

## The 'locked-in' syndrome – comments from a survivor

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In this day and age of denial of sustenance for 'coma' victims, the description of a psychologist's own travail with the 'locked-in' syndrome is very pertinent. There is a real chance of an inexperienced physician mistaking the 'locked-in' syndrome for 'coma' or the 'vegetative syndrome'. People with a pure brainstem lesion can be in real coma for a long time and still have a chance of waking up and be in a state of 'locked-in' syndrome which would superficially look like a vegetative state. These people are completely aware of what is going on, but may not be able to move, breathe, talk or swallow. With rehabilitation they can live a useful life. One of my patients, like Dr Ostrum, lives independently, works and has the same intelligence as before the accident. We must be very aware of this syndrome and prevent these people from being starved to death by a court order.

HENRY STONNINGTON

### Preface

Dr Ostrum is unique in my clinical experience. Locked-in syndrome is itself rare and Dr Ostrum is the only one of traumatic aetiology whom I've treated. Although I first examined her in her contractured, spastic, ataxic and dysarthric states in November of 1988, she had written me innumerable letters during the many months prior to this consultation detailing the horror of her situation, railing against the medical system, and anticipating full recovery once she was admitted to my rehabilitation unit. Clearly, she was a woman with cognitive and behavioural problems when I finally saw her during November of 1988 – with her flailing gesticulations, yelling, interrupting, demanding demeanour and uncooperativeness. I was certain I was dealing with a 'classic' head injured, cognitively and behaviourally impaired person. But that was fallacious as the reader can tell from the intelligent, articulate and accomplished person presented in her article.

I embarked upon a personal and professional adventure that will be with me all my days and that I recount to house staff and new colleagues regularly. I have travelled with her through the depths of bitterness, depression and fatalism, because of the crushing realities of life as a physically challenged person, to the heights of excitement and accomplishment, because she could wash her own hair or stand unsupported. I was not a believer in the beginning, but that changed rapidly and Andrea has become an inspiration. Her accomplishments have continued to beat the odds. She has evolved from unrealistic expectations of herself and others to acceptance of neurological limitations and the lack of superhuman powers in those who care for her.

Denial and unrealistic optimism have their places in healing, both physically and psychologically. Patients must be kept out of the pit of despair while you, the clinician,

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hold the reins on their search for the Holy Grail. Physicians caring for people like Dr Ostrum need to be good listeners, as well as advisors. You need to be an anchor from which possibilities can be explored, providing a safe harbour to which to retreat. This certainly does not sound like the traditional medical model of patient care. But rehabilitation medicine is well known for breaking that mould.

People like Andrea struggle all their lives to be accepted for whom they are, not for what their bodies appear to be. To 'judge a book by its cover' is unfair, but it happens all too often. One of our jobs as rehabilitation clinicians is to recognize the contents of the book, understand the complexity and uniqueness of the prose within and convince others to read it too.

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### Introduction

The most important thing to know about me is that my injury magnifies every sensation, so that I feel every little thing—even the food moving through my intestines. It is important to not let anything touch me hard. Second, my damage is bad but it is all physical. My mind isn't affected at all. Finally, I am not as helpless as I look. The following is an account of what I do.

### Case study

I used to be on life support.

I could not talk comprehensibly until 2½ years ago. Now I can talk to strangers on the telephone, and my doctor says that I am often 90% intelligible. I also wrote this myself on my own computer. I can eat and drink anything. I feed myself with a regular fork and spoon and off a regular plate. I drink unaided. I cut my food and write notes, wash myself, get dressed and undressed, and when brushing my teeth I can take the cap off the toothpaste, squeeze the tube, and return the cap. I can turn all the way round; I can stand up, and I have even done this without leaning on anything. I have taken a step, balancing on my therapists. I can sit at a desk on an office chair and answer the telephone, open the drawers, drink, ring a bell and more. I eat, drink and write at a regular chair and table. I can stand at the parallel bars alone. I have a bank account and I sign and endorse cheques at the table.

I live without my family. I transact my own business and run my own household, although I cannot do the actual physical labour. I am writing a book about my rehabilitation experience, and a film, for which I am to be a consultant, is also being made. I am working with the New York State Committee on Rehabilitation Technology, and I am trying to get funding for a research study I designed. I am also sponsoring an independent research project under the auspices of the Centennial Scholar Program of Barnard College. An article that I wrote appeared in *Longevity* magazine. I run a private consultation business in rehabilitation psychology from my home for which I use a computer. I am on the supervisory staff of the Institute for Contemporary Psychotherapy, a psychoanalytic training institute, and I write magazine articles.

In June 1985, as I was on my way, with my companion, to our country house near Albany, I drove our car into a tree. My companion, who was in the passenger seat, sleeping, was killed on impact. I was found 6 hours later, lying in a ditch, alive

but in a coma. I was in the coma for months; my son says 6, my Doctors say 13. One thing is certain: I was conscious long before I could let anybody know. I was aware of everything that was going on around me. I even have memories that are as clear as if it were yesterday, although it was more than 5 years ago. I was unable to let anyone know because the accident left me paralysed below the neck, unable to signal in any way, and all the technology showed damage so extensive that nobody with that much damage could possibly survive and be aware.

Eventually, the fact that I was out of the coma was discovered by an experienced doctor and gifted clinician, Dr D. Levy, then of New York Hospital, when the court required an evaluation before my feeding tube could be removed. I was saved from death, but then entered a nightmare that was to last 5 years.

Unbeknownst to me at that time, what distinguishes traumatic brain injury (hereafter called TBI) from other forms of brain damage is the impairment of cognition and emotional expression [1].

The impaired cognition can be as localized as to affect only specific functions such as memory or analytic ability, or it can be so general that a person may not know whether or not she or he has ever seen someone before. The emotional impairment can take the form of a lethargy so deep that the person will not initiate anything or even stir themselves at all. Conversely, it may take the form of an impulsivity so extreme that the person can be barely controlled. In my case this meant that for 3 years, until I was living in my own apartment, I was surrounded by people the likes of whom I had only seen on television. Once a man came into my room and began shaking the bars of my hospital bed uttering loud, wordless moans all the while. I was petrified and thereafter closed my door. It meant that I was surrounded by constant screaming and by people who had repeated fits of temper.

If I thought that was bad, a nightmare that was worse was beginning, and it was to go on for years. The nightmare was that although I had injured my brainstem in the automobile accident and, technically, therefore, fell under the rubric of 'TBI patient', I did not conform to the other distinguishing textbook characteristics in any way, for although the damage was severe, it was all physical. In every other way, in my thoughts and my core identity, I was my old self. It was all inside and you couldn't see it. Now, because I was trapped in a badly injured body and because the medical books said it was not possible, I no longer existed. For 3 years, I was addressed by every new person as if I weren't in my right mind; I knew immediately by the voice that was used—kind of like the voice that someone who doesn't know any better uses with a 2-year-old. I soon came to call that 'the hospital voice'.

After people had got to know me for a week they knew my thinking was intact, but emotional damage was to be a lot harder to disprove, and for 5 years my very words were used against me. I have always been by nature blunt and confrontative. What before had been accepted as a personality trait and even admired by some was now used to prove I was emotionally injured, and whenever I protested that I was just being myself it was taken as further proof and called denial. I eventually began to feel like a rat trapped in a maze. The harder I tried to make people in the hospitals accept that I was my old self inside, the more I felt as if I were a rat running in circles chasing my own tail.

Even in physical tasks I do not follow the textbook. I can do more than other paralysed people. Doctors have called me 'the miracle worker'. It may sound as if I am blowing my own horn, but I cannot even recount how much I despaired whenever (and it happened all the time) I wanted to learn how to do something I

knew I could do and can do today only to be refused and told it was impossible and I was 'denying'. It was no miracle, but a lot of hard work and pain.

After coming out of the coma (from which every doctor said I would never emerge) I was completely inert, with tubes to eat and eliminate. Now I am living without my family, directing my medical care, transacting my business and even earning money. After the accident, in the name of being therapeutic they wanted to change my personality—the very thing that has made my recovery possible.

Angry? Sure I was angry. An accident over which I had no control, which was completely random, had permanently and irrevocably altered the course of my entire life—whether for better or for worse only time will tell—but life is already more difficult and painful. And how much longer will it be? It has already been 7½ years, and in some ways I have come far but in other ways not at all. I have to remember that the things other people take for granted, I cannot, and I have to measure my progress in teaspoons. Every time I get a spoon of food in my mouth or drink something without coughing, that is a victory, and I have to put everything else out of my mind in order to do the most simple things. There was a time when I had to deny how badly I was hurt. If I had not, I would have given up. I did not understand why in every hospital I was in I was always put in the room for the worst patients, and I couldn't understand why if I said I was the same inside everyone treated me differently. Thank goodness for that drop of denial when I needed it.

I can see myself very clearly now. In fact, that picture never leaves my mind. It is always a prod to keep myself working to be different. One thing I can take comfort in: nobody else will have to go through what I did. Thanks in part to my experience, David Levy and others discovered more about the kind of coma with which I was afflicted—the 'locked-in syndrome'.

### Reference

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