are often to attuned to and don't tend to notice, trollies and carts, footsteps and perhaps my favourite staff calling out to one another like 'stockbrokers trying to liquidate'* (Bauby, 1997).

I hope that I would be one of the nurses he describes as always trying to decipher his SOS message, not the small minority that pretend not to notice his distress. Appreciating patient perspective fully is an ongoing challenge within healthcare (Ingram, 2015). *The frustration at being conscious and able to communicate, but treated as if you can't or are not trying is difficult to imagine* (Woodward, 2008). *Just as difficult to imagine is that there were staff that lacked empathy, patience, and kindness.*

The chapters are a mix of Bauby's memories of his life, observations, and his deepest and most vulnerable imaginings and fantasies. Bauby fears loneliness and the monotony of hospital exhausts him more than dictating his book does. Bauby experiences a number of realities including the first time he is transferred into a wheelchair, and when he first sees himself in a mirror following his stroke he slips into a depressed state and questions his potential quality of life.

When describing his reality and state of mind, he is honest and open '*There are no words to express it. My condition is monstrous, iniquitous, revolting, horrible*' with descriptions of his appearance including looking like he had '*emerged from a vat of formaldehyde*' and '*horrible to behold*' (Bauby, 1997). *What struck me was that this was raw reality and feelings, this was not a dialogue of self-pity and loathing. Bauby was by no means self-absorbed with his own troubles. His memories and stories are engaging and moving, there is wit and humour, and as you turn the pages you begin to realise the spirit of this inspiring man. Bauby declines to wear hospital provided gowns and attire, expressing that 'if I must drool, I may as well drool on cash-*

mere' (Bauby, 1997). *It is important to accept these frustrations, expressions of personal preference and disclosures as an escape and lifting of the weight of his metaphorical diving bell.* Guzek and Kowalska (2020) suggest acceptance as an important factor in rehabilitation following a cerebrovascular event.

Entrapment

The further I read, the more gratitude I have for my life and for the many means that I can express myself. The book shows us how fragile life is, and how transient our health and our lives are as well as how much we take for granted (Warriner, 2007). Bauby reflects and mediates over his past life and agonises over his entrapment and the fact he is now barely a participant in social settings, he can no longer physically interact with his family and children. He recalls time spent with his family prior to the stroke and unfairly makes comparisons to his current situation.

These comparisons are backwards focused, meaning he is comparing himself to something he cannot be. Although, it is an understandable desire as physical functioning and autonomy have long been viewed as a prerequisite of a life worth living (Chin, Hedberg, Higginson, & Fleming, 1999). In Bauby's case the damage from the stroke event was simply too catastrophic for there to be hope of a full recovery, and the acceptance of any diagnosis like this is difficult to accept. Whilst acceptance is expressed and reflections are tuned towards a sense of nostalgia for his old life, there is still a sense of melancholy. Whilst Bauby's own feelings and self-observations of his situation are processed and accepted, he is responsive to the gossip

and rumours that he is in 'a vegetative state', ensuring that frequent letters and a bulletin are dictated and sent to his family and colleagues in an attempt to quell rumours and keep his identity and memory alive.

This dialogue with his old colleagues also functions to make him feel less alone. Bauby knows his life will never be the same as it was before his stroke and he refuses to retreat into shame, and self-pity. Despite these communications, Bauby does express a degree of isolation, and he longs for his past and to be back in a social community, to have friends and not just staff. The pain of the loss of his old life and present isolation alternates with the knowledge that he can communicate. His old world and career were built on words and the power of communication. Now in his new world, it is a fundamental means to ease his isolation.

The Reality

The book is raw, Bauby speaks for the moment, he expresses regrets and frustrations and there is suffering and sorrow and questions of existence as he faces a future with no relief in sight. He writes of his time off the ward and excursions venturing into public places and the unease in others that he inspires (Raoul et al., 2001). Through Bauby we understand that Locked in Syndrome is more than an illness due to its profound isolation, helplessness and dependence on others (Mathiasen, 2008).

You can feel his internal anguish, knowing that the only individual who really understood such torment was him. Depression comes and goes for Bauby, and grief overcomes him at times (Raoul et al., 2001). Bauby admits that

he struggles and considers surrendering to the 'vultures that claw at his mind' and abandoning attempts at communication. He pushes on and despite the struggles he upholds his belief in the value of communication. It would be a version looking through rose-coloured spectacles without the frustrations, and grief.

The book is not for the faint hearted, but it is for those who want a reality check and a reminder of how life can change in an instant then this is a book for you. Bauby writes of his life, a life lived in his head, but still just as real. He offers a haunting and frightening experience of what it is like to be inside the cruel and unforgiving prison of Locked in Syndrome. He writes '*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*' (Bauby, 1997).

Despite these challenges and frustrations, what shines through is that even when he faced the most challenging and frightening circumstance of being locked in, Bauby draws on his indomitable spirit and chose his course in life and his story is one of great courage and the power of the human mind. It is evident early on in the book that his wit and sense of humour have survived the stroke (Church, 2008). Bauby overcame obstacles with humour and grace, he was proactive and was able to discover meaning in even the most banal experiences.

Bauby's words affirm that life can exist within a man even when one's body appears dead (Mathiasen, 2008). He saw the light of hope and accepted its light even in what must be

one of the most hopeless of circumstances. It is through his attitude, resilience, and enduring force of hope that he was able to discover his purpose in life. Bauby's words go to the core of what it means to be human. *The Diving Bell and the Butterfly* is a read for any nurse who wants to explore the depths of the human spirit and explore the enduring and profound lesson of choosing one's attitude towards circumstances. It opens you to the fact that even in the worst circumstances, something beautiful can be created. It is a unique and powerful insight into the silent world of those with Locked in Syndrome (Kellett, 2000), and so easily Bauby could have survived or died without ever communicating again.

The diagnosis of Locked in Syndrome comes with a poor prognosis, most patients will only gain a small amount of capacity, and the mortality rates are high. Sadly, in March 1997 at the age of 44, Bauby unexpectedly died from pneumonia, two days after publishing the first edition of his book. He never got to know what a wonderful legacy he would leave, or that his book would become an international best seller and translated into over twenty languages. He did not survive to hear the news that 150,000 copies of his book were sold within the first week of its release, and millions since then. He sadly did not survive to receive the acclaim for what was a celebration of the liberating power of memory, consciousness, and imagination.

Bauby also didn't survive to experience and benefit from the technology now available to aid communication. The book and Bauby's story are a recipe for appreciating the smaller things in life, for seizing the moments and being spontaneous and importantly for making

the most of whatever there is. It would be so easy to accept the despair of being 'locked in' and decide it is just too difficult to communicate. Luckily for all, Bauby did not decide that communicating was too challenging and perhaps not worth it, for him it was a godsend and when he was communicating it was the only time that he felt like his true self, he found freedom from his body and relief as he escaped through his mind. This story is more than a simple tale of triumph over adversity. It is thought provoking, and its exploration of the feelings of loss, hope, joy, despair and love of life will perhaps leave you with more questions than answers. It is a medical masterpiece in its uncompromising account of human nature (Warriner, 2007).

Reflections

I was first introduced to *The Diving Bell and the Butterfly* during my postgraduate course work, where I studied the themes in what I found to be an inspirational and moving movie. The illness experience is perhaps best conceptualised and understood when told directly by the patient, and *The Diving Bell and the Butterfly* is simply this. As nurses, when we explore and study the illness experience, we focus on the subjective experiences of illness and care as well as the nurse-patient relationship and interactions. *The Diving Bell and the Butterfly* is explored from a unique perspective of an individual who is suffering from locked in syndrome. It is a rare occurrence firstly for an individual in this position to be able to communicate enough for a book, and perhaps rarer that they have been able to communicate with such eloquence and attention to detail.

Patient stories provide nurses with an understanding of the effects of a disease process (Bennett, 2007) as well a practical insight relating to positive health interventions and the delivery of health care. As nurses, we strive to care about as well as for our patients (Newham, Curzio, Carr, & Terry, 2014). Anyone can read a textbook and recite a policy or procedure, or undertake a technical task, however it's through the revision of patient stories that we develop the skills, observation, compassion, empathy and understanding to care about our patients. For example, the respect of autonomy and the need for maintaining dignity when caring for an individual with locked in syndrome are key issues (Sorenson, Bounds, Huffine, & Moss, 2013). Whilst Bauby's story and outcome are rare, the insight he provides into his existence in a locked in state are thought provoking (Wiltshire, 1999). The clarity with which he describes events, care processes and communication (or the lack of), are the endearing qualities of *The Diving Bell and the Butterfly*.

I have often thought of the movie and did not realise that at the time I was reflecting on characters, plots, and themes and this is what they simply were to me at the time. This disconnect remained until recently when I happened to come upon a written copy of *The Diving Bell and the Butterfly* I was amazed for just under 140 pages, the book was far more detailed than the movie. The problem with movies is that there is artistic licence, and important aspects of the story are misinterpreted or cut completely. Like any film adaption *The Diving Bell and the Butterfly* uses visual and auditory experiences to tell the story. The film, whilst good, is no substitute for reading the book. The book develops the characters with far more depth and dimension and rather than

the visual representation in the movie, the book also provides those essential qualities of emotion and thought.

I found the book far more striking than the film; it is the raw script of Bauby's words and whilst only a slim memoir, one needs to appreciate that it was dictated by Bauby blinking his left eye, painstakingly spelling words one letter at a time, read by his therapists and staff from an intuitive frequency ordered alphabet. Over a period of ten months, for four hours each day, it took 200,000 blinks to write at an average of two minutes per word. A simply outstanding achievement. The sentences are often clipped, minimalistic and it is this brevity that reflects the difficulty and patience required to get Bauby's thoughts onto paper. There is often a break in narrative and some inconsistencies or gaps in the story line. Vivid memories are interspaced with details relating to his days and existence in hospital (Glenn, 2009).

Bauby's narrative forces you to redefine the limits of firstly, what is communication and secondly, what are the functions of communication (Raoul, Canam, Onyeoziri, Overboe, & Paterson, 2001). Importantly it needs to be recognised that for Bauby communicating was dependent on the willingness of others to listen to him and assist him (Raoul et al., 2001). Despite the challenges he makes his feelings, emotions and existence clear 'my heels hurt, my head weighs a ton and something like a giant invisible diving bell holds my whole-body prisoner' (Bauby, 1997). Overall, the language is uncomplicated yet elegant and results in a very easy read. Personally, I think this adds to the book and led me to reflect on the challenges of establishing communication means with individuals in similar situations. I think the

honesty is reflected in the fact that the chapters are not in chronological order, and they vary significantly in length and topic. This only reinforces the fact that dictating a book, one blink and one letter at a time, was both laborious and exhausting. As I sit here typing this review, I begin to appreciate the speed at which I can share an experience, feeling or thought. It is mind boggling to think of undertaking such a task as dictating a book using the blinking of one eye.

There will be times in all our nursing careers when we experience a moment of illumination, of insight or understanding that will profoundly affect, impact and change our nursing practice. Although Bauby's memoir is not an attempt to analyse locked in syndrome from a medical basis, it remains an important account and will inevitably change the way you practice, regardless of your neuroscience specialty area. The book is personalised and portrays the experience and unforgiving reality of locked in syndrome astoundingly, it was moving and effective in enabling the reader to truly understand the experience of being locked in. This book would not have been possible without Bauby's motivation and engagement, but also the skills and patience of his therapists who worked with him letter by letter.

I urge you all to find a copy of the book, it is simply inspirational. Sadly, the copy I have was purchased second hand after being withdrawn from a healthcare library collection. This is a book that should be in every library and accessible for all. It is one of those rare finds that will alter one's understanding of individuals who have experienced severe and devastating neurological events. This book is a must read for all neuroscience nurses. It is also a timely reminder to treat patients how

we would want to be treated (Warriner, 2007). Bauby's achievement is simply undeniable. Not only has he told his story, but at the same time he has raised awareness of locked in Syndrome and highlighted our responsibility as healthcare providers to explore every possible way to communicate with those that we care for. It is a beautiful and poignant account of life. What an aim to live a life of equanimity, joy, humility, compassion, patience, and calm.

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DDCI: DOPA decarboxylase inhibitors, **OLE:** open-label extension, **PD:** Parkinson's disease, **TEAEs:** treatment-emergent adverse events.

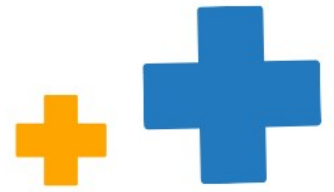
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