

The invisible brain injury

Aurora Lassaletta

Introduction

In May 2005, as the result of a serious traffic accident, I suffered a significant head trauma, along with multiple fractures. At the time, I was 33 years old, married, a mother of two – my eldest child was two and a half, and the youngest just five months old – and I worked as a clinical psychologist in a public mental health service.

I had the immense good fortune to be in the hands of some incredible doctors, thanks to whom I am now able to write this book. Following emergency neurosurgery to resolve the most immediate consequences of my cranial fractures, and two weeks in an induced coma, I spent a long time in hospital. There followed weeks of rest, and many months of physiotherapy and physical rehabilitation, which were slow but effective, and gradually, with time and effort, I was able to move into a wheelchair, and from there to walking with crutches, and little by little, without them.

I noticed that the people around me linked my physical improvements to an overall improvement. Yet, day-to-day, I was noticing new impairments, which I attributed to the accident, that did not only affect mobility. It was hard for me to understand why I was so tired all the time, despite being inactive; why couldn't I follow long conversations or large group discussions? Why couldn't I read or understand a film, when I had all the time in the world? Why was I speaking slowly and less able to retain information? And worst of all, why couldn't I stand the normal noise of my children playing nearby?

With my restless and inquisitive nature, and my former training as a clinical psychologist, I tried to understand and analyse the new impairments I was observing. This constant study of my own symptoms was a vital tool in learning to live with them.

Since I looked normal, and hadn't suffered serious language impairment, many of the cognitive difficulties that I was mentioning to people were not easily identifiable from the outside. Perhaps I wasn't able to explain them very well. Many people confused my apathy, slowness, difficulty concentrating, inexpressiveness and some of the other side effects that I describe in this book with symptoms of depression.

Some of the professionals, when they heard about my cognitive impairments, referred me to the Centro Estatal de Atención al Daño Cerebral Adquirido (CEADAC), the Spanish State Rehabilitation Centre for Acquired Brain Injury in Madrid, for a neuropsychological assessment. The fact that I didn't have very visible injuries led to a few mix ups, such as the visit to the health centre's social worker who had to fill in a referral form for me and asked, "Why didn't Aurora come?", since she was expecting the person referred to in the report to have more visible injuries. I can really empathise with Sophie, who suffered a brain injury as a result of encephalitis, when she describes in her account how, because she shows no residual physical disabilities, people don't understand that she feels fragile, tired and confused on the inside (Easton, 2016).

At CEADAC I received short but excellent treatment, focused largely on attention and organisation, thanks to which my family and I could begin to understand that there was a reason for many of the cognitive impairments I had been noticing. Until then we had been living with these impairments on a daily basis, but we didn't understand them, and we didn't know how to manage them, because we didn't know that they were caused by a traumatic brain injury (TBI).

Magnetic resonance images (MRI) later showed my neurological damage for the first time: extensive left frontotemporal injury and diffuse axonal damage. I was very surprised to hear the doctors who saw the results say, "Poor thing, you must be exhausted!" That had been my main complaint for the last few years, and nobody was listening. It took nearly two years for me to be diagnosed and to receive suitable rehabilitation for my impairments and proof from neuroimaging that showed the damage. I wouldn't want this to happen to anyone else, but, from what I have heard in my groups and what I have read over the last year, it is actually quite common. I really identified with Karen, in the interesting book *Life after Brain Injury: Survivor Stories*, who was also treated for physical fractures after her accident, but took six years to get a diagnosis of TBI (Wilson, Winegardner and Ashworth, 2014).

After the MRI results, I was lucky enough to meet a doctor and psychotherapist with extensive knowledge of the brain and its disorders. Her

first goal, before she started any kind of psychotherapy work with me, was to identify which symptoms were organic and which were emotional. I am very grateful to her; she was the first person to start teaching me the differences and to propose the right treatments. At first, I also believed that all my symptoms were psychological. It is certainly normal to have some, given how difficult it is to adapt to such a sudden change, and they could even aggravate some of the symptoms of brain injury. Now, knowing how to tell the difference and knowing which symptoms are related to the injury, I can be kinder to myself, and I think that sharing my experience could help other people in similar situations to feel better. I have undoubtedly gone the long way round sometimes, but I have learned a lot along the way.

My aim in writing this book is to show some of the symptoms of acquired brain injury (ABI), especially in the cognitive area, which I consider to be the most invisible from the outside. I would also like to reduce the added frustration involved in dealing with these symptoms throughout the process toward recovery without knowing that they are the result of a brain injury. I think it is important to try to raise knowledge and understanding of these deficits in people who have suffered an ABI, because one very common symptom is a lack of awareness of what is happening to us. The book is primarily intended for people affected by brain injury and those around them who are an essential part of the rehabilitation, adjustment and acceptance process, as well as professionals in contact with this group. I would also recommend it to lawyers and insurance brokers who have to determine the damages and necessary rehabilitation for each client. It is very important that we all know that there are residual effects that are not immediately apparent but are just as disabling and require long-term rehabilitation.

My journey to this point has been hard work – both physical and psychological – especially the continuous task of accepting the extent of the effects imposed by each impairment at every moment. I believe that this constant acceptance is fundamental, for both the person affected and the people around them.

My normal appearance meant that I spent a lot of time in the first few years justifying myself and explaining my impairments whenever I was unable to perform a task, since outsiders often expect me to have the speed, agility and normal coping mechanisms that I appear to have. We're not inventing our symptoms! But we're often treated as though we're exaggerating them (Wilson, Winegardner and Ashworth, 2014). As Jade Roberts points out in the book *6 Steps to Understanding and Coping with Mild Traumatic Brain Injury*, it is practically impossible to maintain the right

pattern of cognitive and emotional deficits to fake a brain injury (Roberts, 2014) – so, please, believe us and listen to us!

Now I find it much easier to live with, knowing that there is some neurological damage, especially cognitive effects, that can't be seen from the outside, and I no longer feel such a need to explain myself. From what I have seen, it is much easier to tell that someone has brain injury if they have a significant physical impairment. I laugh whenever I recall the day that I feigned a limp and managed to go straight into the swimming pool with the Brain Injury Sports Club, sick of always having to stop and face the same question when whoever was on the door didn't recognise me as a member of the club: "And where do you think you're going?"

The majority of my physical injuries were reversible, due to the areas of the brain affected and thanks to the rehabilitation work. Those that remain, which limit me every day, are not so visible from the outside. These days, if you don't know my story and you're not with me for twenty-four hours straight to witness the changes during the day, I'm sure you wouldn't be able to tell that I had significant physical or cognitive impairments. Some brain injury is only revealed by living with the person, not in a half-an-hour medical appointment.

I have noticed significant improvements in my cognitive symptoms over the twelve-plus years that I have spent rehabilitating in one way or another. I have been able to recover most of the English that I spoke, my typing, my coordination in swimming and my reading, without working on any of those things specifically, but from neurorehabilitation work overall. I am lucky enough to be able to talk about some of my problems in the past tense, and to have reduced the extent of some of my impairments, after many years of hard work, research and inquiry. Functional MRIs have shown that some impaired functions in the affected cerebral hemisphere have been transferred to the healthy hemisphere. I found confirmation of these results in the investigations presented by N. Doidge in his book *The Brain that Changes Itself*, which reflect the incredible neuroplasticity of the brain (Doidge, 2007). These results give me strength and the hope that I can carry on recovering skills even now, and encourage others to keep trying. I know that the path to rehabilitation and rediscovering your "place" in the world is hard, that it takes determination and patience and that, despite all the outside help and being surrounded by people who love us, we often feel extremely alone, which can lead to depressive thoughts, as described by many survivors (Yeoh, 2018).

It's not that the injury is invisible because it is slight. My own injury, although I believed it was slight, was more than that, and the professionals are still reminding me of that today. Why doesn't it seem disabling enough to be unable to go back to work or to organise your own house?

For a time I felt like the accident had robbed me of my identity as a woman, mother, partner and professional, and I felt like I had to invent a new one. Now I realise that I am recovering some of the features of my old identity and I can integrate them into the new one. What I hope is that I will accept and be at peace with my new reality. My dream is to get the most out of life, to give as much as possible of myself and feel useful as a person and as a professional. I know I'm going to get there.

After many years and a significant improvement, as a family we are managing to adjust and accept our new roles more. I am very pleased that my son Álvaro, the eldest, likes to cook, and he can help to organise and prepare the lunch or dinner if I am very tired. On the other hand, my youngest son Mateo has some kind of sensor that detects when I need peace and quiet, and makes sure I get it.

With my current work on acceptance I feel that I'm making progress when I manage to connect to myself, to know where I am, to be realistic about my plans and to not deny my impairments. I can do this by putting into practice the mountain of resources and tricks that I've learned along the way. I want to share all this to see whether my experience can help other people in my situation.

The history of the book

In this book, I will try to explain the physical, cognitive and emotional changes that I have noticed since the accident, and especially the ones I have been writing in a very disorganised diary over the years.

I've always needed to write down my experiences. I still have all my diaries from my childhood and adolescence, and, as an adult, I still jot down my thoughts and feelings on paper, in notebooks and even in notes on my mobile phone, although I never read them again. Now, several years after the accident, with encouragement from the professionals working with me on my neuropsychological rehabilitation, I have decided to collate many of the notes I've written over the last few years about the impairments that appeared and the treatments and tools I used to alleviate them, and turn them into a book. These professionals told me that my diaries showed my dual perspective: as someone affected by brain injury and as a professional myself.

When I shared my plan with friends with editorial experience, they suggested that I should organise what I was writing with a contents list, and I decided to separate what I had to say about each impairment, which became the different chapters. The observation and follow-up of these symptoms over the years has been an incredible learning experience, in terms of their nature, management and development. I only had a basic concept of neuropsychology, which I learned during my training as a psychologist, but, fortunately, I still have some of my professional skills for observation, analysis and investigation. These have helped me to explore the symptoms in detail, despite my current internal disorganisation.

I asked myself many times whether the symptoms I was writing about were already part of my personality before the TBI, and I still wonder whether these physical, cognitive and emotional changes are just a natural development for my age or the result of not being in work – although I could tell that they were clearly related to the brain injury. I decided to get it confirmed and show my writing to an expert on the subject, Amor Bize, a neuropsychologist at CEADAC, who was responsible for my treatment there in 2007. I remember that, when she discharged me, she was the first person to encourage me to write. She said that I explained very clearly what happens to people with ABI. At that time I couldn't set myself a task like that, as I couldn't even stay focused long enough to read a novel. I was buoyed by her enthusiasm, telling me that my intuition and observations were correct and that the symptoms of brain injury I was writing about had been clearly identified.

Another help with confirming my observations and continuing to learn was my experience in the ABI psychological support groups, which I coordinated on several occasions as a voluntary psychologist at CEADAC. At those workshops, I met survivors of TBI, stroke and different ABIs who had no outwardly visible injuries. And others who had more physical injuries, but shared many of the same symptoms that were imperceptible from the outside. Being able to talk about how difficult this could be at times was very beneficial for everyone.

Something that always came up in those groups was the relief that we all felt when we realised that some impairments we had, which sometimes we had not identified as the effects of brain injury, could be given a name. It is also very important that the people around us recognise these impairments and realise that there is a reason for them. And the most important thing of all: not feeling bad for having them. This really helps in the difficult task of acceptance.

For the majority of symptoms, I tried to follow an outline that reflected the following points:

- 1 “How do I recognise it?” Description of the symptom and how it manifests in daily life.
- 2 “How has the symptom been changing and developing over time?” Treatments, differences.
- 3 “How do I feel, and how do I feel that others perceive it?”
- 4 “What do I do with this?” Resources and strategies for compensating.
- 5 “What do the experts say?”

At first, with minimal understanding of my deficit, I had planned to do the last part myself and started my research in neuroscience books to understand and learn about every symptom, as if I were the person I used to be. After an initial period of frustration, I realised that these days my ability to learn is slow and I carried on focusing on the experience part. I decided to ask the neuropsychologist Amor Bize to collaborate with me and to provide a scientific review, as a specialist, of the symptoms I had identified.

The fact that we worked together was crucial for me in the process of creating and organising the book. She helped me to order and structure my account of the symptoms that I showed her, and to shape the book. She wrote paragraphs to be interspersed throughout mine, presented here in italics, explaining in the more technical language of her own specialism the cerebral changes corresponding to the different symptoms explained in my personal accounts.

It was a very stimulating and rehabilitative task because we had to set ourselves deadlines, which helped me to plan, although it also made me face up to the impairments I was talking about and keep considering them in every situation, discovering and learning things about each symptom as I observed it and time went by.

I tried to plan the book with consideration for other affected people who would read it and their attentional difficulties. This meant that I tried to write easy-to-read paragraphs that are not too long. I also asked the professionals who collaborated in the book to write their coloured notes with accessible words.

The contribution of the psychiatrist Susana Pajares, also from CEADAC, was very helpful when explaining the physical side of the symptoms, as was the input from Christian Salas, clinical neuropsychologist and psychotherapist, in discussing the emotional aspect of identity reconstruction.

There are many books that offer lengthy descriptions of the symptoms of ABI. In 2007, when I finished my short treatment at CEADAC, I looked for books that would help me to understand what was happening to me, and in Spanish I only found technical books, with language that was too difficult to understand. These books didn't mention the problems a person with ABI faces in everyday life; they didn't describe the subjective experience of living with residual disabilities that are invisible. I found no books written by other survivors in my own language. That would also later influence my motivation to publish what I had written.

In this book, I collate, in the form of experience-based accounts, the symptoms that I know best, because they have affected me most intensely and because I have seen many of them replicated in various people in the groups I coordinated. Of course, some of the symptoms are worse in me, and some in others, depending on which hemisphere or area of the brain is injured, or whether the damage affects a broader or more specific area. Over twelve years of contact with people with brain injury, I have been able to see how each ABI is unique, even when they share the same areas of damage (Wilson, Dhamapurkar and Rose, 2016). In addition to the injury, the person's previous personality and *cognitive reserve*, meaning their previous level of intellect and education, also influence the effects (Stern, 2007).

When I set out to write this book, I stopped reading others on the same topic. At that time, at the height of my insecurity, I wanted my book to show who I was, without being influenced by anything I had read. Now, I have gone back to looking for books and thirteen years after the accident I've been able to start reading in English, which has been significant progress for me. In this language, I did find books by other people affected by ABI and by professionals who explain many of the things that I talk about. That was a big surprise. For me, it was also important to read work by other psychotherapists and healthcare professionals affected by ABI, and to learn about how they are coping with their residual disabilities now. If only I could have read those books during my first years of rehabilitation! They would really have helped with understanding, recovery and hope in the acceptance process. I decided to incorporate these new references into my original book to add knowledge and testimonies, and to make sure people know about them. I have also recently found works published in Spanish that help to raise the visibility of ABI.

Writing the book has been a vital experience and an intense learning process. I especially want to thank Amor Bize for her collaboration, hard work and constant support over the years, which meant that the project could go ahead. And, above all, for treating me as an equal. Also Susana

Pajares for contributing a medical viewpoint. Thanks, too, to Álvaro Bilbao, author of the prologue for the Spanish version of the book, for dedicating his time and incredible vision. Thanks to Christian Salas, who I met at his workshop on emotion after ABI, when I made my first return to a conference after thirteen years, and from whom I am still learning. I will never forget the generosity, friendship and incredible work of these professionals. I would also like to thank Barbara Wilson for believing in my book and letting me share my experience in her series.

I will always be deeply grateful to all my family, friends and the professionals and countless people who, over all these years, have been by my side, helping me to get better and make this book a reality. I cannot fail to mention, with heartfelt thanks, the two strangers who unknowingly made this challenge possible: the two doctors who, in May 2005, stopped to rescue me at km 100 of the N-VI motorway between La Coruña and Madrid, just outside Sanchidrián, and took the necessary clinical measures to ensure that I was quickly in the hands of a neurosurgeon who, together with his team, saved my life at the Hospital Universitario de Salamanca. They were my anonymous “guardian angels”. I hope that one day I will be able to meet them again and thank them in person.