

'Keys to the ABI Cage' goes to Washington DC

Christine Durham

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Chris with the mini 'Keys to the Brain Injury Cage' in Washington DC

How did I find myself travelling to Washington with a small bird cage in my suitcase? My journey that led to this journey to The Eighth World Congress on Brain Injury, has been long, confronting and challenging.

Backstory

Bang! In the blink of an eye my life was changed by an horrific car accident! Days passed and then I struggled, slipping in and out of consciousness in intensive care. I thought I was pinned to the bed by steel spikes from innumerable breaks in my ribs, I couldn't move my left side, I didn't know who I was and I was terrified to see two headed people emerging from the gloom (double vision). I had no words to express this strange fact. But somehow in all the trauma and chaos I 'saw the light' that the most important things we own are our own thoughts.

Over the last 19 years I have been challenged to discover how my own thoughts could help me recover my life, and, as a teacher, how thoughts could give hope and help people overwhelmed by brain injury, the 'king of change'. I captured my thoughts slowly on the backs of envelopes and scraps of paper and gradually put them together, typing with large print with one finger. This manuscript "Doing Up Buttons" was published by Penguin Australia in 1997. Since then not a week has gone by without someone contacting me to say how the book helped them 'see' and understand. I've been invited to speak to many groups of people affected by brain injury.



"Doing Up Buttons" was out of print when a young man with brain injury, Harry, was the catalyst to organise a further, and special, printing of the book by Penguin. Harry and I gave away a thousand copies at the 2005 Brain Injury Congress in Melbourne. But still I constantly asked myself is there anything else I can do to help people with brain injury to help themselves?"

Searching for the 'golden keys'



For the past two years I have been working on a PhD at RMIT University. This is maybe not the obvious thing to do when I still have double vision, memory and pain problems (and I'm now 65) but as a teacher I wanted to find a way to use learning principles to help people with brain injury to feel and fare better, carers to understand and cope better and professionals to have a new way to talk about brain injury so they could better help their clients.

We all know the old nursery rhyme about Jack and Jill who went up the hill and then, having fallen, Jack went to bed to 'mend his head with vinegar and brown paper'. We all know that it takes more than vinegar and brown paper to mend broken heads (and hearts, and lives, and dreams). How could I find something better than vinegar and brown paper?

I was interested to discover that one meaning behind this nursery rhyme was that Jack was King Louis XV1 of France and Jill, who came tumbling after, was Marie Antoinette. Apparently in those times consciousness was meant to remain for 8 seconds after your head was cut off. Ah ha, so the head was held aloft, not to show the head to the crowd, but so that the head could see its own body.

Now here was an interesting metaphor for brain injury - you lose your head, you can see your body but in some strange way your head is disconnected and can no longer control your body. My PhD has been a quest to find a way to help re-connect the head and body (and heart, lives and dreams) of people who have experienced brain injury.

In order to re-connect and recapture our lives we need to accept and focus on our difficulties and devise coping strategies. Research indicated that as people reflected on their losses and difficulties they became depressed. Hardly surprising! My challenge was to find a way to help people with brain injury understand more about brain injury and reflect on their experience in a positive way. What information would be helpful? What do people with brain injury want and need?

Where did the idea for 'Keys to the Brain Injury Cage' come from?



I was searching for an interesting, non medical, fun, non threatening way to use symbols to help participants focus on their experience in a completely different way.

In this study I used a fancy bird cage, formerly used when I went on television to talk about my book “Doing Up Buttons”. I’d take my fantail doves Lovey Dovey and Cloud in the cage to prompt me to talk about how I felt I wasn’t a ‘proper’ person, just like fantail doves weren’t ‘proper’ birds (they can’t fly properly, and their walking is pretty wobbly). 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. I decided to use Lovey’s cage, my old walking stick and a pole with a flying pig on top (to hold keys that release us from the ‘Brain Injury Cage’).

Additionally, using learning principles, the visual impact of the cage and a combination of words and symbols to connect with both right and left hemisphere dominant people, I combined the cage with ‘talk-about cards’. These cards had things written on them that people with brain injury had previously talked to me about over the years as having ‘put them in’ to the cage or ‘released them’ from the ABI cage. The study at RMIT allowed me to explore these ideas systematically and add to them over time.

‘Keys to the Brain Injury Cage’ simplifies the very complicated issue by looking at:

1. Our Differences and difficulties that can PUT US IN ‘The Brain Injury Cage’
2. How we feel about our differences and difficulties can LOCK US IN the Brain Injury Cage and
3. ‘Keys’ that can RELEASE US from ‘The Brain Injury Cage’.

How can we acquire better insight into what it’s like and how people cope with acquired brain injury?



This is a very tricky question to answer. Indeed, it is perfect example of Salman Rushdie’s a P2C2E (a process too complicated to explain). Brain injury is complicated; difficulties people with brain injury experience are complicated. It is complicated developing a non-judgmental atmosphere of trust to gain access to personal coping strategies.

These are just some of the things I was considering as ‘Keys to the Brain Injury Cage’ was developed. The cage was both a metaphor of brain injury and an interview tool.

Some of the complicated issues of testing included: Who holds the power? The person conducting the test holds the power. By giving participants a handful of ‘talk-about-cards’ the person with brain injury holds the power and talks about issues prompted by the words on the cards that they have chosen out of those there or, indeed, new ones that we made.

People with brain injury may be reluctant to take another test because we are compelled to participate in a never ending barrage of tests – all of which further empower the tester and dis-empower us. Tests invariably make apparent (or rub our noses in) our difficulties and how we are different to how we were. No one likes to take ‘tests’ and be ‘judged’. Using Keys to the Cage meant that the interviews were

non judgemental, participants quickly felt comfortable and no one was 'pushed' to talk about things they did not feel at ease about. I know that just to voice our private difficulties associated with brain injury is confronting so the 'tone' of the interviews was very important.

As people with brain injury we may feel anxious and fearful in a test like environment. No wonder considering our memory difficulties, communication problems, lack of confidence, and our self-doubt. 'Keys to the Brain Injury Cage' and talk-about cards were developed especially to help make the person with brain injury feel comfortable in sharing their insight.

Over the years I have spoken to people with brain injury who mentioned they felt ashamed, frustrated, scared, angry, afraid, upset, misunderstood, ill at ease and that it was often difficult to stay on track. Participants who took part in the research study also identified these points. Additionally they divulged their loss of trust in the future, in themselves and others and the shame of jealousy as they 'slipped further behind' while friend's prospered and their lives moved forward. 'Keys to the Cage' was devised to especially to develop a rapport and an atmosphere understanding. Often participants said "You know what I mean", they could trust me because I understood and had shared a similar experience.

In the study having objects to see and touch, and also cards to hold as prompts, helped to remind people being interviewed (and also the interviewer) the story or topic they were talking about. Objects, such as a crushed Solo drink can in the Cage gave participants new ways to reflect on their experience and helped them focus on ideas.

The research study had a central aim of doing no harm and a hope that by talking about the change that brain injury has brought to the life of participants, they would gain greater understanding and insight into their brain injury and an awareness of all the 'Keys' that can open the 'Brain Injury Cage' for them.

It was so pleasing that participants could see that 'the ABI Cage' validated their losses and feelings, demonstrated understanding of their differences, difficulties and feelings.

What 'Keys to the Brain Injury Cage' meant to this study?



In all, I interviewed thirty people with brain injury, five family carers and five professionals, and introduced the Cage to three support groups of people with brain injury. Taking Lovey Dovey's large cage, cards, pole of the Flying Pig and/ or a power point presentation to each interview, has at times been a bit of a logistical nightmare, but I have been aided by my husband Ted each time. For some participants with ABI I sent a CD Rom of the cage first, and questionnaire sheets to complete about their feelings, just to see which approach to using the cage was best.

I have now completed over 150 thousand words of transcripts and am still in the process of analysing the data in detail. I am moved, humbled and full of awe at the way participants are coping with the challenges of brain injury and the willingness they have had for sharing their experiences in the hope they could help other people

with brain injury. Frequently as I heard about their courage, wisdom, determination and kindness I felt overwhelmed. I am so pleased that 'Keys to the Brain Injury Cage' has helped many participants to see and understand more.

I now have greater insight into what people with brain injury want so that now I can start putting together a different sort of learning resource – from people with brain injury for people with brain injury. This is indeed an exciting project.

What has 'Keys to the Brain Injury Cage' meant for people with brain injury?



Comments from participants with brain injury include: "The talk-about cards brings back a lot." "I love the Cage, I want it, I want the whole thing." "I feel locked up inside the ABI Cage." "Now I understand. Medical terms are hard enough if you don't have brain injury, but if you do, it's like another language."

Professionals have said "It really resonated with every person, they really 'got it'." "Perceptions change once you've got a metaphor". "It gives me something to always be talking about now, the keys, looking for the keys".

'Keys to the Brain Injury Cage' has been a powerful tool to assist people with brain injury to open up the complicated issues of brain injury in a new and positive way – to identify 'Keys' or things that help us cope.

I will now develop an information resource or learning tool from insights gained in this study.

Some of the issues identified using 'Keys to the Brain Injury Cage' include:

1. People with brain injury want material about brain injury in non-medical language.
2. Some people are not diagnosed with brain injury – this can lead to years of fears and frustration.
3. The key words that were repeatedly used to describe the brain injury experience were: Afraid, Ashamed and Isolated
4. Some people with brain injury: Appreciate being alive, Are aware of their strengths and feel Wiser
5. There are many issues of brain injury currently not being addressed
6. There are many coping strategies and 'Keys' that help people to unlock the 'Brain Injury Cage'. Learning material can be developed to address these issues.

Some of the 'keys' identified by participants included: understanding brain injury, people who understand and are empathetic, animals that love me unconditionally and seem to understand , nature's renewal and beauty and a sense of humour and having hope.

I hope that when completed the 'Keys to the Brain Injury Cage' learning resource will help people with brain injury to have HOPE that will Help Other Possibilities Emerge.

It was an honour to attend and present this study at the Eighth World Congress on Brain Injury in Washington DC. March 2010.

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Note: 'Keys To The Cage' (Trade Mark Pending) is part of a Talk About Change Learning Resource. If you wish to be kept informed on progress with this study please email cdurham@talkaboutchange.com