

LIFELINES TO DEEP WELLS

REACHING THE ACTIVE MINDS IN PARALYSED BODIES

People with brain injuries who exist halfway between coma & consciousness are often described as vegetative. But like Jean Bauby and others, their minds and hearts may be undiminished, writes **Roger Rees**.

In December 1995 Jean Bauby, a 42-year-old father of two, and editor-in-chief of *Elle* magazine in Paris, suffered a massive stroke which left him paralysed and speechless but able to move one muscle: his left eyelid. Yet his mind remained as active and alert as ever.

By signalling with his eyelid, he 'dictated' *The Diving Bell and the Butterfly*, blinking to indicate each individual letter as an alphabet with letters placed according to the frequency of its use in the French language was read to him.

Trapped inside his own body, his dispatches were poignant and often wryly humorous. Bauby told of his life in a hospital overlooking the English Channel, the flights of fancy that sustained him, the meals he could eat only in his imagination.

Bauby invented life for himself in the most appalling circumstances. His story challenged traditional views about the absence of responses from the thousands of people who, like Bauby, are 'locked-in'.

'Locked-in' is a distinct diagnosis applied to people existing in a state halfway between coma and consciousness but who are mentally alert: they can see and possibly hear and they can be roused occasionally by appropriate stimulation.

Many are young or still have skills and talents that can be nourished, but they have few, if any, means of expressing themselves. And unable to tell their story, they cannot improve our understanding of how a damaged brain still contains a substratum of rich mental life.

The most common causes of 'locked-in' state are brain injuries from road accidents or stroke. Parents and spouses have long considered that the feeling, creative person still

existed only to have their tentative views ignored, or on occasions, scorned.

Bauby wrote: "I am fading away, slowly, but surely. Like the sailor who watches his home shore gradually disappear, I watch my past recede. My own life still burns within me, but more of it is reduced to the ashes of memory. Since taking up life in my cocoon, I have made two brief trips to the world of Paris medicine to hear the verdict pronounced on me from medical heights. I shed a few tears as we passed the corner cafe where I used to drop in for a bite. I can weep discreetly, yet the professionals think my eye is watering."

From an economic rationalist's view of rehabilitation or a simplistic absolutist view that a person is either cured or not cured, people in the locked-in state are considered of no account.

In an Adelaide hospital a young woman write notes and letters with a felt-tipped pen about the poetry of Eliot and Whitman, the prose of Jane Austen, and records her feelings of Mozart's music.

Locked-in for six years, swaddled like a newborn, and unable to move or speak unaided, she often lapses into infancy yet her mind has remained intact, eager to emerge when the appropriate time arrives.

Her parents have maintained a six-year vigil, believing that an intact person still exists in their daughter's paralysed body. She cannot speak, but her writings invoke the supremacy of her memory, dreams, reasoning and imaginings.

Those who believed her brain damage was global and total have had to reverse their views. Her parents are vindicated;



A still from the film *The Diving Bell and the Butterfly*

their daughter's meticulous writings, like Bauby's, provide evidence of the mystery of human resilience and the duality of the interaction of the brain and mind.

In her isolation, the young woman records her feelings of sadness, especially when therapists and nurses fail to recognise her potential.

Bauby dreaded Sundays because "there will be nothing at all to break the passage of the hours. Sunday is crossing the desert, its only oasis a sponge bath even more perfunctory than usual. The bath bears more resemblance to drawing and quartering than to hydrotherapy. Yet all over the country, activities are under way for the great domestic event of the legendary French Sunday lunch."

People in the locked-in state are excluded from such fundamental social events. How much could we learn about their potential for participation and at least some internal recovery if they were included?

There is much evidence that appropriate context activates mental events. Put simply, a small library of chosen books

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is useless for the person in the locked-in state if no-one will come to read them.

We should choose only environments that enhance and ennoble the severely brain-damaged. There is a need too for quality research which helps determine the most supporting and ennobling environments for people in this locked-in state.

Until Bauby's book was published, rehabilitation professionals tended to view isolated reports of intact brains inside a locked-in body with scepticism. The former editor of *Elle* provided graphic evidence that a visitor's warmth and ability to recognise his intact talents provided the lifeline he needed to communicate his feelings, needs and dreams.

Effective rehabilitation is about providing a lifeline for them in their deep wells, so that they can live and fight on undaunted. We need to seize the opportunity to change our perceptions of the potential of these people who after all, were once our neighbours, our friends, our sons and daughters.

Can we make the quantum leap from befuddled locked-in thinking, to behaviour which acknowledges that while their physical world may be closed forever, their inner world is full of rich memories and imaginings whose journey can still be nourished and enhanced. ~

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