

Preface

Brain Injury: Broken Brain, Bones, Body, Life and Spirit

I believe I am in hell therefore I am.

Arthur Rimbaud

My life was broken in a split second in 1991. Driving from a day's teaching to Melbourne University, a car running a stop sign hit my car, spinning it 360 degrees until a power pole in my door finished my flight. The other driver went to get a quote to have his damaged car repaired, leaving me unconscious, choking on my seat belt and having an epileptic fit. Providentially, a passer-by witnessed the accident, ran to my aid, smashed the driver's window, removed the seat belt and stayed by my side for forty minutes while the fire department's 'Jaws of Life' cut my car in two.

Eventually, when I briefly opened my eyes, I was told (but immediately forgot) that I was in intensive care in hospital. In this agonising hell everybody had two heads; they would emerge from the fog to torture me and then fade away. Bewildered and terrified, I did not know if it was normal for people to be two-headed and had no words to express this. Agony from injuries that included multiple breaks to more than half of my ribs took my breath away. A collapsed lung and double pneumonia nearly took my breath away permanently.

That was over two decades ago but ever since that day I've struggled daily with brain injury, pain (I still regularly see a physio), double vision, memory and cognition problems and difficulties with balance. Life has been an exhausting and daunting challenge with difficulty understanding, accessing and comprehending information; mourning the loss of the 'old me', not knowing the 'new me'; ashamed to be a 'bumbling idiot' and terrified that I was insane. For many years, I was frustrated, bored and angry to have to relearn everyday tasks of dressing, eating, walking and talking.

Just recently, I had a ‘meltdown’ and could not stop crying. This was brought on by vivid flashbacks to my decades ago pain and powerlessness. Back then, I did not understand brain injury and was humiliated and embarrassed at my loss of privacy and modesty (strangers—medical professionals and lawyers constantly tested and judged me leaving me distraught and disempowered as there did not seem to be any hope I’d ever improve). I remember how for several years after the accident I contemplated how I could end my misery. Luckily, my poor memory meant I forgot my plan to end it all.

As Winston Churchill stated: *‘If you’re going through hell—keep going’*.

After several months in hospital, doctors and nurses spoke of my need to go to a rehabilitation hospital. In my mind, I ‘knew’ that soldiers had rehabilitation and one thing I ‘knew’ was that I was not a soldier! I concluded that they all thought I was a soldier. I refused to go to rehabilitation. I longed to go home because perhaps I’d find ‘me’ at home. But ‘I’ was not there. The ‘new’ me did not even know where the tap was or how to turn it on.

I was also aware that I’d damaged the life of my devoted, devastated husband and four children who all tried to support and help me in different ways. But in the 1990s, prior to wide availability of the newly invented pre the World Wide Web, there was little information about brain injury, so they did not understand brain injury, or my needs, beyond the ‘care’ one would give a close relative who was ‘sick’.

After a month struggling to cope with horrific pain, guilt, and limbs that did not obey me (I’d crawl to get upstairs), my wonderful GP explained how rehab would help me with my balance and give me coping strategies for my bewildering double vision. Two half days a week, a taxi would pick me up at noon. As I had no concept of time, I would eat my lunch at 9 a.m. and pace about the drive in panic, waiting for the taxi. I’d be exhausted by the time I got to rehab to do balance classes, occupational training and to complete numerous terrifying tests—tests that proved to me that I was now stupid and dumb. I was overwhelmed with shame: I could no longer do simple arithmetic, the sort that I’d give seven year olds at school.

After my accident I saw many professionals, but not one explained brain injury to me so that I could understand that I had not gone mad, that my difficulties were typical of brain injury—I needed a translation from the medical terms. It was not until several years after my accident that I saw the wonderful late Dr. Maureen Malloy who after giving me one test, remarked with great empathy, ‘You must have difficulty understanding conversations in the staff room’. Just writing of Maureen, decades later, tears spring to my eyes because this was the first time someone demonstrated to me they understood how I grappled with life. For several years before seeing Maureen I had felt a like I was living in a plate glass box, separated from the everyday world.

I can’t figure where I leave off and everyone else begins.

George McCabe

I had tremendous difficulty comprehending what people were saying to me. It was Rudyard Kipling who stated ‘Words are, of course, the most powerful drug used by mankind’ and Maureen’s words removed a massive weight from my shoulders and

from that moment I understood more and could start to forgive myself for being stupid and dumb. For years I had believed all the experts and professionals who told me there was no cure for brain injury, that I'd make the most improvement in the first six months (I was a helpless hopeless mess at six months) and then at two years I'd plateau out (I was an inarticulate, weeping, fearful, dependent, confused lost soul at two years post injury). I'd discovered that their words were true because no matter how hard I tried I didn't 'get better'.

Your nightmares follow you like a shadow, forever.

Aleksander Hermon

As my children cooked the evening meal, I would weep and wish I was dead. I'd be shaking with dread as the nightmare of the long night ahead approached when I'd be overwhelmed by petrifying pain from my smashed ribs.

I struggled to hold on to ideas so I could try to make sense of my predicament. Being like a child again, the words my father used to say to me when I was a child floated to my mind. He used to say 'Chick, a problem stated is a problem half solved'. So, I struggled and wrote a list of things that really upset me and gave it to my occupational therapist (OT). Her reaction was to sternly say 'I'm the expert I know what you need, you need to learn how to cook'. I did not have the words to say 'I've got a fridge full of casseroles from friends! I really need to know what to do when the phone rings because I don't know who is talking—me or the caller'. It scared me. It made me think I was mad. I nearly gave up trying to write after that experience, but somehow I felt compelled to record my experiences with very bad handwriting and even worse spelling on the backs of envelopes or scraps of paper—anything that was handy. I could not say the words or thoughts but I could capture them with a pencil and paper.

Still searching for the 'old' me I thought I would find 'me' at school, so six months after the accident I insisted on returning to school. But the 'old' me was not at school. Ivanhoe Girls' Grammar was wonderful and said I could help in the library for two half days a week. This was a challenging nightmare because of my balance difficulties, double vision and complete loss of the alphabet. My students would hug me, which was rather painful, and I was baffled as I could not follow conversations in the staffroom. The taxi trip to home was frightening. I would then stand under a boiling shower to try to get warm and then collapse in bed, totally exhausted. The following years were spent in a similar way: school, resting, visiting doctors and completing tests for the lawyers. But I kept writing.

If there's a book that you want to read, but it hasn't been written yet,

Then you have to write it. Toni Morrison

Some early mornings when my brain and eye (one was patched) were 'fresh', I tried to record my experience and what I'd learned about brain injury. My sons set up our new computer with bold size 18 point font, and I tapped away with one finger (I still type this way). I was determined that no one else with brain injury should ever be as

lost and frightened as I was. I also wanted to show the man who caused my accident what he had done to another human being. I thought about giving him a copy of my subsequently published book *Doing Up Buttons* (Durham, 1997, 2005), but did not contact him. ‘Buttons’ as it became ubiquitously known as autoethnographical text, a personal narrative exploring my experience of brain injury and my subjective experience of a changed life. It also gives readers insights into their own problems of brain injury.

I discovered that reading can help people find themselves.

I gave my manuscript to a literary agent and within a week I had signed a contract with Penguin Books. *Buttons* immediately struck a chord with many people whose lives had been changed by brain injury or who worked with people with brain injury, because it translated brain injury into something people could understand. For over a decade, letters continued to arrive with positive messages.:

.....yesterday, I bought it and last night I read it. I couldn't put it down. I laughed, I cried, I became angry and I read large chunks of it out loud to my husband. At the end I was emotionally exhausted but also astounded...I started reading it during dinner and did not move until I had finished it. I literally could not put it down...For me your book is about a whole lot of things—tragedy, enormous struggle, courage, support, love, loyalty, triumph and a journey that never ends...but most of all it is about guts...

...As I can no longer rely on my memory to recall, I ‘dog eared’ the pages of your book as I came across relevant information. Would you believe when I came to the end I had ‘dog eared’ nearly every page!...For me it is so confirming of my head injuries...

Over the subsequent years, invitations came to speak at conferences, meetings and workshops for people with brain injury, brain injury organisations and rehabilitation professionals and lawyers in Australia and overseas. Often people had travelled great distances to attend. It was humbling to think that the book had made such a difference to their lives. I formed a speaking business *Talk About Change* and spoke to a wide variety of groups at first assisted by my sons or daughters. Handicapped by pain, memory problems and faulty balance, double vision and difficulty expressing my thoughts, I drew on my teaching experience and used pictures, analogies and stories and Alice from ‘Alice in Wonderland’ to translate information about brain injury so it could be easily heard and understood.

One good analogy is worth three hours discussion.

Dudley Field Malone

At the conclusion to my talk, in order to capture the curiosity of the audience (and give them a take-home message to remember), I'd asked my 20-year-old son to walk down the aisle from the back of the auditorium carrying a mixing bowl and ingredients to make a cake while I donned an apron. As he placed these objects onto a table on the platform, I encouraged the audience to reflect on their previous knowledge of brain injury and what they had been reminded of with pictures, objects and analogies of my presentation.

I'd place the ingredients in a bowl to make a cake, I called it 'The Coping Cake', and I asked the audience to suggest what the ingredients could represent. For example, flour, (the greatest ingredient volume in the cake), what did they think the most important 'ingredient of 'recovery' was? Frequently they would suggest flour could stand for hope, sugar could represent the sweet/good things of life, milk could stand for the milk of human kindness and eggs denoted thinking and talking to bind together information and ideas. Once these ingredients were assembled in the bowl, I would ask the audience if this was a cake. Of course, the answer was 'No'. From the show of hands someone said, 'First you have to beat the mixture, then cook it'.

I produced a giant golden spoon and explained that the job of these professionals was to encourage their patients to *put in the effort and pick up the spoon* to put an *effort* into their own recovery (they, the specialist could not 'give' them 'recovery'). I gave the participants golden spoons with the label 'Changes in life to understand? Remember Alice in Wonderland' as a take-home message.

Using a number of devices like this, I continued delivering scores of presentations over the years and was amazed at the audience reaction. So I discovered that by using learning principles in producing a symbol of a concept, then making connections between the objects/symbols to practical everyday issues, the interest and understanding of the audience could be enhanced. In addition, this use of humour, the unexpected and a twist to make an association, proved to be a powerful vehicle whether I was speaking to professionals or people with brain injury. This was very different to just giving them information—they had to put in the *effort* and make connections and understand.

Alice from *Alice in Wonderland*, an analogy I used firstly as 'blurb' on the back cover of 'Buttons', was later used to explain to professionals what it feels like to experience brain injury. This analogy also resonated with people with brain injury. I spoke to one woman who became blind because of her brain injury—she had obtained an audio book of *Doing Up Buttons*. She told me she had had to listen to the reading of the back cover blurb several times because she was crying with relief that, at last, *here was someone who understood brain injury*. Such recognition committed me to listening to people's stories.

When people talk, listen completely. Most people never listen.

Ernest Hemmingway

I spent a decade speaking to groups about brain injury. *Doing Up Buttons* had been out of print for several years when a young man, Harry Troedel, contacted me to get a copy of the book for his friends 'so they would understand'. He said the book should be available for people and he made phone calls and obtained some funding and I put in sufficient money for Penguin Books to reprint 1,000 copies of the book. Together Harry and I gave away the books from the Transport Accident Commission's stall at the 5th Congress on Brain Injury in Melbourne, 2005. I purchased another 100 copies to give to organisations that had supported the publication and to give to Headway, a leading brain injury organisation in Australia.

With the book, we gave out what I called ‘Hope Stones’—beautiful, black polished river pebbles purchased from a garden supply outlet. I attached small gold stars (like I used as a teacher to reward good work) to the stones. The message of this object was that people with brain injury *can* tackle the hard things (like the hard stone) and reach for the stars. Although these take-home messages (like the golden spoons) had been enthusiastically received by audiences after presentations, I was unsure of how they would be received by the delegates of this conference.

But I did not need to fear. The keynote speaker from the USA requested thirty stones to take back to her students. We gave away forty kilograms of these stones! Attendees would come up to me on subsequent days of the conference and pat their pocket saying ‘I’ve still got it with me’—and over the years when I’ve encountered some of these people, they still speak about the influence of their ‘Hope Stone’.

The experience of this conference was remarkable. I met nurses who told me how they had purchased copies of the book to give to people with brain injury, and I learnt that the book was a recommended text at universities from Darwin to Perth to Sydney. It affirmed to me that the book was useful to people with brain injury, their families and professionals. I now faced a quandary, I had put such a tremendous effort into regaining my life and I still experienced so many brain injury and accident-related difficulties that some days I thought to myself, ‘I’m 63, at last now I can put my brain injury experience behind me’. Yet on other days, I felt compelled to speak for all those people who could not speak for themselves and I realised I had discovered a different way to communicate, ‘translate’ the consequences of brain injury.

Personally I’m always ready to learn, although I do not always like to be taught.

Winston Churchill

When I returned to ‘teaching’ for a few hours a week, I progressed from weeping into my eye patch, struggling to be of use in the library, to taking small groups of students for enrichment activities. As a Founding Member of Philosophy for Children, I’d returned from speaking at an International Conference in Mexico a few days before my car accident. I believed it was vital to teach children to think for themselves. This was grounded on my father’s ‘Thinking Walks’ where we’d go for walks along the beach and he’d discuss politics, opera or chess moves with me and ask for my opinion. I frequently did not totally understand the conversation; however, the experience of being treated as an intellectual equal boosted my belief in the importance and power of thinking, and proved to me that through exploring ideas you could find ways to solve problems.

As double vision and memory loss meant that reading was difficult, I used objects similar to the ‘coping cake’ to engage and focus the students’ (and my) attention. I made notes (or the children took the pen from my hand saying ‘I’ll do it, you know you can’t spell Mrs D’), and from these notes I wrote *Chasing Ideas* (Finch Publishing, Jessica Kingsley Publishing) (Durham, 2001, 2014), a book about helping children to think for themselves. I was fortunate that Dr. Edward de Bono endorsed the book, and it has been translated into Taiwanese, Chinese and Arabic.

This book led to invitations to speak about ‘thinking’ and conducting workshops for Melbourne University, Nan Yang University, Singapore and speaking to principals, teachers and parents. Little did I think that over ten years, teaching part-time I would have the challenge and privilege to conduct 4,000 philosophy/thinking workshops and *my students* would teach *me* how to talk and think again. I adored teaching, however, reluctantly, I acknowledged that the effort of pushing through the pain, double vision and fatigue to teach two days a week consumed most of my energy. I left teaching.

Sixteen years after the accident, every day I felt fortunate to be alive—that I did not die in the accident, or by my own hand. I kept asking myself ‘What more can I do to help people with brain injury?’ After a presentation to University Disability Liaison Officers, several audience members suggested I should use my experience and knowledge to a Ph.D. About this time, I also heard about the philosophy of phenomenology, and this fired my imagination. At an Open Day at RMIT University, I met Dr. Paul Ramcharan and with his great knowledge he guided me as supervisor of my Ph.D. We both had evidence that although every brain injury is *biologically* different, the way people *feel* about their injury contains many similar themes. The question for the Ph.D. study was aimed at identifying these uniting and mundane themes that negatively and positively affect the life of people with brain injury with a view to identifying factors that help them feel and fare better. I am delighted that Paul Ramcharan agreed to co-author this book.

I have explained how the ‘Coping Cake’ and the ‘Hope Stone’ were used to gain the attention and curiosity of audiences and how these metaphors were employed on scores of occasions for a wide variety of audiences. In the search for an engaging, original, non-medical and non-threatening way to connect and communicate with people with ABI, I was drawn to the metaphor of how brain injury ‘imprisons the individual’. I thought about symbols that could be used to help participants with memory, cognitive and physical difficulties to focus on their experience in a completely different way with foundations based on Vygotsky’s theory of the ‘zone of proximal development’.

Sir James Frazer, in ‘The Golden Bough’, introduces the reader to the book by presenting the vivid picture of the scene and the forest from which a ‘golden bough’ may be cut by an escaping slave, and be used in self-defence. If victorious, the slave may take the ruler’s place. The book then unpacks and expounds on the plethora of issues that explain the reasons for this seemingly strange custom/belief, set in both mythology but also culture.

In similar fashion, borrowing from Frazer’s concept of setting out the metaphor which directs, questions and explains concepts, Paul Ramcharan and I now present our own metaphor, one that is employed to provide an explanation and overview of the research approach. ‘Keys to the ABI Cage’ was developed to address some of the problems associated with brain injury (ABI) while being at the same time, a data collection tool. Below the history, origin and description of ‘Keys to the ABI Cage’ is given in order that the reader can understand the significance of each part and the nature and relevance of the whole.

I have an ornamental bird cage that has significant meaning for me. For several years following my accident, I wore a black eye patch, like a pirate. Friends gave me brooches and China parrots as a joke, but I longed for a dove, a symbol of peace and freedom. My son Ken located two baby fantail doves, which he presented to me when I was working on the manuscript of *Buttons*. These tame white doves kept me company. I'd wrap them in a towel and they rested on my lap, or they would perch on my shoulder, while I worked at the computer. I would take them outside to let them walk about, and I tried to give them flying lessons. Fantail doves are not like 'proper' birds, as they can neither fly nor walk properly. I felt I was not a 'proper' person as I could neither walk nor talk 'properly'. These doves appear to have lost their head as they frequently position it behind their shoulders along their back. I felt as if I'd completely lost my head—we had a lot in common and we developed a great bond.

Once Penguin Australia published the book, I had numerous media interviews and the doves were often included in the photographs taken to accompany the story. When I went on television, or spoke to groups, I'd take the birds in the fancy travelling cage to remind me to explain how these birds are bred to be like this, so when they are released, they cause a commotion, and flutter in the air, providing a guide to help the homing pigeons find their way home. This provided me with a prompt to say I hoped my book could cause a flutter to help people with brain injury find peace and hope—and to find their own way home too.

Over the years, I've often looked at the cage and thought brain injury is just like being locked in a cage and the key is thrown away. This was how I decided to use the cage, my old walking stick and a wooden pole topped by a wooden flying pig, as an interesting structure to hold cards on which were written words that had been spoken by people with ABI in my fieldwork prior to this study. Thus, symbols and words were combined to assist people reflect on their experience of ABI. The participant-guided interview was a conversation with a purpose—to help participants review things that helped them in a positive way.

The cage was labelled 'The ABI Cage' and once the interview/learning tool was fully developed I called this metaphor-model *Keys to the ABI Cage* to give the process a positive focus. The cage, walking stick and pole held what I initially called 'talking-cards' (after Cameron & Murphy's Talking-mats, 2002) but later changed the name to 'talk-about' cards because the cards did not 'talk', but they did contain information people had talked to me about and the statements were used to invite participants to *talk about their experiences*.

The *Keys to the ABI Cage* is presented on the following page. The assembled metaphor tool is 160 cm high and, 100 cm wide.

It immediately captured the attention and interest of the participants with ABI who did not expect to be confronted with a bird cage, a metaphor-model visually attention-grabbing 'tool' to facilitate reflection, communication and learning. This simplification allowed the participant to reflect and more easily understand how ABI affects their lifeworld.

The ‘talk-about’ cards and other objects in the cage were employed in the interviews to provide interactive prompts for participants to think about and talk about their own chosen concepts and ideas in the three focus areas. The tool was ‘organic’. If people wanted to add categories that did not already exist, they were able to write on a blank ‘talk-about’ card and add to the cards to use in subsequent interviews. The ‘talk-about’ cards allowed participants to ‘wander’ through the concepts as they chose, make connections and change their mind after further reflection. “The tool divides the complicated issues and consequences of ABI into three main themes.”

Theme 1. ‘Our Differences and Difficulties Can PUT us in ‘the ABI Cage’

This sign can be seen hanging on my old walking stick horizontally inserted into the left side of the cage, along with black-backed ‘talk-about’ cards held in plastic pockets. Like the two other themes described below, the choice of ‘talk-about’ cards for this theme was drawn from the literature reviewed, from public information and personal and wider experiences of people with ABI.

Theme 2. ‘How We Feel About Our Differences and Difficulties Can LOCK us in ‘the ABI Cage’

This sign can be seen near the padlock on the cage door. Hanging **inside** the cage were red-backed ‘talk-about’ cards, hung on hooks held by bird-shaped mirrors—to remind people to look and reflect. Words on the ‘talk-about’ cards were drawn as for Theme 1. Additionally, there were objects that were metaphors or symbols—a crushed Solo[®] drink can (to symbolise a crushed life), a snuffed out candle (a finished life) and a toy snake (people see me as scary).

Theme 3. ‘Keys Can RELEASE us from the ABI Cage’

This sign can be seen on the right side of the cage at the top of the long wooden pole with golden keys attached to it. The pole was crowned with a wooden pig with flywire wings—a flying pig—symbolising achieving the impossible. Hanging on the pole were white-backed ‘talk-about’ cards fixed to a rigid Perspex sheet. These cards had mini objects attached to them (e.g. sun for sunshine, mushroom for nature, tiny cup for coffee, a tiny dog for animals, a ring for love, a rubber band for stretch outside my comfort zone and so forth) to capture the interest and hold the attention of participants, as by the time they reached this most important stage of the interview, participant’s attention might be flagging and they might be experiencing fatigue. These particular cards and objects focused on factors that help to ‘release’ people from the cage. Words on these ‘talk-about’ cards were drawn as for themes 1 and 2.

Chapters 1–6 describe in detail how and why *Keys to the ABI Cage* was developed and used in this study. Participant data obtained from this unique object is then explored in Chaps. 7 and 8. This leaves us to support the reader to see the relevance of the cage to everyday lives and to practice in Chaps. 9 and 10.

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