Empowering People With ABI To Acquire Better Insight Into Brain Injury: An Application Of Educational Principles

APPENDICES

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A thesis submitted in the fulfillment of the requirements for the degree of

Doctor of Philosophy

RMIT University

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School of Health Sciences

May 2012
# APPENDICES

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APPENDIX CHAPTER 1

1.1 Groups spoken to by C. Durham - ‘Talk About Change’ Talks

The following speaking presentations by invitation indicate the interest and peer support of ‘Doing Up Buttons’ and ‘Chasing Ideas’.

1.1.1 Brain injury support groups, rehabilitation/professional groups including:

Head West (WA); Perth’s Women with Brain Injury Forum (WA); Flinders University (SA), Charles Sturt University, Albury-Wodonga (Vic); North Coast Head Injury Association (NSW), Brain Box (Qld); Headway, Melbourne, Bendigo, South Gippsland (Vic); Headway Victoria Writers Forum (Vic); Sydney Brain Injury Rehabilitation Team, Randwick (NSW); HeadEast, Pagewood (NSW); Barwon Health, Geelong (Vic); Shepparton Advocacy Day, Regional Information and Advocacy Council Inc. (Vic); Australian Occupational Therapy Victorian State Conference,(Vic); South West Brain Injury Rehabilitation Service, (NSW); Transport Accident Commission (Vic); Head East (NSW); Sydney Children’s Hospital (NSW); Private Healthcare Providers (Vic); Victorian Neuro-Trauma Initiative, TAC Seminar Series (Vic); Headway, Oxford (UK); Western Suburbs Acquired Brain Injury Support Group, Footscray (Vic); City of Stonnington Aged and Diversity Staff Social Support, quarterly General Meeting (Vic); Guide Dogs Association, Fairfield (Vic); Bendigo TAFE Disability Liaison Officers Conference, Bendigo (Vic); Acquired Brain Injury Road Trauma Support, Shepparton (Vic); Acquired Brain Injury Road Trauma Support, Hawthorn (Vic); Brain Link Support Group, Blackburn (Vic); Bear In Mind writer’s group (Vic); Brain Injury Matters, Melbourne (Vic); Mobile Intensive Care Ambulance (East and West) Paramedics team meeting, Moorabbin (Vic); Victorian Rehabilitation Centre, Glen Waverley (Vic); Cedar Court, Hawthorn (Vic); Mercy Health and Aged Care Inc., East Melbourne (Vic); Commonwealth Rehabilitation Service Conference (Victoria and Tasmania), Flemington (Vic); Disability Employment Service Conference, Benalla (Vic); Regional Information and Advocacy Council Inc. (Hume Area), Benalla (Vic); Spastic Society Annual General Meeting, Melbourne (Vic).

Titles of presentations included:

‘Facing life’s challenges with insight, ideas and hope’
‘Headhunting: A survival guide to life’

‘Hope keeps us afloat’

‘Growing through life’s challenges’

‘Thinking, Talking and Writing’ workshops

Powerful practical tools and tips for growing through life’s challenges’

‘Ideas, Habits and Hope’

‘Making the best of brain injury by fostering insight and understanding’

‘Making Connections and building bridges’

‘Talk About Brain Injury’

Opportunities to speak about the experience of ABI to the media:


- Television Interviews: Channel 10 National TV; Good Morning Australia National; Bert Newton Morning Show, Melbourne; Morning Show with Kerry Ann Kennelly, Sydney.

1.1.2 Educational organizations – academics in the field of education, principals, teachers, parents, students in pre-school, primary and secondary schools including:

Nanyang University, Singapore; MacPherson Primary School, Singapore; International School, Singapore.

In Victoria: University of Melbourne; Lady Gowrie Centre, Pre-School Teachers Conference; Eltham North Pre-School; Eltham Woods Pre-School; Briar Hill Pre-School; Wonga Park
Pre-School; Northcote Pre School; Robert Cochrane Kindergarten; Beaconsfield Primary School; Camberwell Primary School; Briar Hill Primary School; Harrisfield Primary School; Doncaster Primary School; Werribee Secondary College; Ivanhoe Girls’ Grammar School; Boroondara Primary School; Tintern Grammar School (Year 12 Students); Sacre Coeur (Year 12 Students); Ruyton Girls’ School; Mentone Girls’ Grammar School (Valedictory dinner), Adult Multicultural Education Services, Merri Cluster Conference, Daylesford; Victorian Primary Principals’ Association; Victorian Association for Philosophy in Schools; Catholic Education Principals’ Conference; Victorian Association for Teaching English Conference; Principals’ Resilience Seminars for Department for Education and Training; Drug Education and Student Wellbeing Conference; Gresswell School Services Officers Network Conference; Incorporated Association of Registered Teachers of Victoria; Brunswick Special School; Fairfield Primary School; Diamond Valley Kindergarten Teachers’ Association.

Titles of presentations included:

Chasing Ideas: building better brighter thinkers

Enhancing your student’s (child’s) learning by teaching them how to think

Thinking skills for young children to maximize their potential

Handy Thinking Tools – Tools and Tips to maximize your student’s potential

Boost your student’s self esteem and judgement – watch them thrive

Chase ideas to teach our students how to think for themselves

I think, I can.

The Resilience Principle or Bouncing Back

1.1.3 Other Associations including:

Australian Institute of Management Conference, Melbourne (Vic); Perri Cutten Management Seminar, Richmond, (Vic); Shepparton Fairley Leadership Dinner (Vic); The Alexandra Club, Melbourne (Vic); S.W.A.P. Conference, Yarra Valley (Vic); Australian Funeral Directors Conference Canberra (ACT); Nursing Mother’s Hotmilk Conference Melbourne (Vic); Banyule City Council Management Seminar, Ivanhoe (Vic); National Australia Bank
1.1.4 **Presentations to conferences about this study**

Brain Injury Australia, Insights and Solutions Conference September, Melbourne (2008)


ASSBI International Conference, Sydney (2009), 32nd Annual Brain Impairment Conference. ‘Acquiring better insight into acquired brain injury – investigating what it’s like to have ABI & searching for answers.’


The Eighth World Congress on Brain Injury, Washington DC, (2010). ‘How can we acquire better insight into what it’s like to have ABI?’
investigating what it’s like to have ABI & searching for answers.’

better/ faring better; knowing better/ coping better; understanding better/ managing better: the
role of educational principles and materials in the reconstruction of self following ABI.’

Health Sciences Seminar (2010). ‘Helping people with brain injury make the best of living
with brain injury.’

Health Sciences Seminar (2011). ‘Fostering Insight and Understanding of the Challenges of
Brain Injury What ‘Keys’ open the ‘Acquired Brain Injury Cage?’
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<th>Audience 2</th>
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<td>Monash / Epworth Information Concussion</td>
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1.2 Matrix of analysis of websites reviewed 2008
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<th>Rehabilitation</th>
<th>Balance</th>
<th>Sensory</th>
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<th>Hearing</th>
<th>Visual disorders</th>
<th>Speech and swallowing</th>
<th>Sexual problems</th>
<th>Memory</th>
<th>Poor concentration</th>
<th>Poor problem solving</th>
<th>Lack of initiative</th>
<th>Flexibility</th>
<th>Impulsivity</th>
<th>Tempor/ anxiety</th>
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1.3  Analysis of websites for audience, relevance, writing style
1.4 Books about brain injury and the brain injury experience

The following list of books about brain injury has been compiled from a number of web sites including:

Christopher and Dana Reeve Foundation Paralysis Resource Centre
http://christopherreeve.org/site/c.myKZKgMWKwG/b.445315/k.9E34/Brain_injury.htm


Society for Manitobans With Disabilities http://smd.mb.ca/bibliographies_brain_damage.aspx


Brain Injury Association of Georgia http://braininjurygeorgia.org/education.htm


Note: Code used to provide information about author and whether a narrative or guide:
N-Narrative, F-Family member, P person with ABI, G-Guide


Bruno, L. (2008). If I only had a Brain Injury. Bloomington,IN: Xlibris Corporation P N


Skloot, F. (2003). In the Shadow of Memory. Nebraska: University of Nebraska Press. P N


Books for Children


APPENDICES CHAPTER 2

2.1  The development of ‘Keys to the ABI Cage’

2.1.1  The Cage #1

1997 ‘Doing Up Buttons’ was published by Penguin Books. My fantail doves were used during media interviews by photographers, the ornate cage was purchased as a ‘travelling cage’ to house the doves for television interviews in studios and for presentations to Headway and other places.

Photograph 2.1  Cover of ‘Doing Up Buttons’ showing the dove
Photograph 2.2 Newspaper articles showing dove

Photograph 2.3 Newspaper and journal articles about ‘Doing Up Buttons’ and ‘Chasing Ideas’
1997 – 2009 I spoke to a variety of audiences including brain injury support groups, professional organizations involved with rehabilitation.

2002 My book ‘Chasing Ideas the fun of freeing your child’s imagination’ endorsed by Dr. Edward de Bono, was published by Finch Publishing Australia, Jessica Kingsley Publishes UK and translated into Chinese, Taiwanese and Arabic.

2003 ‘Doing Up Buttons’ was out of print. Penguin Australia required a print run of one thousand to print new copies. I had weekly contact from people with brain injury wishing to obtain a copy of the book but I did not want one thousand copies.

2005 Harry Troedel (a young man with brain injury), contacted me to obtain a copy of the book. And I lent him my last copy. After reading the book he emailed to say that he believed book should be available for people and he would obtain funding towards a printing run of

Photograph 2.4  Covers of different editions and translations of ‘Chasing Ideas’
1000 copies. We did not know how we would distribute the books. I had heard that some nurses at trauma hospitals purchased copies and gave them to patients. We were going to donate the books to hospitals.

We decided that the best way to help people with brain injury was to give away 1000 copies to ‘the experts’ attending the 6th World Congress on Brain Injury, Melbourne, May 2005, hoping this would help them understand what it was like to have brain injury.

John Olver, Associate Professor, Monash University, and director of rehabilitation, Epworth Hospital and Caulfield General Medical Centre, wrote an introduction to this edition and sponsors including TAC, Headway Victoria, Healthscope Community Programs, and the Brain Foundation Victoria were acknowledged in the book. Penguin Australia worked through a weekend to print a special edition of the book. I made up the shortfall in funds so that 1000 copies of the book could be handed out at the Conference. TAC provided an area for Harry and I to give away the copies, and speaking with professionals involved with brain injury I learnt that ‘Doing Up Buttons’ had been recommended reading at various universities throughout Australia.

As I was concerned that people at the conference might not notice us giving away the book (this turned out not to be the case – with people queuing to get copies) I had prepared a display of a number of symbols to represent brain injury. As my fantail doves had been widely featured in the media coverage of the book, I put together an interesting looking display and used the bird cage to draw attention to the book table. Attached to the cage was a bunch of honesty plant (honesty in discussion of problems associated with ABI is important, honesty in talking about things with the family is important) a large key and padlock (to denote the way people can be ‘locked in a cage by ABI, but there are ways to unlock the cage’), and a large pig, with wings constructed from metal hung on fishing line from a vertical walking stick tied to the cage - to denote that impossible things can happen - a theme used widely in presentations to groups of people with ABI and professionals as part of my speaking business ‘Talk About Change’.
This creation looked very interesting, was thought-provoking. Unfortunately on arriving at the Conference Centre the available space for distributing and signing books had insufficient room to display the Cage which was left in the car and later dismantled and remained as a decorative piece in my study.

November 2007: I attended open evening at RMIT and made contact with Dr. Paul Ramcharan.

March 2008: PhD commenced. Focus of study was to be how could people with ABI learn to help themselves, to find out what information was available, what information they needed and how information could be presented in an engaging, non-threatening manner.

June 2008: RMIT Health Sciences Conferences. Presented my work as a poster.

2.1.2 The Cage #2

The ABI Cage as presented at the RMIT School of Health Sciences Conference July 2008 – Awarded Best Diorama

I decided to use the Cage as a diorama to present and hold information. I put together a series of cards holding words to provide information about ABI that had emerged from literature reviews about ABI, information from interviewing people with brain injury, carers of people with brain injury, and experts working in the field of brain injury.

Photograph 2.5 Diorama using the bird cage
The aim of the diorama was to engage and interest the audience as well as presenting information in an easy to access manner.

Support material included several large sheets to confront the viewer about ABI and assist them to become involved and immersed in the topic of brain injury. This included

1. A poster – ‘Brain injury in a nutshell’ (note the wall nut shell). This contained a series of large glossy pictures of the wives of Henry VIII - and suggested that having ABI is like being a wife of Henry VIII: Catherine Howard lost her head - brain injury can involve ‘losing your head’. Jane Seymour died as result of surgery – when you have brain injury you can die as a result of surgery. Catherine of Aragon was banished and died of a broken heart. Many PWABI feel ‘banished’ from life, feel like an outcast and decline and eventually die of a broken heart. Katherine Parr, on the other hand, survived her brush with doom and went on to live in spite of the king. Many people with ABI live on in spite of their brush with ‘King ABI’.
Photograph 2.6 Poster ‘Brain injury in a nutshell’ (note walnut shell on top right)
Photograph 2.7  How I see my two daughters

This second picture of my two daughters demonstrated how double vision impacts on my sight. People have two, three or four eyes – these are constantly moving as they or my head moves.
Photograph 2.8 To demonstrate how I see the printed page.
Photograph 2.9  How people with ABI ‘see’

This fourth picture entitled ‘How people with ABI ‘see’ (understand) – demonstrated difficulties understanding a conversation when you only understand some of the dialogue.
Photograph 2.10 How people with ABI understand

This fifth picture also about how people with ABI ‘see’ (understand) is a cartoon drawing entitled cat with piano tuna to demonstrate that you only need to miss one word to miss the plot.
Photograph 2.11  How people with ABI can get stuck on ideas

This sixth picture how people with ABI ‘see’ (understand) demonstrated how ideas can go round in your head and are only loosely connected to other ideas.

The ABI Cage was the centrepiece of the presentation and the letters ABI were purchased and sprayed black and attached to the Cage. Three attractive mirrors in the shape of birds had hooks attached to them. The mirrors were chosen because viewers were meant to look into the mirrors and reflect on what it would be like to have ABI. A wooden pig was purchased
and wings made out of flywire were attached. This was fixed to the top of the Cage, along with a large cut out star covered in sequins and the word ‘hope’. Cards were then cut from cardboard with words glued to the cards.

![Keys to the ABI Cage](image)

**Photograph 2.12** Keys to the ABI Cage

![The importance of hope](image)

**Photograph 2.13** The importance of hope

Objects were collected to attach to the cards by punching a hole in using black ribbon. The cards were then covered in contact.
Photograph 2.14   Objects were attached to the cards

- The cards themselves:

I did not wish the information to appear to be a list, but to be separate cards that could be picked up by the viewer, certain cards could be selected to be discussed and organised in different ways.

Photograph 2.15   Some cards were locked inside the cage

After considerable experimentation I divided the issues into three categories.

Different fonts were selected for the different categories. Font:

Difficulties, Feelings and Coping strategies all needed to be represented by different font.
Difficulties used chiller font to try to express ‘difficulties’ in a visual way. Feelings were written in Gill Sans Ultra Bold font -thick, heavy, overpowering and black. Hopeful coping strategies were written in Cooper black font to be rounded and hopeful and comforting.

All the printed words were mounted on black card. The coping cards had small symbols attached to them by ribbon. For example a tiny coffee pot, a small dog, a pen and so forth.

The RMIT School of Health Sciences Conference July 2008 the Cage was set up with the difficulties cards (with the word on both sides of the card so they could be viewed through the bars of the cage) inserted into the bars of the Cage. Inside the Cage was placed a crushed Solo drink can (a symbol of crushed lives) with the feelings cards. Spread out on the table were the coping cards with their symbols attached. This diorama generated interest and was awarded best diorama prize.
2.1.3  The Cage #3

Photograph 2.16  C. Durham with the cage at the Acquired Brain Injury Insights and Solutions Conference in the lobby of the Sofitel Hotel Melbourne

‘The ABI Cage’ as presented at the ABI Insights and Solutions Conference Sofitel Hotel Melbourne HeadCase Art Exhibition September 2008 Also as featured on ABC TV Lateline Program. Portrait in Headcase photographic exhibition of people with ABI and their story
November 2009 Acquired Brain Injury Conference held at the Sofitel Hotel Melbourne. Durham was interviewed for the Head Case exhibition, for information to go beside a large portrait in this art exhibition. Curiosity was raised when she spoke about her ABI Cage and she was subsequently invited to bring the ABI Cage to display it at the Sofitel Hotel.

What had been a diorama now had to be turned into a freestanding ‘sculptural’ piece.

The walking stick was held horizontally through the bars of the cage and cards with ‘difficulties of ABI’ were stapled together and wooden curtain rings sewn to the top most cards so the rings could be threaded through the walking stick. Numbers 1,2 &3 were printed on coloured card which was fixed to other curtain rings to make ‘frames’ for the numbers – which were then attached to the walking stick, the cage and the pole.

Wooden pegs were painted black, an assortment of house keys were attached to the pegs. The pegs and the pole had fine holes drilled in them and then the pegs were attached with fine nails to the wooden pole of the flying pig.

This pole was to represent a signpost – a way forward for the future, so the cards were held in different directions. This looked exciting and ‘in the round’ rather than flat – but it was tricky
to move from the car and the cards needed to be attached once the cage and the walking stick was in situ. The pole was then tied to the cage. After the Cage had been transported to the Sofitel Hotel and the ABC studios for a TV segment on ‘The ABI Cage’ it was obvious the cards would be damaged very easily.

The Cage caused a great deal of interest. Attendees had their photo taken with the Cage. Both people with ABI and professionals were fascinated by it. The simplicity with which it ‘spoke’ about so much about ABI was appreciated. Professionals and aboriginals from Northern Territory were particularly interested. Apparently there is no easily accessible information to explain ABI to aboriginal people.

There was a ‘People’s Choice’ Award for art works at the exhibition. Durham was informed that many people wanted the Cage to be awarded People's Choice (it was not part of the art exhibition). The Cage was shown on ABC television.
The ‘Keys to the ABI Cage’ was used on the CD with ‘What Brain Injury means to me fill in sheets, and CD to introduce ideas behind the concept of ‘Keys to the ABI Cage’.

Due to the success so far of the ‘Keys to the ABI Cage’, I decided to adapt it to use as an interviewing tool for the study ‘How Can we Acquire Better Insight into Acquired Brain Injury?’ (working title). The ‘Keys to the ABI Cage’ and all the cards would need to be moved to 30 different locations.

Changes needed to be made to simplify transporting the Cage and cards. ‘Talking cards’ (the cards were now referred as ‘talking cards’ after ‘talking mats’, this was later changed to ‘talk-
about cards), needed to be protected from damage and assembled quickly and easily. The content and the way cards were displayed needed to be reviewed and changed.

The ‘Differences and Difficulties’ talk-about cards were assembled in plastic pockets (with clear gaps between the cards – so it was obvious they were separate cards, not simply a list of difficulties). The plastic pockets were connected so that they could be hung over the walking stick when it was inserted into the cage.

The ‘Feelings’ talk-about cards were hung on hooks on the bird mirrors inside the cage and could remain in situ whilst the cage was moved.

Photograph 2.19   Photograph of ‘Keys to the ABI Cage’ – taken out of doors

‘Keys to the ABI Cage’ talk-about cards with attached objects were attached to a heavy Perspex sheet which had a hole drilled at the top to be hung on the Pole of the Flying Pig. Later a series of golden keys were attached to the pole.
A new series of talk-about cards were made and covered in contact for the participants to handle. These were colour coded for easy organization: Difficulties and Differences were stuck on heavy black card, Feelings on heavy red card and Keys on white card with photographs and pictures attached.

Discussions with people with brain injury and professionals made it apparent that ‘difficulties’ needed to be adapted to ‘differences in difficulties’. It was realised that ‘talking cards’ made no sense as the cards did not talk. The term ‘talk-about’ was adopted as it was friendly (had a walk about sound) my speaking business was called ‘Talk About Change’ and the cards were about things people had talked about and their purpose was to assist people talk about their experiences.

Prior to conducting the interviews I had plans for participants to construct their own ‘ABI Cage’ and considerable effort was put into devising a way to accomplish this goal – so that a photo of the participant and their personal cage could be sent to be them with their thank you card.
Photograph 2.21  It was envisaged that at the completion of the interview the photo would be like this:

Unfortunately due to participant fatigue none of the participants actually completed this step. If ‘Keys to the ABI Cage’ was used in a rehabilitation setting over a greater length of time – perhaps over several sessions this would be an excellent way to remind people of conclusions they reached during the interview time and issues to tackle in the future.
Photograph 2.22 To show the difference between initial interior photograph of the Cage see photograph 2.21 and the cage when photographed out of doors.

There was a different ‘feeling’ once the Cage was photographed outside. This different was really apparent when ‘Keys to the ABI Cage’ was used with the three ABI support groups – sitting inside in a building.
2.1.5  

The Cage #5

When presenting at the 8th World Congress on Brain Injury Washington D.C. a small version of ‘Keys to the ABI Cage’ was compiled and displayed in the foyer of the Conference Exhibition Hall.

Photograph 2.23   The mini Keys to the ABI Cage in Washington

Photograph 2.24   C. Durham and the mini Keys to the ABI Cage in Washington
APPENDIX CHAPTER 3

3.1

Box 3.1 Some Journals reporting ABI research:


3.2

Box 3.2 Examples of IQ tests and scales:

Wechsler Adult Intelligence Scales (WAIS) (Wechsler, 1955).
WAIS-IV (Pearson, 2008).
WAIS Short Form (Reynolds, Williams and Clarke, 1983).
3.3

Box 3.3 Examples of memory tests:

- The Inventory of Everyday Memory Experiences (IME) (Harrann and Neisser (1978).
- Subject Memory Questionnaire (SMQ) (Bennett-Levy and Powell (1980).
- Cognitive Failures Questionnaire (CFQ) (Broadbent et al., 1982).
- The Everyday Memory Questionnaire (Sunderland, Harris and Badderley (1983).

3.4

Box 3.4 Example of tests to determine severity of depression:

- Beck Depression Inventory (BDI-11) (Beck, 1961).
- Beck Depression Inventory for Primary Care. (Beck, Guth, Steer, Ball, 1997).
- A Self-rating Depression Scale. (Zung, 1965).
- State-Trait Anxiety Inventory (STAI) (Curran, Ponsford & Crowe, 2000).
- Centre for Epidemiological Studies Depression Scale (CES-R) (Radloff, 1997).
- Hospital Anxiety and Depression Scale (HADS) (Zigmund and Snaith, 1983).
- Diagnostic and Statistical Manual of Mental Disorders, (DSM-IV-TR); (American Psychiatric Association).
Assessment of Quality of Life. (AQoL). (Hawthorne, Richardson et al. 1999; Richardson et al. 2000).

Ahort Form-36 Survey Questionnaire (SF-36). (Ware & Sherbourne, 1992).


3.5

Box 3.5  Example of scales employed to measure fatigue:


The Fatigue Impact Scale, (FIS) (Fisk et al. 1994).


Visual Analogue Scale–Fatigue (Ziino & Ponsford, 2006).

Causes of Fatigue Questionnaire (COF) (Ziino & Ponsford, 2006).

VAS-F (Ziino & Ponsford, 2006)

VAS (Belmont, Agar, Hugeron, Gallais & Azouvi, 2006).

Fatigue Impact Scale (Belmont, Agar, Hugeron, Gallais & Azouvi, 2006).

Causes of Fatigue (COF) Questionnaire (Belmont, Agar, Hugeron, Gallais & Azouvi, 2006).

BNI Fatigue Scale (Belmont, Agar, Hugeron, Gallais & Azouvi, 2006).

Fatigue Severity Scale (FSS) (Ziino & Ponsford, 2006).
3.6

Box 3.6 Example of inventories and measured employed to investigate coping:

- The Billings and Moos Coping Measures (Kendall and Terry, 2008)
- The Ways of Coping Checklist (Medley et al, 2010)
- The European Brain Injury Questionnaire (Medley et al, 2010)
- The Ways of Coping Questionnaire (Lazarus, 1991)
- The Headley Court Psychosocial Rating Scale (Malia, Powell, Torode 1995)
- Coping Strategies Questionnaire (Abbot 2010)
- The COPE Scale (Finset and Andersson, 2000)
- The Multidimensional Health Locus of Control Scale (Moore and Stambrook 1992)
- The Billings and Moos Coping Measures (1981)

3.7

Box 3.7 Example of scales and assessments regarding pain include:

- The Psychosocial Pain Inventory (PSPI). (Heaton et al. 1982).
- Impairment Rating for Posttraumatic Headache. (Packard & Ham, 1993).
3.8

Box 3.8  Example of scales employed to measure PTSD:

- The Overt Aggression Scale (OAS) (Yudofsky, Silver & Jackson, 1986).
- The General Health Questionnaire (GHQ) (Goldberg et al., 1978).
- The Satisfaction with Life Scale (SWLS) (Diener et al., 1985).
- The Perceived Stress Scale, (PSS) (Cohen, Kamarck & Mermelstein, 1983).
- The Post Traumatic Stress Diagnostic Scale, (PDS) (Foa, Cashman, Jaycox, & Perry, 1997).
- Detailed Assessment of Post-Traumatic Stress $^\text{TM}$ (DAPS$^\text{TM}$) (Briere, 2004).

3.9  Considering tests from the perspective of people with ABI

People with ABI have expressed the following problems they have had with testing:

Considering problems people with ABI have talked about to me – these issues may affect the willingness of people with ABI to be involved in this study:

- Testing can be disempowering.

Knowledge about ABI has historically been in the hands of people involved in medical/legal/rehabilitation. Professionals administer tests which may mean the person with ABI feels ‘tested’ and ‘judged’. Class, race, and gender may indicate that some people with ABI acquire their ABI through taking part in reckless behaviour and/or excessive
consumption of alcohol. The person may have problems thinking because of their cognitive and memory deficits.

- Association of unpleasantness with tests.

The person with ABI might feel their voice has not been heard – “What’s the use? They may feel ‘judged’ and may be distressed because they feel they cannot or do not have the words to give the ‘right’ answer. Involvement in the process of remembering could lead to feeling more disempowered, hopeless, and/or depressed. The person may feel anxious and fearful of a test like environment due to memory difficulties, communication problems, lack of confidence, self-doubt etc.

- Some people with ABI feel they have been ‘over tested’.

If litigation/compensation has been involved person with ABI would have been compelled to undergo intense testing and forced to undergo innumerable assessment sessions. Performance in each test would have significantly affected compensation or lack of compensation. They may feel uneasy about doing ‘another test’ because these processes can be dis-empowering and upsetting as testing points out difficulties.

- They may feel frustrated, scared, angry, afraid and upset (Cresswell, 1993) by the lack of care they perceive they have received by professionals.

Participants may be afraid to encounter another ‘uncaring’ experience.

- They may feel misunderstood in situations of testing.

Because participants may perceive that they are viewed as ‘faking’ or ‘putting it on’ (in comparison to someone who has diabetes or cancer - experts are not constantly trying to prove they are pretending to have the disease). If the ABI was caused by a car accident, added layers of complexity affect how the person is treated. This, in turn, mirrors back to how people with ABI feel about themselves – guilty, perplexed and unsure.
APPENDIX 4

4.1 The Blind man and the elephant John Godfrey Saxe

Poem: The Blind Men and the Elephant - John Godfrey Saxe (1816-1887)

It was six men of Indostan  
To learning much inclined,  
Who went to see the Elephant  
(Though all of them were blind)’  
That each by observation  
Might satisfy his mind

The First approach’d the Elephant,  
And happening to fall  
Against his broad and sturdy side,  
At once began to bawl:  
“God bless me! But the Elephant  
Is very like a wall!”  
“….like a rope!”  
“… like a spear!”  
“….like a snake!”  
“….like a tree!”  
“….like a fan!”

Moral  
So oft in theologic wars,  
The disputatants, I ween,  
Rail on in utter ignorance  
Of what each other mean,  
And prate about an Elephant  
Not one of them has seen
Elephant
Christine Yvonne Durham after John Godfry Saxe (1816-1887)

The outside of an Elephant
’s made up of different parts
But that’s not all Elephant is
- *Elephant’s got mind and heart!*
Elephant’s more than leg and trunk and hide and eyes and meat.
Elephant’s more than tail and ears and side and tusk and feet.

In circus, zoo, and forest too
Elephant works in fields and more
A family pet, a faithful friend,
She can run amok and gore.
Carrying tourists, logs or heavy loads, her attributes are many
But rogue and wild, and strong and huge, Elephant’s very scary!

Why, oh why, I ask you,
Does this massive wrinkly beast
Disobey her master
Or sit upon a seat?
She sways and dances (it is true) when tethered to a stake
When looking into all of this, of sense we cannot make!

The essence of an Elephant
Is mighty hard to find
It’s not locked up in books or film
Or held in someone’s mind
*If only Elephant could speak, and tell us what she knows*

Then, and only then, could we discover how she goes!
### Qualitative literature reviewed

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<td>Karpmann, Wolfe &amp; Vargo, 1986</td>
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APPENDIX CHAPTER 6

Note: These Appendices appear very messy as some are in size 16 print for ease of reading by people with ABI who may have limited vision, there are pictures and illustrations. To make it easier for the reader to negotiate through these Appendices the heading has been shaded in grey.

6.1 Handy Thinking Tools

Method B: Handy Thinking about what it is like to have ABI

Handy Thinking Tools are tactile, tangible, mnemonic devices that utilize senses of touch, sight and hearing to reinforce analytical, practical, creative thinking about an issue or problem. By ‘counting on their fingers’ digits of the hand are used as symbols to prompt specific questions. Handy thinking Tools can help in brainstorming and understanding of issues, and lead to the individual finding solutions and make informed decisions.

HANDY THINKING $\odot$ TOOLS
THUMB: Pigeonhole it: Ask ‘What is ABI like?’
Sort, organize and group the problem or issue.

POINTER FINGER: Find the Facts about ABI
Ask ‘What are the facts?’

MIDDLE FINGER:
Find the Feelings: Ask ‘What are the feelings I have about my ABI?’
See the issue from your and others’ points of view

RING FINGER:
Judge the issue Ask: ‘What are the Good, Bad and Curious points about having ABI?’

LITTLE FINGER:
Great Original Wise Thinking Ask: ‘What if?’
Look for possible consequences of taking certain identified steps to help myself.

For participants in the interview situation who do not appear to understand or enter into the spirit of ‘Keys to the ABI Cage’, and/or for participants who are ‘stuck’ on a particular problem or issue I will change methods and change to using ‘Handy Thinking Tools’ (Durham 2001) to try to open up and discuss that issue, with the aim of discovering commonalities with the experience of others with ABI and to lead the participant to reflect on their coping strategies.
‘Handy Thinking Tools’ could provide the structure for the interviews. These personal tools facilitate getting to the essence of what it is like to have ABI, or supporting forms of intentionality.

When Handy Thinking Tools are used the participant will learn new tools to use in their daily activities to understand issues and problems.

Both ‘Handy Thinking Tools’ like ‘Keys to the ABI Cage’ are learning/discovery tools to assist the unpacking of the many facets of ABI:

Provide a structured framework to build a discussion around

Jog memory (before answering open-ended questions, and notes taken throughout the interview under the specific headings (3 headings for the Cage and 5 for Handy Thinking)

Lead to reflection

Lead to self discovery

Lead to reflection about what coping strategies are used

Lead to thinking about coping strategies that could be used in the future

Provide a positive interesting experience

Questions will include:

1. **Pigeonhole what it is like to have ABI?** What is the essence of ABI for you?

What does it feel like to have ABI?

2. **What are some facts that you know about ABI?**
What do you know about ABI? What would you like to know about having ABI? What do you do/say to yourself that helps you cope with ABI?

3. **Find the Feelings about what it’s like having ABI?**

What are some of the feelings you have about having ABI?

What do you do/say to yourself to help you cope with your feelings about ABI?

4. **Bad and good things about what it’s like to have ABI**

What are the bad things about having ABI?

Is there anything good that has come out of your having ABI?

5. **What have you discovered?** What has helped you cope with your ABI. What could you do to help yourself in the future? Has a sense of humour helped you?

What do you think would help you in the future to cope with your ABI?

If the participants do not become engaged with either ‘Keys to the ABI Cage’ or ‘Handy Thinking’ about what it’s like to have ABI they might be stuck with one of the following issues or problems, or another similar problem. Their problem would be written on a ‘Talking card’ if it is different to the following problems that will be written on large cards with a cartoon type illustration.

The participant may choose to have Durham write their problem on a ‘Talking card’ or the participant could choose a ‘Talking card’. The issue or problem would then be unpacked the issue using ‘Handy Thinking’. Once they had unpacked the issue they might wish to engage with ‘The ABI Cage’ or talk about ABI using ‘Handy Thinking Tools.’
Method C Handy Thinking About ABI problems or issues

The following issues have been identified in workshops with people with ABI over the past 15 years. If the participant does not want to talk about issues of ABI they may be happy to give advice to one of the following ‘people’. ‘Talk-about cards’ could be looked through and a problem tackled to break the ice and get the participants talking.

Using Handy Thinking the participant could choose one of these problems or issues to unpack:

1. Crushed
Sally: “I hate myself, I’m a waste of space” Paul: “I don’t think I’ll ever feel better. Will I?”

2. Temper
Sean: “The OT kept telling me I wasn’t trying enough. It made me mad.”
Jim: “How can I deal with my temper?”

3. Sad
Sam: “I can’t stop crying. I’m so sad.”
Phillipa: “How can I deal with my sadness – I’ve lost myself and my life!”

4. Bad thoughts
Dean: “I can’t let go of awful thoughts.”
Brian: “My thinking – sometimes I think I’m crazy. I don’t understand.”
Heidi: “I keep jumping to conclusions. I was convinced my husband was having an affair – I saw it in a dream.”

5. Understanding
Mark: “How can I learn to understand again?”
John: “I can’t understand what people say. I feel stupid.”

6. Memory

Christopher: “I can’t remember what day it is or even my own name. What can I do?” Mary: “I’ve forgotten how to tell the time, what money is and how to work change out in a shop. What things could help me?”
6.2a Information/advertisement for ABI support organizations to place in newsletter (note large print for ease of reading)

Acquiring Better Insight into ABI

Shining a light on what it’s like to live with ABI and searching for answers

Many people have had their world turned upside down by Acquired Brain Injury, like I did when I got my ABI.

We are looking for people with ABI, people who care for and support people with ABI, professionals and advocates who work with people with ABI to help us find a way to help people with ABI help themselves.

If you have an ABI, care for or work with people with ABI Chris Durham would like to interview you, or send you a CD and sheets to fill in, to learn about your experience of ABI including:

1. Differences and difficulties of ABI.
2. How people with ABI feel about these differences and difficulties.
3. How people with ABI cope and help themselves.
4. Information that has been helpful for them.

Information collected will be used to put together an easy to read Information Resource to help PWABI help themselves and will remain confidential.
If you would like to take part in this study and you would like more information please phone xxx University on xxx xxxx and leave your name and phone number for Chris and she will ring you back, or email her at christine.durham@student.xxxx.edu.au

WANTED: RESEARCH PARTICIPANTS WITH ABI, CARERS, PROFESSIONALS AND ADVOCATES

Photograph 2.17 Photograph of ‘Keys to the ABI Cage’ used for introductory power point and digital storage disk (CD) as part of the ‘Reflection Kit’
Letter to accompany advertisement sent to brain injury support groups to ask for advertisement to be placed in journals/newsletters

Name
Address
Date

Re: How can we Acquire Better Insight into Acquired Brain Injury?(ABI): What’s it like to live with ABI? Examining the insight of people with ABI (PWABI), people who care for and support people with ABI, professionals and advocates who work with PWABI.

Dear….

Thank you for the opportunity to discuss the above project with you. I do hope that you will be able to support this research by placing the attached information in your newsletter ‘xxx’. Just to reiterate a point made in our phone discussion this research is part of a study being conducted at RMIT University. It is supervised by Dr. Paul Ramcharan and Dr. Josephine Lang.

Acquiring Better Insight into Acquired Brain Injury research project is seeking to recruit 45 participants: 30 PWABI, 5 people who care for and support people with ABI, 5 professionals and advocates who work with people with ABI. The study aims to discover information that is of value to help PWABI live with ABI. Data collected will be used to inform an Information Resource to empower PWABI to help themselves.

The interviews:

Chris Durham will conduct individual 45-60 minute interviews with 10 PWABI, another 10 PWABI will first view a CD and complete sheets on ‘What ABI means to me before taking part in an interview, another 10 PWABI will only view the CD and fill in the sheets ‘What ABI means to me’. Other interested PWABI will be sent the sheets to fill in and return.

People who care for and support people with ABI will take part in a 45 minute interview, professionals and advocates will be invited to attend a 60 minute finterview to give their points of view.

It is realized that the interview may bring up distressing memories for PWABI and people who care for and support people them, so many safeguards have been put in place to ensure that the experience will be interesting and positive.
This research has the permission of the RMIT University Human Research Ethics Committee (Project No. 04/09) and the research team has put in place a number of checks to reduce risks to a minimum. Records relating to the study will be kept in secure storage at RMIT and destroyed after five years. Steps will be taken to ensure confidentiality.

We are asking for your help to recruit participants by placing the attached information in your newsletter, on your website and by approaching people you think might be interested in participating in this study and directing them to the information in your newsletter.

Thank you for your help with this study.

By gathering important information to include in a Resource Information we aim to help PWABI to feel and fare better, people who care for and support people with ABI to understand and cope better and for professionals and advocates who work with people with ABI to better perceive the different aspects of ABI so they can better assist their clients.

Kind regards,

Chris Durham, MEd., BEd Studies, Grad Dip Ed (Curriculum) TPTC. (Investigator)
Paul Ramcharan, BSc (Hons) Grad Dip Ed, PhD. (Principal Supervisor)
Josophine Lang, BEd; GDPlan & Design (Env); Ma EnvStud; GC Ed (TRIP); Ma Ed; PhD. (Supervisor)
Edward Durham (Support Assistant)
6.3 Checklist filled in during phone conversation with possible participants after they had contacted the university to say they were interested in participating in the study after seeing the advertisement

1. Check Sheet people with ABI:
   - Name
   - Phone number
   - Address
   - Email address
   - ABI how long ago…… not longer than 14 years ago
   - Not feeling fragile or having a bad time at the moment
   - Don’t think I’ll get too upset thinking about and talking about my experiences
   - Computer
   - Computer skills
   - Older than 19 years of age /not older than 60 years of age
   - No court case in 2009
   - OK for interview to be tape-recorded
   - Understands that this study wants to find out about my experience of ABI
   - OK to be interviewed for up to 60 minutes
   - Want to take part in this study

2. People who care about and support people with ABI
   - Name
   - Phone number
   - Email address
   - Address
   - Suitable place for interview
   - Not feeling fragile or having a bad time at the moment
   - Don’t think I’ll get too upset thinking about and talking about my experiences
 OK for interview to be tape-recorded

3. Professionals
 Name
 Occupation
 Phone number
 Email Address
 Address
 Ability to attend 60 minute interview Date…. Time…. 
6.4 Invitation for people with ABI, plain language statement, inclusion exclusion

Acquiring Better Insight into ABI

Shining a light on what it’s like to have ABI and searching for answers

Investigators:
Christine Durham (PhD student, Health Science/Education
christine.durham@student.xxx.edu.au Ph. xxx xxxx mobile phone number xxxx- ring and leave a message and Chris will return your call)
Dr. Paul Ramcharan (Project Supervisor, emailxxx Ph. Xxx)
Dr. Josephine Lang (Other Investigator, email xxx Ph. xxx)
Edward Durham (Support Assistant)

Dear fellow ABI sufferer,
It was good to talk to you on the phone. Thank you ringing me to say you are interested in being part of this study.

My name is Chris Durham and I suffered ABI 18 years ago in a car accident and wrote about it in my book ‘Doing Up Buttons’.

I really want to find out how people with ABI can help themselves so I have gone back to university. With my supervisors I am working on this project with to find out how people with ABI live and cope with ABI.

Will you tell us about what it is like to live with ABI?
Will you share some of your ideas about how you cope?

It would be so good if you could help us find a way to help PWABI help themselves.
As we discussed on the phone I would like to interview you, or sent you a CD or some sheets to fill in to learn about your experience of ABI:

1. The difficulties you have had.
2. How these difficulties have made you feel.
3. Things that have helped you cope with your ABI - things you have figured out to help yourself.
4. Information that has been helpful to you.

This letter is to give you more information so that you can make up your mind if you want to be involved.

There are 3 steps for you to take.

Step 1: Can you say “yes” to all the statements on the next page? If yes read more… If no, thank you for your interest.

Step 2: Read some more information.

Step 3: If you want to help, please sign the Consent Forms. Keep one for yourself and send the other to Chris in the enclosed stamped self-addressed envelope.

What’s next? Chris will phone you within three weeks once she has received your forms.

We do hope that you will be willing to be part of this study, and to give it the thumbs up.
STEP 1: CAN YOU SAY “YES” AND TICK THESE BOXES?

- I have an ABI
- I am older than 19 years of age
- I am not older than 60 years of age
- I will not have a court case in 2009
- I am not feeling fragile or having a bad time at the moment
- I don’t think I’ll get too upset thinking about and talking about my experience of ABI
- I got my ABI not longer than 14 years ago
- It is OK for my interview to be tape-recorded
- I can understand that this study wants to find out about my experience of ABI
- It’s OK to be interviewed for up to 60 minutes
- I have decided that I want to take part in this study

OK? Read on....
STEP 3: SOME MORE INFORMATION

If I agree to be interviewed what will I be asked to do?

Chris Durham will meet you in a place that suits you such as your ABI support organization or your local library for about an hour.

Chris will ask you to talk about your experience of ABI. She will use pictures, ideas, objects to help you think about your answers and ideas. There are no ‘right’ answers, she just wants you to tell about your experience of ABI.

No one related to you can be part of this study.

OK? Read on....

When I am interviewed are there any risks or difficulties?

When you are talking to Chris you may have upsetting or unpleasant memories about your experience. We do not want you to be upset so you are asked not to be part of the study if you are having a bad time at the moment.

As Chris suffers from ABI herself she understands it can be hard to think of an answer so she has been busy making things to help you. She will understand and guide you if you forget what she is saying or you are saying.

At the interview Chris will give you a list of organizations that could provide counselling support if you need it.

If you disclose something illegal or you tell Chris that you intend to do something to hurt yourself, or other people (or you have done so in the past), Chris will have a duty to report this to XXXX University, and the interview will be ended.

OK? Read on....

What are the benefits of being in this study?

You will have the chance to think about things you have done to help yourself cope with ABI, and be able to share your ideas to help other people with ABI.
It should be good to be part of a positive program to help people with ABI. You may pick up some helpful tips from other people who help with the study.

➢ OK?  ⚱️  Read on….

What will happen to the words I say?
Your interview will be tape-recorded so that Chris can write down your ideas. No one will know your real name because she will use a made up name, a pseudonym, when she writes down the information you give. This will be kept on a password-protected computer, locked in a filing cabinet at XXXX University for 5 years, then destroyed. The ideas brought up by this study will be written for a journal and used to write an Information Resource to help people with ABI help themselves.

OK?  ⚱️  Read on….

What are my rights as a participant?
You have the right to withdraw from the interview at any time, without prejudice. You have the right to have any unprocessed data that can be readily identified withdrawn and destroyed at any time.

OK?  ⚱️  Read on….

If I have any questions whom should I contact?
Please contact Chris Durham  christine.durham@student.x.edu.au,  x Ph. X to leave your name and number then Chris will contact you.
Dr. Paul Ramcharan, paul.ramcharan@x.edu.au,  Ph. X or josephine.lang@x.edu.au Ph. x

OK?  ⚱️  Read on….

STEP 3: SIGN THE FORM
If you want to be part of this study please sign the following form, have someone witness it, put in the enclosed stamped self addressed envelope and send it to me. (Mrs. Chris Durham, School of x, PO Box x)

Thank you for reading this material and agreeing to help us. I will look forward to phoning you within three weeks after I have received your signed form.

Kind regards,

C.Durham (Principal Investigator)

Dr. P. Ramcharan (Senior Supervisor)

Dr. J. Lang (Supervisor)

E. Durham (Support Assistant)

Any complaints about your participation in this project may be directed to the Executive Officer, xxx Human Research Ethics Committee, Research & Innovation, x, GPO Box x. The telephone number is (03) x.

Details of the complaints procedure are available from the above address.
Consent form included with the previous letter (for people with brain injury)

*Prescribed Consent Form For Persons Participating In Research Projects Involving Interviews, Questionnaires or Disclosure of Personal Information*

**Acquiring Better Insight into ABI**

Shining a light on what it’s like to have ABI and searching for answers

<table>
<thead>
<tr>
<th>Portfolio</th>
<th>School of Health Sciences</th>
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</thead>
<tbody>
<tr>
<td>Name of participant:</td>
<td></td>
</tr>
<tr>
<td>Project Title:</td>
<td><strong>Acquiring Better Insight into Acquired Brain Injury</strong></td>
</tr>
<tr>
<td>Names of investigators:</td>
<td></td>
</tr>
<tr>
<td>(1)</td>
<td>Chris Durham</td>
</tr>
<tr>
<td></td>
<td>Phone: xxxxxxxxx University</td>
</tr>
<tr>
<td></td>
<td>Mobile with specific phone number for this study</td>
</tr>
<tr>
<td>(2)</td>
<td>Dr. Paul Ramcharan</td>
</tr>
<tr>
<td></td>
<td>Phone: University number</td>
</tr>
</tbody>
</table>
1. I have received a statement explaining the interview/questionnaire involved in this project.

2. I consent to participate in the above project, the particulars of which - including details of the interviews or questionnaires - have been explained to me.

3. I authorise the investigator or his or her assistant to interview me or administer a questionnaire.

4. I acknowledge that:

   (a) Having read Plain Language Statement, I agree to the general purpose, methods and demands of the study.

   (b) I have been informed that I am free to withdraw from the project at any time and to withdraw any unprocessed data previously supplied.

   (c) The project is for the purpose of research and/or teaching. It may not be of direct benefit to me.

   (d) The privacy of the personal information I provide will be safeguarded and only disclosed where I have consented to
the disclosure or as required by law ie if I disclose something illegal or say I intend to harm myself or others (or I have done so in the past). Chris is required to report this to XXXX University and the interview will be terminated.

(e) The security of the research data is assured during and after completion of the study. The data collected during the study may be published, and a report of the project outcomes will be provided to XXXX University School of Health Sciences. Any information which will identify me will not be used.

**Participant’s Consent**

Participant: ________________________________ Date: ________________

(Signature)

Witness: ________________________________ Date: ________________

(Signature)

My email address is…………………………………

If I have an interview I would like it to be at

.................................

- It is OK For my interview to be tape recorded
- I have a computer and I can use it to type and I can put in a CD
- I can write or a family member can write for me

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Participant please sign the forms, have someone witness your signatures and keep one form and return the other form to Chris in the enclosed stamped self addressed envelope.

Any complaints about your participation in this project may be directed to the Executive Officer, X Human Research Ethics Committee, X, GPO Box X, Melbourne, X. The telephone number is (03) X.

Details of the complaints procedure are available from the above address.
YOU ARE INVITED TO PARTICIPATE IN A RESEARCH PROJECT
PROJECT INFORMATION

Project Title: Acquiring Better Insight into Acquired Brain Injury

Investigators: Christine Durham (PhD student, Health Science/Education, cdurham@student.X.edu.au, Ph. X mobile X)
Dr Paul Ramcharan (Project Supervisor, Health Sciences, email paul.ramcharan@x.edu.au, Ph. X)
Dr. Josephine Lang (Co-supervisor, Education, email Josephine.lang@x.edu.au, Ph. X)
Edward Durham (Support Assistant)

Dear …

You are invited to participate in this research program being conducted by RMIT University. This information sheet describes this project. Please read the sheet carefully and be confident that you understand its contents before deciding whether to participate. If you have any questions about the project, please contact Chris Durham, Dr. Paul Ramcharan or Dr Josephine Lang.

Who is involved in this research project?
Chris Durham, a PhD student from X University, a person with Acquired Brain Injury, author of the book ‘Doing Up Buttons’ (Penguin Books) is working with her supervisors Dr. Paul Ramcharan, and Dr. Josephine Lang on this project.

What is this research project about?
This project will compile information about how PWABI understand and cope with their ABI to provide information to be used in compiling a user-friendly Information Resource that will assist PWABI help themselves.

Why is this research project being conducted?
The project seeks to discover what it’s like to live with ABI, how it feels to have ABI, things that help people with ABI to cope with ABI (ways they have helped themselves cope with the changes of ABI) and information that would be helpful for them.
Chris will interview 5 people who care for and support people with ABI for up to 60 minutes each. She will also interview 30 people with ABI, 5 health professionals and 5 advocates who work with people with ABI. Chris will use the material gathered to compile a user-friendly Information Resource to assist PWABI help themselves.

Why have you been approached?
In response to you indication of interest to participate in the study you are now being approached to give you further information to give you the opportunity to decide to participate.

If I agree to participate, what will I be asked to do?
To meet with Chris Durham for a period of 45 minutes for an interview to talk about how the person with ABI you care for and support copes with ABI. She will use pictures, ideas and objects to help you think about your answers and your views.

What are the risks or disadvantages associated with participation?
The main risk with participating in an interview is that memories about your experience of caring for a person with ABI may be upsetting or unpleasant. For this reason you are asked not to participate if you are feeling particularly fragile. Note If you disclose something illegal or you tell Chris that you intend to do something to hurt yourself, or other people (or you have done so in the past), Chris will have a duty to report this to X University, and the interview will be ended.

What are the benefits associated with being interviewed?
You will have the opportunity to revisit things you have done to help your family member to cope with ABI, to remember strategies to reuse, and to reflect on what empowers the person with ABI to help themselves.

You should feel pleased to be part of a positive program that aims to empower people with ABI. You will have the opportunity to share your thoughts, ideas and wisdom knowing that you can help other people with ABI.

You will be able to access other helpful ideas other people with ABI have discussed with Chris.

What will happen to the information I provide?
Your interview will be tape-recorded and Chris will then transcribe the interview and record your answers to the four questions. Your ideas and comments will be anonymous and will be given another name. Your information will also be confidential and will only be seen by the project team: Chris Durham, Dr. Paul Ramcharan and Dr Josephine Lang.

The results of study may be used as the basis for journal articles or related publications and ideas and comments will be used with other participants' ideas, to write an Information Resource to help PWABI help themselves.

All transcripts of interviews will use pseudonyms (made up names) and will be kept securely at RMIT for 5 years and then they will be destroyed.

What are my rights as a participant?
You have the right to withdraw from the interview at any time, without prejudice.
You have the right to have any unprocessed data that can be readily identified withdrawn and destroyed at any time, provided it does not increase the risk for the participant.

Whom should I contact if I have any questions?
Please contact Chris Durham or Dr. Paul Ramcharan or Dr. Josephine Lang.

What other issues should I be aware of before deciding to participate?
You may not take part in the study if the person who you care for and support is taking part in the study. We may have too many volunteers, so a spread of people will be chosen.

If you agree to take part in this study please sign the following consent form.
Yours sincerely,
C. Durham

Dr. P. Ramcharan

Dr. J. Lang

E. Durham (Support Assistant)

Any complaints about your participation in this project may be directed to the Executive Officer, X Human Research Ethics Committee, Research & Innovation, X, GPO Box X, Melbourne, 3001. The telephone number is (03) X

Details of the complaints procedure are available from the above address.
6.7 Consent form for people who care for and support people with ABI

Acquiring Better Insight into Acquired Brain Injury

Shining a light on ABI and searching for answers

*Prescribed Consent Form For Persons Participating In Research Projects Involving Interviews, Questionnaires or Disclosure of Personal Information*

Portfolio

Health Sciences / Education

Name of participant:

Project Title: Acquiring Better Insight into Acquired Brain Injury

Name(s) of investigators: (1) C. Durham  Phone Mobile x

(2) Dr. Paul Ramcharan  Phone: x

(3) Dr. Josephine Lang  Phone: x

1. I have received a statement explaining the interview/questionnaire involved in this project.

2. I consent to participate in the above project, the particulars of which - including details of the interviews or questionnaires - have been explained to me.

3. I authorise the investigator or his or her assistant to interview me or administer a questionnaire.
4. I acknowledge that:

(a) Having read Plain Language Statement, I agree to the general purpose, methods and demands of the study.

(b) I have been informed that I am free to withdraw from the project at any time and to withdraw any unprocessed data previously supplied.

(c) The project is for the purpose of research and/or teaching. It may not be of direct benefit to me.

(d) The privacy of the personal information I provide will be safeguarded and only disclosed where I have consented to the disclosure or as required by law ie if I disclose something illegal or say I intend to harm myself or others (or I have done so in the past). Chris is required to report this to X and the interview will be terminated.

(e) The security of the research data is assured during and after completion of the study. The data collected during the study may be published in scientific journals and in a report submitted to X. Any information which will identify me will not be used.

**Participant's Consent**

Participant: ____________________________ Date: ____________________________

(Signature)

Witness: ______________________________ Date: ______________________________

(Signature)

**CAN YOU TICK ALL THESE BOXES?**

- I care for and help a person who has ABI
- I am not feeling fragile or going through a period of crisis with the person with ABI
- The person with ABI does not have a court case to do with their ABI in 2009
- Their ABI did not happen more than 14 years ago
- I understand that this study is trying to find ways to help people with ABI help themselves
- I would like to be part of this study
- I’m willing to have my interview tape-recorded
☐ I’m willing to think and talk about my experience of ABI without becoming distressed
☐ It is OK for my interview to be tape recorded

A suitable place for my interview with Chris Durham would be
...........................................................................................................................................

A suitable time for my interview would be:

☐ mornings
☐ afternoons

My email address is............................................................................................................

Please return these forms to Chris Durham by x date

Chris will ring you to inform you if you taking part in the study or not and to finalize interview details within three weeks of receiving your completed consent forms.

After your interview if you feel you need some help you could call….. Lifeline on 13 11 14 24 hours a day, or Griefline 03 9596 7799 12, or Dr. X at X University X (9am-5pm Monday to Friday) or Chris on X and leave your name and number and she will return your call.

Yours sincerely,

C. Durham

Participants will be sent two copies of this consent form to sign and have witnessed. They will retain one copy, and post the other to Durham in the enclosed stamped, self addressed envelope..
Any complaints about your participation in this project may be directed to the Executive Officer, X Human Research Ethics Committee, Research & Innovation, X University, GPO Box X, Melbourne, 3001. The telephone number is (03) X

Details of the complaints procedure are available from the above address.
6.8 Letter inviting professionals and advocates who work with people with ABI to attend an interview

Acquiring Better Insight into Acquired Brain Injury

Shining a light on ABI and searching for answers

INVITATION TO PARTICIPATE IN A RESEARCH PROJECT

Project Title: Acquiring Better Insight into Acquired Brain Injury

Investigators:
Christine Durham (PhD student, Health Science/Education, christine.durham@.x, Ph. x mobile x)
Dr Paul Ramcharan (Project Supervisor, Health Sciences, email paul.ramcharan@X.edu.au Ph. x)
Dr. Josephine Lang (Supervisor, Education, email josephine.lang@X.edu.au Ph. x)
E. Durham (Support Assistant)

Dear …
Thank you for indicating your interest in participating in this research program being conducted by X University.

Who is involved in this research project?
Chris Durham, a person with Acquired Brain Injury, author of the book ‘Doing Up Buttons’ (Penguin Books) is working with her supervisors Dr. Paul Ramcharan and Dr. Josephine Lang on this project.

What is this research project about?
This project will work directly with people with ABI (PWABI), people who care for and support PWABI, professionals and advocates working with PWABI in order to obtain data to inform the compilation of a user-friendly Information Resource that will assist PWABI help themselves.

This project aims to discover information that is vital for PWABI to learn: information they have not learnt before, information that will help them to re-engage with their changed selves, manage and cope with their ABI difficulties, navigate through a changed world and help themselves.

Why is this research project being conducted?
This project addresses the issue of the one in 45 Australians who suffer Acquired Brain Injury (ABI). These people cannot “get better” (return to how they were before the ABI) but must cope with ABI for the rest of their lives. Previous approaches to support PWABI with rehabilitation have focused on inputs from professional therapists. Not all PWABI take part in rehabilitation; time spent undertaking rehabilitation is limited; often difficulties emerge after the PWABI complete rehabilitation. Freeman (1998), Lewis (2004), Durham (1997) have all stated the need for PWABI to ‘relearn’.

Why have you been approached?
In response to you indication of interest to participate in the study you are now being approached to provide further information to give you the opportunity to decide to participate.

If I agree to participate, what will I be asked to do?
To meet with Chris Durham at a place that suits you for a 45 minute interview. Chris Durham will introduce you to her unique model, which she has called ‘Keys to the ABI Cage’ and then ask you to share your insights into ABI.

What are the benefits associated with being interviewed?
You will have the opportunity to revisit things you have done to help PWABI cope. You will have the opportunity to share your thoughts, ideas and wisdom knowing that you can help other PWABI. You will be able to access other helpful ideas from this study.

What are the risks with being interviewed?
If you disclose something illegal or you tell Chris that you intend to do something to hurt yourself, or other people (or you have done so in the past), Chris will have a duty to report this to RMIT University, and the interview will be ended.

What will happen to the information I provide?
Your interview will be tape-recorded and will then be transcribed and your comments recorded. You will be given a pseudonym so your ideas and comments will be anonymous and will only be seen by Chris Durham, Dr. Paul Ramcharan and Dr. Josephine Lang.
The results of study will be reported in relevant journals and publications but data will be used in ways that protect your identity and retain your anonymity. Ideas and comments will be used to inform an Information Resource to help PWABI help themselves.

All transcripts of interviews will use pseudonyms and will be kept securely at RMIT for 5 years and then they will be destroyed.

What are my rights as a participant?
You have the right to withdraw from the workshop at any time, without prejudice
You have the right to have any unprocessed data that can be readily identified withdrawn and destroyed at any time, provided it does not increase the risk for the participant.

Whom should I contact if I have any questions?
Please contact Chris Durham, Dr. Paul Ramcharan or Dr. Josephine Lang.

Yours sincerely,

C. Durham
Dr. P. Ramcharan
Dr. J. Lang
E. Durham

Any complaints about your participation in this project may be directed to the Executive Officer, X Human Research Ethics Committee, X, GPO Box X, Melbourne, 3001. The telephone number is X.

Details of the complaints procedure are available from the above address.
Consent form for professionals working with people with ABI

Acquiring Better Insight into Acquired Brain Injury

Shining a light on ABI and searching for answers

Prescribed Consent Form For Persons Participating In Research Projects Involving Interviews, Questionnaires or Disclosure of Personal Information

<table>
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<tr>
<td>School of</td>
<td></td>
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<tr>
<td>Name of participant:</td>
<td></td>
</tr>
<tr>
<td>Project Title:</td>
<td>Acquiring Better insight into Acquired Brain injury</td>
</tr>
<tr>
<td>Name(s) of investigators:</td>
<td>(1) C. Durham</td>
</tr>
<tr>
<td></td>
<td>(2) Dr. Paul Ramcharan</td>
</tr>
<tr>
<td></td>
<td>(3) Dr. Josephine Lang</td>
</tr>
</tbody>
</table>

1. I have received a statement explaining the interview/questionnaire involved in this project.

2. I consent to participate in the above project, the particulars of which - including details of the interviews or questionnaires - have been explained to me.

3. I authorise the investigator or his or her assistant to interview me or administer a questionnaire.

4. I acknowledge that:
Having read Plain Language Statement, I agree to the general purpose, methods and demands of the study.

I have been informed that I am free to withdraw from the project at any time and to withdraw any unprocessed data previously supplied.

The project is for the purpose of research and/or teaching. It may not be of direct benefit to me.

The privacy of the personal information I provide will be safeguarded and only disclosed where I have consented to the disclosure or as required by law. If I disclose something illegal or say I intend to harm myself or others (or I have done so in the past). Chris is required to report this to RMIT and the interview will be terminated.

The security of the research data is assured during and after completion of the study. The data collected during the study may be published in scientific journals and in a report submitted to RMIT. Any information which will identify me will not be used.

Participant’s Consent

Participant: __________________________                  Date: __________________________

(Signature)

Witness: __________________________                  Date: __________________________

(Signature)

- I GIVE PERMISSION FOR MY INTERVIEW TO BE TAPE RECORDED

SIGNED……………………………………………………………………………………………………

Participants will be given a photocopy of this consent form after it has been returned signed and witnessed, at the subsequent interview.

Any complaints about your participation in this project may be directed to the Executive Officer, x Human Research Ethics Committee, x, GPO Box x, Melbourne, 3001. The telephone number is x.

Details of the complaints procedure are available from the above address.

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Caring and non-caring nurses /researchers

Cresswell’s study (1998), identified the qualities of nurses (I suggest ‘nurses’ could be replaced by ‘researchers’) who are seen as ‘caring’ and ‘non-caring’) by their patients (PWABI). These findings were adopted for the phone calls and interviews.

In a ‘caring interaction’

- “The nurse's (researcher's) existential presence is perceived by the client as more than just a physical presence.
- There is the aspect of the nurse (researcher) giving of oneself to the client. This may be in response to the client’s request, but it is more often a voluntary effort and unsolicited by the client….perceived by the client as an attitude … really listening and responding to the unique concerns of the individual as a person of value.
- The relaxation, comfort, and security that the client experiences both physically and mentally are an immediate result of the client’s stated and unstated needs being heard and responded to …” From Cresswell, (1998:289).

In a ‘non-caring interaction’

- “The nurse’s (researcher's) presence is perceived by the client as a minimal presence only.
- The nurse (researcher) is viewed as being there only because it is a job and not to assist the client or answer his or her needs.
- Any response by the nurse (researcher) is done with a minimal amount of energy expenditure and bound by the rules.
- The client perceives the nurse (the researcher) who does not respond to his request for assistance as being ‘non-caring’.
- Therefore, an interaction that never happened is labelled as a ‘non-caring interaction’.
- The nurse (researcher) is too busy and hurried to spend time with the client.
- The client is further devalued as a unique person because he or she is scolded, treated as a child, or treated as a nonhuman being or an object.
- Because of the devaluing and lack of concern, the client’s needs are not met and the client has negative feelings, that is, frustrated, scared, depressed, angry, afraid, and upset.” From Cresswell (1998:289)

All interaction with participants will be ‘caring’ interaction.
6.11 Hermanowicz’s (2002) identification of vital interviewing information

The strategies I will employ during the interviewing sessions reflect Hermanowicz’s (2002) identification of vital information. The interview will be like a conversation: I will listen carefully to “hear” data … to have an “ear” for what the respondents are saying and focus on what my research participants finds important. In exploring to find meaning I will endeavour to discover what is important or unimportant to the research participants in their search for meaning. Searching for meaning is a major reason to use interview method and qualitative methods generally.

I will sometimes remain quiet when the research participant is quiet.

The ‘silent probe’ will mean that I will need patience to giving the research participant time to consider the issue and make a response. A characteristic of PWABI is they frequently have a one track mind, and can give more thoughtful responses than people in general (who can perhaps think of a dozen ‘off the top’ surface answers to a question) – when the PWABI will ponder for a long time to really deeply consider the issue. If they are having particular difficulty with a concept I will re-state or re-phrase the question, and then sit quietly until they open up.

To find a way to someone’s ‘core’ I will need discuss issues and ask sub-questions before I get to the ‘probe questions’ where I ask them about coping strategies. I will need to be creative and flexible, and willing to ask questions in different ways - re-stating, re-phrasing, and recasting them, sometimes in different tones of voice. The goal is to get respondents to open up, to convey detailed meaning; this will usually happen by being persistent and patient.

I will appeal to the altruism of the participants asking them to help me and other PWABI. Most people want to be helpful, they have agreed to be interviewed, and they especially want to be helpful to other PWABI. I will ask: ‘Can you help me understand what you are saying?’ ‘I'm not sure I understand what you're saying, can you help me understand what it is like to have experienced this difficulty?’
The interview will be around 90 minutes in length with two breaks or more if needed. Most PWABI suffer from fatigue and grow tired after about 30 minutes. When they are tired they will not be as forthcoming, detailed, or candid.

The interview open questions have been clearly devised.

The interview will be structured by questions that are well sequenced, strategically organised and planned. Given questions within a topic will anticipate the next question, so there will be a progression and flow to the conversation. In sequencing questions the interview will always end on a positive note.

The conversation will be divided into separate stages. Both Keys to the ABI Cage and Handy Thinking Tools have been developed for this purpose.

Interviews will be audio taped. Categories of questions are sequenced. They will be separated by cards/objects in Keys to the ABI Cage. In Handy Thinking Tools - areas are divided. The sections will have specific names (see Keys to the ABI Cage and in Handy Thinking Tools). These sections - like the questions - follow a progression of heating up and then cooling down.

I will take simple notes with large writing – to allow the participants to see ideas they have put forward. I will explain this as a strategy to help me with my memory difficulties.

Care will be taken when dealing with sensitive confronting issues - questions that tap into the disappointments, let downs, private worries, dreams and aspirations; the content of the inner core.

During the process all conduct, both formal and informal, spoken and unspoken will be courteous and respectful. Maintaining a sense of equality, but at the same time I will run the interview, asked questions and so on. I realise there will be real difficult stopping some respondents when they want to dwell too long on an issue. I will have to find a way to redirect the respondent; to get them back on course.
Keys to the ABI cage and Handy Thinking have been developed to show respect to the respondents. Respect extends a courtesy and thereby acknowledges the dignity of people interviewed.

Questions will be constantly reviewed to determine if they get participants to open up and if they elicit the right kind of information.

I will start off on a strong note by reading the introductions to the research participants to:

a. Tell the respondent what the study is about in slightly more detail than discussed the previous times.

b. Tell them that some questions will ask them to think about themselves and how they cope.

c. Inform them of their rights, and get their consent to record the interview.

I will read the instructions to: ensure all of the points are covered and convey what the study is about and so that the respondent takes it seriously. This will also help to define what I will be looking for and lead to a candid frank discussion.

I will end on a positive note with ‘Cool down’ questions for the respondent and conclude with an effusive, sincere thank you at the end: ‘You've been so helpful; I really appreciate the time you've taken to talk with me. Thank you very much.’

I will send a thank you note and a small token gift to convey additional respect; and help me to preserve the field and method of enquiry for others who follow.

I will record findings of insights gained both during and immediately after the interview. With my memory difficulties information is readily lost if not noted. Note-taking will be kept to a minimum during interviews but will be utilized as a tool to allow participants to revisit what they have said. I will write also write field notes (a written storm of mental activity of all of the many thoughts, impressions, hints, possibilities, and suggestions that arise from the interview) immediately upon returning from the field. These notes will stimulate subsequent thinking as I attempt to assemble pieces of the research puzzle.
I will ask participants permission to tape record. This will allow review of the narrative itself, intonation, nuance, meaning and sequence. Some people may feel uncomfortable being tape recorded but I will inform them about how I intend to use the recording, and its benefit in maintaining accuracy, that they will always remain anonymous, and that subsequently the tape will be stored in a locked cabinet for five years then destroyed. Some might feel nervous or be distracted by the recorder, but I will reassure them and hope that most people quickly forget the recorder is even there.
INSTRUCTIONS FOR CD

Dear fellow ABI sufferer,

Thank you for your help.

It will be so good to try to understand what ABI means to you.

INSTRUCTIONS:

1. Turn off the music, shut the door, make sure you are not distracted.

2. Place the CD in the CD compartment of your computer.

3. Please look at the pictures, listen to and read the words. At the end of each slide think for a little while, then push the down arrow to move to the next slide.

4. Once you have gone through the program once (or more if you like) it is time for you to go through the program and stop and write on the four sheets ‘What ABI means to me’.

Take your time, stop if you are tired, come back when you have had a rest. Think about your experience of ABI and tell us about it.

You could ask someone who cares for and supports you to help you write on the sheets if you wish.

You might want to answer just one sheet a day, or try to write a bit on each sheet on one day, then think about what you have written and write some more thoughts another day.

5. When you have finished please put the sheets in the stamped self addressed envelope and send it to Chris within a week. She is really looking forward to reading your ideas.

Chris will ring you to thank you for your time and help and to make sure all has gone well.

Note: If you feel sad thinking about your experiences talk to someone you care for or you could ring Lifeline on 13 11 14 24 hours a day, or Griefline 03 9596 7799 12, or Dr. X at X University X (9am-5pm Monday to Friday) or Chris on X and leave your name and number and she will return your call.
6.13 ‘What ABI means to me’ sheets to fill in after viewing the CD - for people with brain injury

WHAT ABI MEANS TO ME SHEET 1

My name………………………………………………………………………

Differences and difficulties that have PUT me in the ‘ABI Cage’

How my life is different to how it was before my ABI:

My difficulties include:

Note: If you feel sad thinking about your experiences talk to someone you care for or you could ring Lifeline on 13 11 14 24 hours a day, or Griefline 03 9596 7799 12, or Dr. X at X University X (9am-5pm Monday to Friday) or Chris on Xand leave your name and number and she will return your call.
WHAT ABI MEANS TO ME SHEET 2

My Name:........................................................................................................

How I feel about my differences and difficulties can lock me in the ‘ABI Cage’

How I feel about living with ABI:

Note: If you feel sad thinking about your experiences talk to someone you care for or you could ring Lifeline on 13 11 14 24 hours a day, or Griefline 03 9596 7799 12, or Dr. X at X University X (9am-5pm Monday to Friday) or Chris on X and leave your name and number and she will return your call.
WHAT ABI MEANS TO ME SHEET 3

My name:………………………………………………………………………

‘Keys’ that have ‘unlocked’ my ‘ABI cage’.

Things that help me cope with ABI include:

Note: If you feel sad thinking about your experiences talk to someone you care for or you could ring Lifeline on 13 11 14 24 hours a day, or Griefline 03 9596 7799 12, or Dr. X at X University X (9am-5pm Monday to Friday) or Chris on X and leave your name and number and she will return your call.
My name………………………………………………………………………..
Information from health professionals that has been helpful:

What information from health professionals would have been helpful?

Note: If you feel sad thinking about your experiences talk to someone you care for or you could ring Lifeline on 13 11 14 24 hours a day, or Griefline 03 9596 7799 12, or Dr. X at X University X (9am-5pm Monday to Friday) or Chris on X and leave your name and number and she will return your call.
My name……………………………………………………………….

My 3 Wishes

If I could have 3 wishes to change 3 things about my brain injury
those three things would be:

1..............................................................................................................
.............................................................................................................
..............................................................................................................

2..............................................................................................................
.............................................................................................................
..............................................................................................................

3..............................................................................................................
.............................................................................................................
..............................................................................................................

.............................................................................................................

Note: If you feel sad thinking about your experiences talk to someone you care for or you could ring Lifeline on 13 11 14 24 hours a day, or Griefline 03 9596 7799 12, or Dr. X at X University X (9am-5pm Monday to Friday) or Chris on X and leave your name and number and she will return your call.
6.14 Evaluation sheet

WHAT ABI MEANS TO ME FEEDBACK SHEET

My name…………………………………………………………………………………..

Could you please give us some feedback on ‘Keys to the Cage’?

1. When you received this CD did you want to understand more about your ABI?   YES   NO

2. Did ‘Keys to the ABI Cage’ help you think things through and understand more about your ABI?   YES   NO

3. Was ‘Keys to the ABI Cage’ an interesting way to do this?   YES   NO

4. What could improve this CD?

..................................................................................................................

..................................................................................................................

..................................................................................................................

..................................................................................................................

..................................................................................................................

THANK YOU FOR YOUR HELP. PLEASE POST THESE SHEETS TO ME. I WILL RING YOU WHEN I RECEIVE THEM. CHIRS DURHAM

98
6.15 Some more thoughts sheet

‘SOME MORE THOUGHTS’ SHEET TO FILL AND SEND TO CHRIS DURHAM IN THE ENCLOSED STAMPED SELF ADDRESSED ENVELOPE

My name is……………………………………………………………………

I have been thinking some more about what we discussed at my interview. Here are some more thoughts I have had:

Note: If you feel sad thinking about your experiences talk to someone you care for or you could ring Lifeline on 13 11 14 24 hours a day, or Griefline 03 9596 7799 12, or Dr. X at X University X (9am-5pm Monday to Friday) or Chris on X and leave your name and number and she will return your call.
‘Keys to the ABI Cage’ sheet with counselling list and my contact to be given to participants at conclusion of interview

Acquiring Better Insight into Acquired Brain Injury

Thank you for sharing your thoughts with me.

Remember we discussed the many ‘keys’ that can help us escape from the ‘ABI Cage’ some of the suggestions were:

Hope, love, family, friends, knowledge, wisdom, sense of humour, stretching outside my comfort zone, effort, information, time, proof (what other people with brain injury have done), curiosity, encouragement, religion, music, sunshine, nature, understanding and being kind to myself – be my own best friend rather than my own worst enemy.

If you feel sad thinking about your experiences talk to someone you care for or you could ring Lifeline on 13 11 14 24 hours a day, or Griefline 03 9596 7799 12, or Dr. X at X University X (9am-5pm Monday to Friday) or Chris on X and leave your name and number and she will return your call.
Table 6.1 Procedures/Steps in acquiring data

<table>
<thead>
<tr>
<th>PWABI Groups A, B, C, D</th>
<th>STEP 1 Recruitment of participants</th>
<th></th>
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</thead>
<tbody>
<tr>
<td></td>
<td>What?</td>
<td>How?</td>
</tr>
<tr>
<td>1.1 Phone call – silent landline</td>
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<tr>
<td></td>
<td></td>
<td>a) Durham phones organizations to introduce study and gain interest.</td>
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<td></td>
<td></td>
<td>b) If interest is expressed inform them Durham will send letter with greater detail, and advertisement.</td>
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<td></td>
<td></td>
<td>c) Durham compiles data on organizations, key contact people, suggestions they may make etc.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>d) Durham asks if the organization would provide a meeting room that could be used for Durham to conduct interviews</td>
</tr>
<tr>
<td>1.2 Letter sent to organizations asking them to:</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>a) advertise in newsletter</td>
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<tr>
<td></td>
<td></td>
<td>b) advertise on website</td>
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<td></td>
<td></td>
<td>c) ask people via personal contact – people involved with</td>
</tr>
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<td></td>
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<td></td>
</tr>
<tr>
<td>1.3 Potential participants phone Durham – leave name and number at University xxxx Durham will return their call on silent landline</td>
<td>organization directly</td>
<td>directly and then give them the ad so they remain anonymous</td>
</tr>
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<tr>
<td>a) Phone conversation about study – explanation about study, what it is, reason for study.</td>
<td>As PWABI have memory problems within three days Durham will send:</td>
<td>a) Letter with plain language statement</td>
</tr>
<tr>
<td>b) Exclusion criteria mentioned</td>
<td>b) Consent, and time date place form sent to groups 1 and 2</td>
<td>b) Consent, and time date place form sent to groups 1 and 2</td>
</tr>
<tr>
<td>so time and energy not wasted. These should include that for carers they are not related to anyone else taking part in the study.</td>
<td>c) Consent form for group 3 CD only</td>
<td>c) Consent form for group 3 CD only</td>
</tr>
<tr>
<td>c) Permission to tape record necessary.</td>
<td>d) Place of interview – Durham will meet them at their home or in a suitable place of their choosing where comfortable.</td>
<td>d) Place of interview - Durham will meet them at their home or in a suitable place of their choosing where comfortable.</td>
</tr>
<tr>
<td>d) Clarify witness</td>
<td>e) If they require support feel free to bring someone with them.</td>
<td>e) If they require support feel free to bring someone with them.</td>
</tr>
<tr>
<td>e) 3 groups of PWABI – Group 2 and 3 need computer skills.</td>
<td>f) With memory difficulties etc they need letter with info PLS so they don’t feel concerned/ unsure of what was discussed. Also can explain it to husband/wife when they get home.</td>
<td>f) With memory difficulties etc they need letter with info PLS so they don’t feel concerned/ unsure of what was discussed. Also can explain it to husband/wife when they get home.</td>
</tr>
<tr>
<td>If no computer skills group 1 or survey group.</td>
<td>g) Knowing the difficulty of getting forms signed etc</td>
<td>g) Knowing the difficulty of getting forms signed etc</td>
</tr>
<tr>
<td>f) If computer skills participant suggests which group they would be interested in, – interview and CD or CD only.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>g) Durham lists people, phone number, email, address, computer, computer skills, suggested meeting</td>
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</tbody>
</table>
| 1.4 Durham posts them letter | a) Durham posts letter with PLS including they will be informed whether in study or not with a month.  
   b) Consent, permission to tape record, time date and place, witness form to sign and return to Durham in stamped, self  
| place People invited to participate.  
   h) Durham tells them they will be sent a letter setting out all that has been discussed during phone call.  
   i) If they are interested in the study they should sign the consent, permission to tape record sheet and return to Durham within a week.  
   j) They will be notified within a month whether they will or won’t be involved.  
   k) Explanation about signing and returning consent form, permission to tape record, date, time and place form  
   l) Clarify witness believe if they are willing to returned signed forms is a good ‘filter’ to say will put the effort/are capable for interview.  
   h) If there are too many applicants who have gone to the effort of ringing Durham, filling in and returning forms can’t just say “You’re not wanted”. They will be Group 4 and be sent the sheets “What ABI means to me” that will be sent to Groups 2 and 3 - without the CD. May/may not use this data – but they will not feel rejected and will feel pleased included.  
|  a) To determine if they can understand what will be involved in the study.  
   b) If they forget what was discussed have material to revisit.  
   PLS and Consent Form stress statement ‘if you disclose something illegal or that they intend to harm See Appendix 5A: letter with PLS They will be informed whether in study or not with a 4 weeks maximum.  
   b) See Appendix 5A: consent, permission to tape record, SUGGESTED time date and place, (final sheet will be sent after selection) witness form to sign |
<table>
<thead>
<tr>
<th>Step 2 Selection of participants Interviews only</th>
<th>What?</th>
<th>How?</th>
<th>Ethics issues and solutions</th>
<th>Action</th>
</tr>
</thead>
<tbody>
<tr>
<td>2.1 Selection of participants</td>
<td>Participants chosen from notes taken during phone call (Appendix 4c) also they: a) have said robust/not going though a difficult time b) they have not become upset during phone call c) no court case in 2009 d) spread of – age, sex. Time since the ABI e) 2 or 3 'understudies' – people who might be included if</td>
<td></td>
<td></td>
<td>Appendix 5a: Consent, permission to tape record, Date, time place, witness form  See Appendix 4c: Notes taken during phone conversation Appendix letter PLS</td>
</tr>
</tbody>
</table>
| 2.2 Phone call Durham calls them on a silent landline | All participants called  
Thanked for interest.  
If successful told to expect confirmation letter. Letter will explain if they will have interview, interview and CD, CD only, questionnaire only.  
b) discuss date time and place |
<table>
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<tbody>
<tr>
<td>2.3 Confirmation letter sent</td>
</tr>
<tr>
<td>2.4 Phone call day before interview On silent landline</td>
</tr>
</tbody>
</table>

some of the participants have to pull out due to ill health etc  
f) Location suitable for Durham to travel to or area where two interviews could be conducted in one day.
## Step 3. The Interview

<table>
<thead>
<tr>
<th>What?</th>
<th>How?</th>
<th>Ethics issues and solutions</th>
<th>Action</th>
</tr>
</thead>
<tbody>
<tr>
<td>3.1 The Interview</td>
<td>a) Durham meets them at agreed venue</td>
<td>a) Tape recording – tell them how tapes stored, destroyed, Confidentiality discussed</td>
<td>Appendix 3: Research methods: Semi structured interview Page 55: Data analysis p.</td>
</tr>
<tr>
<td>Groups 1 and 2</td>
<td>b) Put them at their ease</td>
<td>PLS and Consent Form stress statement 'if you disclose something illegal or that they intend to harm themselves or others' - Durham has a duty to report them to RMIT and the interview will be terminated.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>c) give them copy of signed Consent Form</td>
<td></td>
<td>If disclosure of name etc made Durham states the informed consent sheet statement and confirms that they take it these are fictitious names etc.</td>
</tr>
<tr>
<td></td>
<td>d) Goes through PLS, signed consent and permission to tape record form, clarify witness.</td>
<td></td>
<td>If it a threat the interview should be suspended as quickly as possible.</td>
</tr>
<tr>
<td></td>
<td>e) Explain interview will cease if disclose something illegal or if intend to harm self or others</td>
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<td></td>
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<tr>
<td></td>
<td>f) Discuss options: ABI Cage, Handy Thinking about ABI, Handy Thinking about problem, story of 'fictional' PWABI</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3.2 The Interview</td>
<td>Watch for signs of discomfort, emotional distress: People not</td>
<td>a) Ask them if they wish to continue – remind them they can withdraw at any</td>
<td></td>
</tr>
</tbody>
</table>
| 3.3 The Interview | a) Given self addressed envelope and sheet to send Durham 'some more thoughts'.  
b) Given sheet with 'Keys to the ABI Cage' contacts for counselling and Durham’s contact  
c) told to contact Durham if experiencing difficulties. | b) Remind them about counselling  
c) Will give them information at conclusion | a) Appendix 5D: ‘Some more thoughts’ sheet  
b) Appendix 5G: ‘Keys to the ABI Cage’ sheet including Durham's contact numbers and list of counsellors including RMIT Psychology |
| 3.4 After the interview | a) Phone call the next day  
b) Thank you card sent  
c) Phone call the following week | | Appendix 5F: Thank you letter |

### Group B CD and Interview

<table>
<thead>
<tr>
<th><strong>What?</strong></th>
<th><strong>How?</strong></th>
<th><strong>Ethics issues and solutions</strong></th>
<th><strong>Action</strong></th>
</tr>
</thead>
</table>
| Step 1 and 2 as before  
Recruitment, selection, consent | Recruitment, selection, signed consent, permission to tape record, date place and time form | As before | As before |
| forms as before | returned to Durham as before… These participants have a computer and can insert a CD | Steps 1-2 as before Participants return completed sheets in stamped self addressed envelope | a) Letter, instruction sheet and sheets to fill in sent  
b) CD sent  
c) Participants given a period of two weeks consider the CD  
d) List of support organizations and Durham’s contact number  
P) list of support organizations and Durham’s contact number |
|---|---|---|---|
| 2.1 Selection of participants Participants chosen from notes taken during phone call (Appendix 4c) They must have computer and computer skills, also they:  
a) have said robust/not going though a difficult time  
b) they have not become upset during phone call  
c) no court case in 2009  
d) spread of – age, sex. Time since the |  |  | a) See Back cover of Thesis: CD – power point with voice-over  
b) See Appendix 5E: Instruction sheet  
c) Stamped self addressed envelope for return of sheets  
d) Reminder sheet with interview dates and times (send back with consent sheet)  
e) List of support organizations and Durham’s contact number |
| | | | Appendix 5A: Consent, permission to tape record, Date, time place, witness form  
See Appendix 4C: Notes taken during phone conversation  
Appendix letter PLS |
ABI

e) 2 or 3 'understudies' – people who might be included if some of the participants have to pull out due to ill health etc

f) Location suitable for Durham to travel to or area where two interviews could be conducted in one day.

| 2.2 Phone call - silent land line | All participants called
Thanked for interest.

If successful told to expect confirmation letter. Letter will explain if they will have interview and CD, CD only, or questionnaire only.

b) discuss date time and place |

| 2.3 Confirmation letter sent | Confirmation, date time place sent. See Appendix 5e
See Appendix 5B: Instructions for CD |

| 2.4 CD and instructions sent | CD and instructions sent
See Appendix 5E: Instructions |
### 2.4 ‘What ABI means to me’ sheets returned to Durham

| Durham reflects on information to modify interview | Follow-up phone call after Durham has received the completed returned sheets. If participant is experiencing difficulties and cannot share these issues and resolve them… contact Durham and support can be provided within 24-hours. | See Appendix 5C: ‘What ABI means to me’ sheets | Reminded of the list of support organizations |

### 2.5 Phone call day before interview - silent landline

| Durham rings them the day before the interview to remind them of the interview | Interview Same as before… | Same as before… 4 questions and evaluative questions |

### GROUP C PWABI CD only

<table>
<thead>
<tr>
<th>What?</th>
<th>How?</th>
<th>Ethics issues and solutions</th>
<th>Action</th>
</tr>
</thead>
<tbody>
<tr>
<td>Steps 1, 2, 3 as before Recruitment, selection, Sent letter with PLS. Signed consent form returned to Durham</td>
<td>As before…</td>
<td>As before….</td>
<td>As before….</td>
</tr>
</tbody>
</table>
| 4.1 CD, instructions and 'What ABI means to me' sheets sent to participants | CD and Instruction sheet sent to participants | a) See Appendix 5E: instructions for CD  
b) See Appendix 5C: ‘What ABI means to me’ sheets  
c) Stamped self addressed envelope for return of sheets  
d) Reminder sheet with interview dates and times (send back with consent sheet)  
e) List of support organizations and Durham’s contact number |
<table>
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</thead>
<tbody>
<tr>
<td>4.2 Participants post completed ‘What ABI means to me’ sheets to Durham</td>
<td>Participants post filled in sheets to Durham</td>
<td>Ethical issues – Emotions</td>
</tr>
</tbody>
</table>
| 4.3 Follow up phone call to check all is well – silent landline | Follow-up phone call after Durham has received the completed returned sheets.  
If participant is experiencing | |
difficulties and cannot share these issues and resolve them…contact Durham and support can be provided within 24-hours.

5. Thank you letter

<table>
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<tr>
<th>People who care for and support PWABI</th>
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**Step 1 Recruitment**

<table>
<thead>
<tr>
<th>What?</th>
<th>How?</th>
<th>Ethics issues and solutions</th>
<th>Action</th>
</tr>
</thead>
</table>
| 1.1 Durham rings ABI organizations - silent landline | a) Explains study  
Will send PLS and letter of explanation  
b) Durham asks if the organization would provide a meeting room that could be used for Durham to conduct interviews | | See Appendix 4B: Advertisement – same organizations to carry this ad  
See Appendix 4B: Plain Language Statement for family carers (exclusion criteria) |
| 1.2 Recruitment Letter sent to organizations | Letter sent to same organizations, same request for advertisement in  
a) newsletter  
b) webpage  
c) people contacted directly | | |
### 1.3 Participants

Phone conversation about study, what it is, and reason for study.

a) People invited to participate.

b) Permission to tape record necessary.

c) Some exclusion criteria mentioned so time and energy not wasted. These should include that for carers they are not related to anyone else taking part in the study.

d) Explanation about signing consent form, witness etc (such as you disclose something illegal or that you intend to hurt yourself or others or you have done so in the past.)

<table>
<thead>
<tr>
<th>PLS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Appendix 6A: Invitation letter/PLS, inclusion</td>
</tr>
</tbody>
</table>

### 1.4 Durham posts letter

a) Durham posts letter with PLS including they will be informed whether in study or not with a month.

b) Consent, permission to tape record, time date and place, witness form to sign and return to Durham in stamped, self

<p>| |</p>
<table>
<thead>
<tr>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>See Appendix 6A: letter with PLS They will be informed whether in study or not with a three weeks maximum.</td>
</tr>
</tbody>
</table>

<p>| |</p>
<table>
<thead>
<tr>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>b) See Appendix 6B: consent, permission to tape record, SUGGESTED time date and place, (final sheet will be sent after selection) witness form to sign</td>
</tr>
</tbody>
</table>
Step 2. Selection of participants

<table>
<thead>
<tr>
<th>What?</th>
<th>How?</th>
<th>Ethics issues and solutions</th>
<th>Action</th>
</tr>
</thead>
</table>
| 2.1 Selection of participants | Participants chosen  
a) have said robust/not going though a difficult time/ have not become upset during phone call  
b) the person they care for and support will not have a court case in 2009  
c) the person they care for and support will not be in the study  
d) spread of – age, sex. Time since the ABI  
e) 2 or 3 understudies’ – people who might be included if some of the participants have to pull out due to ill health etc | Fragile people excluded | See Appendix 4C: checklist filled out by Durham during phone conversation |
<table>
<thead>
<tr>
<th>Section</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>2.2 Phone call</td>
<td>All possible participants phone call and thanked for interest. If successful told confirmation and date time place will be sent</td>
</tr>
<tr>
<td>2.3 Selection of participants</td>
<td>Forms sent to participants letter, PLS, consent, permission to tape record form plus Date, time place form</td>
</tr>
<tr>
<td>2.4 Selection of participants</td>
<td>Signed consent, tape record Forms returned to Durham in stamped self addressed envelope</td>
</tr>
</tbody>
</table>

Appendix 6B: Confirmation, Date, time, place

See Appendix 6B: Confirmation, Consent, permission to photocopy, date, time, place
### 3. The Interview

<table>
<thead>
<tr>
<th>What?</th>
<th>How?</th>
<th>Ethics issues and solutions</th>
<th>Action</th>
</tr>
</thead>
</table>
| 3.1 The Interview | a) Durham meets them at agreed venue  
b) Put them at their ease  
c) Goes through PLS, signed consent and permission to tape record form, clarify witness and the fact that if they disclose something illegal or that they intend to hurt themselves or others or they have done so in the past Durham must report them and the interview ceases.)  
d) Discuss options: ABI Cage, Handy Thinking about ABI, Handy Thinking about problem, | a) Tape recording – tell them how tapes stored, destroyed,  
b) Confidentiality discussed  
PLS and Consent Form stress statement if you disclose something illegal or that they intend to harm themselves or others Durham has a duty to report them to RMIT and the interview will be terminated.  
If disclosure of name etc made Durham states the informed consent sheet statement and confirms that they take it these are fictitious names etc.  
If it a threat the interview should be suspended as quickly as possible. | Appendix 3  
Research methods - Semi structured interview  
Page Data analysis, Evaluation of the process |
<table>
<thead>
<tr>
<th>3.2 The Interview</th>
<th>Watch for signs of discomfort, regret, frustration, emotional distress: People not engaging, looking bored or confused, going red, looking elsewhere, shifting about.</th>
<th>a) Appendix 5D: 'Some more thoughts' sheet b) Appendix 5G: 'Keys to the ABI Cage' sheet including Durham's contact numbers and list of counsellors including RMIT Psychology</th>
</tr>
</thead>
<tbody>
<tr>
<td>Problems to watch for</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3.3 The Interview</td>
<td>a) Warmly thanked b) Invitation to contact Durham if need to c) Given stamped self addressed envelope for 'Some more thoughts' for further reflections d) Given sheet 'Keys to the ABI Cage' with counselling contacts, Durham's contact e) Durham takes pictures of their 'talk-about-cards' to send with thank you letter</td>
<td>a) Self addressed envelope with sheet for 'Some more thoughts' b) See Appendix 5D: 'Some more thoughts' sheet c) See Appendix 5G: 'Keys to the ABI Cage' sheet including Durham's contact numbers and list of counsellors including RMIT Psychology</td>
</tr>
<tr>
<td>Conclusion of semi-structured interview</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3.4 Thank You letter</td>
<td></td>
<td>See Appendix 6C: letter of appreciation And photos of 'talk-about-cards'</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
**Interviews with professionals and advocates who work with PWABI**

### Step 1 Recruitment

<table>
<thead>
<tr>
<th>What?</th>
<th>How?</th>
<th>Ethics issues and solutions</th>
<th>Action</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.1 Recruitment</td>
<td>as before…</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1.2 Recruitment</td>
<td>a) Phone conversation about study, what it is, and reason for study.</td>
<td></td>
<td>See Appendix 7A: Letter with PLS, See Appendix 4C: Checklist filled in by Durham during phone conversation</td>
</tr>
<tr>
<td></td>
<td>b) People invited to participate.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>c) Consent form and Permission to tape record form.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>d) Required for 90 minute presentation and workshop</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1.3 Recruitment</td>
<td>a) Letter with PLS sent including statement if disclose something illegal or that they intend to harm themselves or others Durham has a duty to report them</td>
<td>Confidentiality PLS and Consent Form stress statement if you disclose something illegal or that they intend to harm themselves or others</td>
<td>Appendix 4C: checklist occupation, years of experience, areas of interest/curiosity about empowering PWABI</td>
</tr>
</tbody>
</table>
1.4 Recruitment Professionals confirm interest in phone call or email to Durham

2.1 Selection of participants

<table>
<thead>
<tr>
<th>What?</th>
<th>How?</th>
<th>Ethics issues and solutions</th>
<th>Action</th>
</tr>
</thead>
<tbody>
<tr>
<td>2.1 Selection of participants</td>
<td>Durham compiles list of possible participants from return letter, email or from phone call</td>
<td>Spread of participants: age, experience, sex</td>
<td>Advise 2 understudies</td>
</tr>
</tbody>
</table>
### 2.2 Selection of participants

Phone call to all interested participants.

### 2.3 Selection of participants

Forms sent to participants. Letter, PLS, consent. See Appendix 7C Consent, permission to tape record, Date, time place form.

### 2.4 Selection of participants

Participants return forms to Durham.

---

**The Interview**

### Step 3.1 The Interview

<table>
<thead>
<tr>
<th>What?</th>
<th>How?</th>
<th>Ethics issues and solutions</th>
<th>Action</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) Durham meets them at agreed venue</td>
<td>b) Put them at their ease</td>
<td>c) Goes through PLS, signed consent and permission to tape record form.</td>
<td>PLS and Consent Form stress statement if you disclose something illegal or that they intend to harm themselves or others Durham has a duty to report them to RMIT and the interview will be</td>
</tr>
<tr>
<td>Witness. sent including statement if disclose something illegal or that they intend to harm themselves or others Durham has a duty to report them to RMIT and the interview will be terminated.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>---</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>d) Durham introduces the ‘ABI Cage’, Handy Thinking about ABI, Handy Thinking about problem</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>e) Discuss the above f) Evaluation</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>3.2 Thank you letter</th>
</tr>
</thead>
<tbody>
<tr>
<td>See Appendix 7E: Thank you letter for professionals and advocates</td>
</tr>
</tbody>
</table>
6.18 Ethical considerations regarding the three different groups of participants.

Appendix 6.17 provided an overview of ethical issues considered for the three groups of participants.

The inclusion/exclusion criteria of participants included the following ethical considerations:

- All participants should be willing to reflect on the ramifications of ABI without becoming too distressed.
- If a person with ABI is taking part in the study the person who cares for and supports them cannot take part in the study or vice versa

Inclusion/exclusion criteria for people with ABI:

- Participants should be able to understand the plain language statement about the study, and be able to participate meaningfully with words or actions.
- Participants must be between the ages of 19 and 60 years of age
- Participants must be willing to have the interview tape recorded. Tapes will be stored in a locked filing cabinet and destroyed after 5 years.
- If the participant acquired their ABI due to a motor vehicle or other accident and they have physical injuries, time needs to be allowed for them to heal physically. This will be discussed in the initial phone conversation with Durham.
- Participants should not be in a fragile state, stressed or in the midst of a crisis. Situations raised with the participants may bring to the surface difficult memories.
- Participants must not be awaiting a court case related to an accident associated with their ABI that is due in 2009.

As is usual, participants They were provided with a plain language statement and an informed consent sheet, though the consent process was less a single signing than a processual consent process (Cutcliffe and Ramcharan, 2002), the contents of the signed sheet was read and discussed prior to the interview.
Throughout the interview participants were observed for signs of discomfort—such as tears in the eyes, sweating, distancing, shifting about in the chair, long pauses, or becoming emotional. In some interviews participants became overwhelmed by their memories. They were allowed time to overcome their distress and I did not ask them to explain their distress, or divulge ‘secrets’ they referred to in passing.

I was supportive at all times: participants’ perceptions were believed - I did not quiz them nor ask for clarification but allowed them to lead the discussion.

I had the firmly held opinion that participation in this study should ‘do no harm’ and to be ethically responsible, and not make the participant feel ‘out of their depth’, ‘foolish’, or ‘stupid’ (as can be the result of being involved with some assessment tools) the following issues were considered in compiling the interview tool ‘keys to the ABI Cage’:
Table 6.2

‘Keys to the Brain injury Cage’ addressed issues identified in Chapters 1, 3, 4 and 5

<table>
<thead>
<tr>
<th>Tool was devised to:</th>
<th>How the tool addresses the issue</th>
</tr>
</thead>
</table>
| Demonstrate understanding  
Provide a caring atmosphere | 1. My brain injury and the advertisement, information sheet, phone calls and information on the talk-about cards’ demonstrated that I understood their difficulties /issues/ beliefs/ challenges |
|                      | 2. The atmosphere was kind and caring and interviews were conducted in a patient, non-hurried way |
|                      | 3. By physically holding a pile of ‘talk-about cards’ to place in a “DO” or “DON’T” box if participants were gently directed to move onto some of the other cards that had relevance for them. |
| The treatment of participants was positive | 4. The positive point of the whole exercise - identifying ‘keys’ that had helped them cope with their brain injury - was a valuable visual prompt |
|                      | 5. The method was encouraging, motivational, engaging, non-confrontational, |
|                      | 6. Participants were allowed to choose what they discussed making the tool organic. If new ideas were mentioned new talk-about cards were developed. |
7. The interview focused on the person – their courage, humour, determination and strengths were noticed and commented upon.

| The Tool itself | 1. Provided a novel way to discuss ideas in a positive way  
| | 2. It was an excellent discussion starter  
| | 3. As a prompt and it provided a framework to build ideas upon  
| | 4. Having the ‘talk-about-cards’ allowed participants to have a handy reminder of what they were talking about.  
| | 5. It was interesting that even if they had wandered from the topic on the card, the card mostly allowed them to retrace their thoughts.  
| | 6. It was engaging,  
| | 7. It was adaptable,  
| | 8. It had built-in success,  
| | 9. It was imaginative and contained an element of humour/fun,  
| | 10. It was non-threatening and non-confrontational,  
<p>| | 11. It motivated and supported them to |</p>
<table>
<thead>
<tr>
<th>Reflect,</th>
<th>12. It involved principles of active learning, multiple intelligences, different ways of learning/knowing and encouraged questioning</th>
</tr>
</thead>
<tbody>
<tr>
<td>The Tool addressed issues in a holistic manner.</td>
<td>The interconnectedness of the three stages provided a way to revisit and understand concepts</td>
</tr>
</tbody>
</table>
| To Tool was devised to address issues of power and who holds the power. | 1. Giving them a voice  
2. Giving the opportunity to tell their story  
3. They were in control/choice  
4. The tone of interview was of equals |
| To Tool was devised to address issues if they had unpleasant associations in a ‘tests like’ environment | 1. They were assured they were in control  
2. Non test-like  
3. Conducted in a public place – cafe – coffee – not like a test |
| Lack of confidence/fear of tests | 1. Being non-threatening  
2. Being non-confrontational  
3. Being told that I was aware it could be upsetting to remember  
4. Sense of humour with the objects |
| Too many tests | 1. This was something different  
2. It was an interesting way to think about things  
3. There were no right or wrong answers |
| Nervous to encounter another potentially ‘difficult’ situation. | 1. Obvious care and attention had been put into ‘Keys to the ABI Cage’ |
| Fear they will be told there is nothing wrong with them | Purpose of project explained several times in different ways |
| Fear lawyers or others in position of power will obtain copies of their ideas. | The anonymity of their participation along with the fact that all names would be changed in all documents was emphasized |
### Table 6.3 How the tool addressed issues around brain injury

<table>
<thead>
<tr>
<th>Issues identified in Sections Two and Three</th>
<th>How the tool addresses these issues</th>
</tr>
</thead>
<tbody>
<tr>
<td>Need for ‘education’ to understand brain injury and how to help self</td>
<td>The interview/learning tool encourages people to think about issues in a non-confrontational atmosphere</td>
</tr>
<tr>
<td>Can’t be bothered</td>
<td>Interesting, engaging, unusual, amusing</td>
</tr>
<tr>
<td>People at different levels</td>
<td>It can be understood by a variety of people on different levels</td>
</tr>
<tr>
<td>Frightened it’s something else I can fail at</td>
<td>No right or wrong answers – built in success for participants</td>
</tr>
<tr>
<td>Frightened I’ll forget what to do</td>
<td>Repetition of introduction and what is required in different ways – touching and looking at, discussing, CD, handling the talk-about cards</td>
</tr>
<tr>
<td></td>
<td>Prompts and reminders of experiences</td>
</tr>
<tr>
<td>Loss of status, pride, shame</td>
<td>Know that they are understood because I have brain injury</td>
</tr>
<tr>
<td>Busy ‘pretending’ to be ‘normal’</td>
<td>Opportunities provided to find positive things to comment upon – courage, sense of humour, ideas</td>
</tr>
<tr>
<td>Frightened of test</td>
<td>Not like a test</td>
</tr>
<tr>
<td>Disempowered, disenchanted, can’t be bothered</td>
<td>The atmosphere has been set up through information, 3 phone calls to make it encouraging, motivating. Participants appreciate the effort put into the model</td>
</tr>
<tr>
<td></td>
<td>Strategies built into the tool so that participants are encouraged and motivated to ‘bother’ to focus and concentrate on the interview.</td>
</tr>
<tr>
<td>Patient non hurried atmosphere</td>
<td></td>
</tr>
<tr>
<td>--------------------------------</td>
<td></td>
</tr>
<tr>
<td>Bored with tests</td>
<td></td>
</tr>
<tr>
<td>Active learning – participants actively engaged with process – handling cards, placing cards, telling stories</td>
<td></td>
</tr>
<tr>
<td>Prompts to support self reflection</td>
<td></td>
</tr>
<tr>
<td>Don’t want to face deficits/difficulties</td>
<td></td>
</tr>
<tr>
<td>Consider difficulties in order to identify things that have helped and things that can help in the future</td>
<td></td>
</tr>
<tr>
<td>Hopeful that their ideas can help others</td>
<td></td>
</tr>
<tr>
<td>People with brain injury may have negative self-talk. How can this be changed to positive self-talk?</td>
<td></td>
</tr>
<tr>
<td>The Cage depicts the importance of the ‘Keys’. In a rehabilitation setting people could write their own talk-about cards for what they say to themselves when for example they can’t walk properly, when they feel sad or frightened. They can keep these cards in a pocket to refer to.</td>
<td></td>
</tr>
</tbody>
</table>
### Table 6.4 How the tool addresses issues around testing

<table>
<thead>
<tr>
<th>Issues around testing</th>
<th>How the tool addresses these issues</th>
</tr>
</thead>
<tbody>
<tr>
<td>Power and who holds the power.</td>
<td>1. Participants were given the talk-about cards – they had the choice to talk if they wanted to</td>
</tr>
<tr>
<td></td>
<td>2. The cards were prompts to help them tell their story</td>
</tr>
<tr>
<td></td>
<td>3. They were the ‘experts’ in their experience</td>
</tr>
<tr>
<td></td>
<td>4. The tone of interview was friendly</td>
</tr>
<tr>
<td>Unpleasant associations in a ‘tests like’ environment</td>
<td>1. Assured they were in control</td>
</tr>
<tr>
<td></td>
<td>2. Non test-like</td>
</tr>
<tr>
<td></td>
<td>3. Public place – café – coffee – not like a test</td>
</tr>
<tr>
<td>Lack of confidence/fear of tests</td>
<td>1. Cage was different and non-threatening</td>
</tr>
<tr>
<td></td>
<td>2. Non-confrontational – they were allowed to choose</td>
</tr>
<tr>
<td></td>
<td>3. Cards proved that I was aware of difficulties and that it could be upsetting to remember</td>
</tr>
<tr>
<td></td>
<td>4. Sense of humour with the objects</td>
</tr>
<tr>
<td>Too many tests</td>
<td>1. Different</td>
</tr>
<tr>
<td></td>
<td>2. Interesting</td>
</tr>
<tr>
<td></td>
<td>3. No right or wrong answers</td>
</tr>
<tr>
<td>Nervous to encounter another potentially ‘difficult’</td>
<td>1. Obvious care and attention put into ‘Keys to the ABI Cage’</td>
</tr>
<tr>
<td>situation.</td>
<td>2. I had ABI – I would understand</td>
</tr>
<tr>
<td>Fear they will be told there is nothing wrong with them</td>
<td>Purpose of project explained several times in different ways</td>
</tr>
</tbody>
</table>
Fear lawyers or others in position of power will obtain copies of their ideas. The anonymity of their participation along with the fact that all names would be changed in all documents was emphasized.

### Table 6.5  How the tool addressed issues around memory

<table>
<thead>
<tr>
<th>Issues around ABI difficulties</th>
<th>How the tool addresses these issues</th>
</tr>
</thead>
<tbody>
<tr>
<td>Shame</td>
<td>Kind understanding atmosphere</td>
</tr>
<tr>
<td></td>
<td>Strengths and ways to help self stressed</td>
</tr>
<tr>
<td>Memory problems – forget what doing</td>
<td>Repetition of introduction and what is required in different ways – touching and looking at, discussing, CD, handling the talk-about cards</td>
</tr>
<tr>
<td></td>
<td>Talk-about cards - Prompts and reminders of experiences</td>
</tr>
<tr>
<td>Memory – forget what problems are</td>
<td>Talk-about cards</td>
</tr>
<tr>
<td>Lack of self-awareness</td>
<td>Talk-about cards</td>
</tr>
<tr>
<td>Participants may experience difficulty answering questions.</td>
<td>Talk-about cards</td>
</tr>
<tr>
<td></td>
<td>‘Do’ or ‘Don't' boxes</td>
</tr>
<tr>
<td>Some people blame people with brain injury for their injury</td>
<td>Treated with kindness, understanding and empathy.</td>
</tr>
<tr>
<td>People with brain injury may blame themselves for their ABI</td>
<td>Treated with kindness, understanding and empathy.</td>
</tr>
<tr>
<td>Reality may be skewed due to ‘faulty thinking’</td>
<td>Kindness – acceptance of their ideas but offered ‘keys’ to help</td>
</tr>
<tr>
<td>Difficulty staying on track, or staying fixed on a specific concern and not moving on.</td>
<td>Cards and Handy Thinking were used to nudge participants forward</td>
</tr>
</tbody>
</table>
Table 6.6  How the tool addressed issues around language processing

The tool encouraged reflection using speech, reading, writing, signs, gestures, facial expressions, body language, physical movement and physical contact. (Rees, 2005:128).

<table>
<thead>
<tr>
<th>Issues around language processing problems</th>
<th>How the tool addresses these issues</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Effective orientation and attending be achieved</td>
<td>It uses visual as well as auditory input to conjointly support language and comprehension. Uses pictures, reading and writing to enhance receptive and expressive language.</td>
</tr>
<tr>
<td>2. Difficulties of language processing (Rees 2005:132)</td>
<td>i) See the word, hear the word, read the word, see the picture.</td>
</tr>
<tr>
<td>i) Lexical - vocabulary difficulties involving access to words and content:</td>
<td>ii) Simple sentences used, hearing and seeing at the same time, repetition of sentences used, ‘talk-about’ cards used – understanding of sentence not needed.</td>
</tr>
<tr>
<td>ii) Syntactic – grammar difficulties in relation to structure of a phrase, clause and sentence</td>
<td>iii) Understanding assisted by setting the scene and the context</td>
</tr>
<tr>
<td>iii) Discourse – difficulties in relation to context and function of language in different contexts</td>
<td></td>
</tr>
<tr>
<td>Difficulties in receptive and expressive language.(Rees 2005:132)</td>
<td>Participants have process modelled several times before they engage in it. They were given plenty of time to understand and respond: One to one discussion allowed time and space for considered response. Cage will help them attend, participate and respond in their own time</td>
</tr>
<tr>
<td>People with brain injury ‘get lost’</td>
<td>Cage will facilitate orientation and attending, providing cues and modelling of responses,</td>
</tr>
</tbody>
</table>
‘Talk-about’ cards provide cues and modelling of responses. Participant prepared for topics of discussions before each section – told what they will be told about, told the information, asked to respond to the information by writing their own ‘talk-about’ cards. Reminders of what topic is being looked at by the Cage and the talk-about cards should minimise ‘getting lost’.

Communication may need to be supported and sustained throughout the process of the involvement with the study (interview or CD)

By giving them confidence because they are supported through their reflection and problem solving processes. They will progress from easier tasks to harder tasks requiring greater reflection. e.g from simply identifying physical difficulties ‘Difficulty walking, talking’ etc to reflecting on their feelings and emotions to the third category – ‘Keys’ – where they reflect on previous success with the simpler tasks should help them to gain confidence. They will receive cues that they can do the tasks.

There is a sense of humour/imagination built into the whole process.

There is a structure that defines the ‘beginning, middle and end’ of the interview/CD process.

The process ends on an enjoyable note. They have contributed to helping others with ABI.

Learning requires ‘readiness’. How can ‘readiness’ be supported?

The Cage and cards prompts and guides them to consider positive things - they see the Cage, view the CD, and are ‘talked through’ the steps. This supports readiness and participation in problem solving, along with successive repetitions, is a function of ‘broad tuning’. (Rees, 2005 p.228)
| Lack of motivation, fear of trying something new and failing. How can participants be motivated to engage with the ‘Keys to the ABI Cage’? | By preparing them for the task ahead, modelling, showing them the Cage in an interesting and fun way.  
The participants will be encouraged to feel they have something worthwhile to contribute to help other people with brain injury.  
Success is guaranteed and no comment is ‘wrong’ – and each successive step should develop greater motivation to achieve ‘success’.  
‘Talk-about’ cards are in simple easy-to-understand language and the goal of the process is apparent throughout the process. |
|---|---|
| People with brain injury may experience difficulty reflecting and problem solving | Ideas and examples are introduced in a ‘rehearsal’ of the process.  
Then the participant engages with the material and information and puts forward their own personal views. As the ‘talk-about’ cards are assembled they have the opportunity to review their thoughts and determine if they have further ideas to add. (Rees 2005, p239)  
They will be given a sheet to take home to record ‘further thoughts’. |
<table>
<thead>
<tr>
<th>Language processing difficulties</th>
<th>How the tool addressed these issues</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unsure of what to expect</td>
<td>Process modelled twice before they are involved</td>
</tr>
<tr>
<td>Easily confused</td>
<td>Clearly set out</td>
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<td>Easily confused</td>
<td>No confusing extra information</td>
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<tr>
<td>Comprehension difficulties</td>
<td>Simple language</td>
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<tr>
<td>Difficulty concentrating</td>
<td>Brief segments - short clear information/directions</td>
</tr>
<tr>
<td>Engagement/attention difficulties</td>
<td>Stories used</td>
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<td>Engagement/attention difficulties</td>
<td>Illustrations/Objects/pictures/clear symbols used</td>
</tr>
<tr>
<td>Afraid of new situations</td>
<td>Language/tone treats participants with respect</td>
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<tr>
<td>Do not understand medical terms</td>
<td>Voice/learning culture/writing style - informal</td>
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<tr>
<td>May feel powerless</td>
<td>Inspires them and motivates and encourages them to learn – keep stating</td>
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<td>Unsure</td>
<td>Starts with simple and becomes more involved</td>
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<tr>
<td>Slower at thinking and word finding</td>
<td>Participants were given thinking time and space to process information</td>
</tr>
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</table>
6.19 The RMIT HREC ethics submission approval letter was dated 27th April 2009

Phone: 9925 2251
Fax: 9925 2387
peter.burke@rmit.edu.au

27 April 2009

Christine Durham
28 Porter Street
ELTHAM VIC 3095

Dear Christine

Project No 04/09: Acquiring better insight into Acquired Brain Injury (ABI)

I am pleased to advise that this project is now approved by the Human Research Ethics Committee for the period from the date of this letter until 31 December 2010. The project has been classified as level 3 as it involves higher risks to the participants than discomfort or inconvenience.

Responsibilities of primary investigator
It is important to emphasise that primary investigators are responsible for ensuring that the project proceeds according to the proposal approved by the Human Research Ethics Committee. The Committee’s approval of the project is not absolute. New and unforeseen ethical issues may arise. A researcher should continue to consider the ethical dimensions of the research as the project progresses.

Adverse events or unexpected outcomes
As the primary investigator you have a significant responsibility to monitor the research and to take prompt steps to deal with any unexpected outcomes. You must notify the Committee immediately of any serious or unexpected adverse effects on participants, or unforeseen events, which may affect the ethical acceptability of your project. Any complaints about the project received by the researcher must be referred immediately to the Ethics Officer.

Reporting
Approval to continue a project is conditional on the submission of annual reports (see attached sample form). A final report should also be provided at the conclusion of the project. If your work is completed within twelve months a final report only is required. Report forms are available from the Human Research Ethics Committee web site: (http://www.rmit.edu.au/research/hrec_apply).
Please note that failure to submit reports will mean that a project is no longer approved, and/or that approval will be withheld from future projects.
Conditions of approval
The Human Research Ethics Committee may apply additional conditions of approval beyond the submission of annual/final reports.

Conflicts of interest
When reporting the research, the researcher should again disclose any actual or potential conflicts of interest, including any financial or other interest or affiliation that bears on the research. Conflicts of interest can arise after a project has been approved, and where they do they must be reported as soon as possible.

Amendments
If, as you proceed with your investigation you find reason to amend your research method, you should advise the Human Research Ethics Committee and seek approval for the proposed changes. If you decide to discontinue your research before its planned completion you must also advise the Committee of this and of the circumstances. Depending on the type of amendment — whether it is minor or major — will determine how long the review process for an amendment will take.

Storage of Data
All data should normally be stored on University Network systems. These systems provide high levels of manageable security and data integrity, can provide secure remote access, are backed up on a regular basis and can provide Disaster Recovery processes should a large scale incident occur. The use of portable devices such as CDs and memory sticks is valid for archiving, data transport where necessary and some works in progress. The authoritative copy of all current data should reside on appropriate network systems; and the principal investigator is responsible for the retention and storage of the original data pertaining to the project for a minimum period of five years.

If you anticipate any problems in meeting this requirement please contact me to discuss an alternative secure data storage arrangement.

All reports or communication regarding this project is to be forwarded to the Ethics Officer.

On behalf of the Human Research Ethics Committee I wish you well with your research.

Yours sincerely

Peter Burke
Ethics Officer
RMIT Human Research Ethics Committee

cc: Dr Paul Ramcharan
6.20 The RMIT HREC ethics submission approval letter was dated 8th October 2009

8 October 2009

Dr Paul Ramcharan
Co-ordinator of Research and Policy
Australian Centre for Human Rights and Education
Building 98
102 Victoria Street
CARLTON

Dear Paul

Amendments to project No 04/09: Acquiring better insight into Acquired Brain Injury (ABI)

Thank you for your letter dated 22 September 2009 regarding the proposed amendments to the above project. These proposals were considered at the recent Human Research Ethics Committee meeting and I am pleased to report that the changes were reviewed and approved. It was also recommended that the suspension of the project be lifted so that the research may continue.

On behalf of the Human Research Ethics Committee I wish you and Chris well for the research.

Yours sincerely

Peter Burke
Ethics Officer
RMIT Human Research Ethics Committee

cc: Christine Durham
28 Porter Street
ELTHAM VIC 3095
APPENDIX CHAPTER 7

Summary audit trail of factors that have a negative effect on the lifeworld of the person with ABI.

7.1 People with ABI

Lost of identity: the phenomena of the ‘new’ and ‘old’ me: Comparisons Loss of ‘self’ and the ‘old’ me

“I think differently to what I used to and I notice that and I notice it every day.”

“There’s confusion.”

“I’ve lost the plot.”

“I can’t remember where I live, my children’s names, how old I am.”

“I miss the old me because I think humans find it much easier not to change. I think brain injury is change to the power of 93.”

“Every day is a new beginning, but I still feel so far away from my old self…”

“… the frustration of not knowing who I am, and the lack of understanding of brain injury.”

“… I don’t know if I’m unlucky or… have I done something wrong, or is it karma… I don’t know, why have I had… like, no-one has so much bad luck, no-one… so I don’t know if I’m unlucky or not.”

“I wish I could have one more day without a brain injury just to be the person that died once more – to be with my family the way I used to.”

“In all likelihood I will never be my old self. I have to learn to accept this. It is so hard.”

Comparisons

“I compare myself to my family/friends/peers/workmates; to what I want to do with my life and what I am capable of.”
“When I don’t understand what people are saying I feel frustrated... embarrassed.”
“I am not the person I would have been if I hadn’t had the accident.”
“I’m frightened because I can’t trust myself and I can’t trust other people and I can’t trust health professionals.”
“I walked outside and never came back – what else might happen?”
“Man plans - God laughs.”

_Not like a ‘normal’ person any more_

“My hands didn't work properly.”
“I forgot to eat. I didn’t have any appetite; I didn’t know when I was hungry and when I wasn’t...”
“I scare myself - I must be a bit of a freak if I have to help myself swallow with my finger down my throat.”
“My brain can no longer go to that special place called sleep but I had terrible fatigue.”
“I have a great deal of trouble enunciating words – people find it hard to understand me” (can only whisper – put tremendous effort into the ‘Reflection Kit’).
“I didn’t know how to tell the person...didn’t know the words to tell the person I couldn’t use the phone...”
“I went sort of the opposite, I just found everything hilarious. I was really extreme. I'd sit there and just laugh at everything. Well, I couldn't help myself...”
“I have not cried since accident – I feel like I need to cry to get it out you know – I’d love to cry – I have so much to cry about.”
“I can’t cry – I don’t have tear ducts.”
“I used to cry a lot in that first year.”
“I... I... I can’t cry – but that’s - ok - because I never – was - a - big sook.”
“The first time they came in and said we’re going to get you up walking, I thought this was just absurd. Because I thought there was just one leg. How do you stand with one leg... If I was granted a wish today, it wouldn’t be to have my sight back. It would be can I have my left side back, to make me whole again. But the sight loss I can overcome, workaround. The left loss…” (amazing intelligent woman – felt the cage and pig and remarked how the pig would have trouble flying because it’s wings were made from fly wire).

“I can’t see properly…”

“I saw like a fly, the scene was multiplied many times over. I remember saying this to people I was with and we all had a good laugh about it, and talked about the fly, like maybe when I hit my head, my head was transposed with a fly!”

“My peripheral vision was only about to here, and so everything else was a blind spot. So if a person was in the blind spot, I didn’t know that they was there and I couldn’t see them, but my body could sense they were there and I’d move away, so I was forever falling over. So I’d say to my sister, ‘walk over there, you’re on top of me, get away from me’, and she couldn’t understand.”

**Loss of emotional control - I can’t control my emotions – I cry/I laugh**

“I cried all the time in hospital, at the drop of a hat. I was very emotional. It’s still with me, but needs to be something that triggers it now.”

“I can’t change that – I’ll just water and cry when I speak to a friend or to my parents”

“Actually I went through a long time when I couldn’t cry after the accident which was actually painful and when I did eventually cry it was in mourning and it was a real sense of loss...pretty horrible actually” (long pause - distress).

**Loss of cognitive and communication skills- I can’t talk, listen or understand**

“...because I look normal if you know what I mean and people would probably get confused that I...you know didn’t remember their name or I’d say the same thing over and over again.”

“I couldn’t say my address – hang on a second I’ve forgotten my address now”
“I can’t read...I feel frustrated and embarrassed when I can’t understand what people are saying.” (Participant Number 3 who identified he was glad that he had brain injury).

“The fact I couldn’t use the phone made me doubt myself. Totally. No actually, I think, looking back now, I thought there was something really really bad, wrong, and that I’d better not tell anyone. No, not that I shouldn’t tell anyone, but that I was embarrassed, ashamed... I don’t know, I think I was terrified...”

“It was really hard talking on the phone, because I never knew who was talking... I couldn’t work out how to use it, because you know how to use it, you know, but you can’t... like I knew how to do the dishes but I couldn’t work out how to do them.”

“I didn’t know how to tell the person...didn’t know the words to tell the person I couldn’t use the phone. It’s weird telling you... because you understand what I’m talking about... But then you forget that you couldn’t remember to use the phone, so you couldn’t actually get any help anywhere, because you couldn’t remember what you couldn’t remember.”

**Loss of energy - Fatigue**

“I feel tired I want a rest from it all.”

“With fatigue, I couldn’t do anything, I couldn’t even yell because I was so exhausted. And I’d just dread going to the toilet, it’s really hard work especially in winter when you’ve got so many clothes on, because I got so cold.”

“I’m good in the morning when I’m fresh but in the afternoon I must have a rest.”

“I was so exhausted and I had a big problem, I had to carry a pillow around because I couldn’t sit on anything I was so skinny and in pain...”

“Mum and Dad say I’m lazy but I’ve got bad fatigue.”

**Eating problem**

“People laughed at me because I couldn’t get the food on the fork, because my eyes couldn’t see properly, and then I’d stab myself in the face with the fork.”
“Disappointed is an interesting word, it’s too mild for what I felt. I was probably disappointed with myself, disappointed with the doctors, and disappointed with everyone and everything for a while. Um, sad, distressed, and absolute abject despair and futility. Because I think brain injury it’s the unknown as well.”

**Grappling with emotional fallout**

“I get very frustrated when my body/brain won’t keep up with or handle my spirit.”

“I constantly plotted how I would just leave, and just go somewhere else, where could just forget ... what would stop me was my cats.”

“And what really annoyed me was that no one would talk to me about it (wanting to kill myself). I mean... I didn’t want to talk to a psychiatrist of course, they would just give me more drugs. But my friends wouldn’t talk about it. And the friends that would – would deny it. They would be like, this is a really bad thing, and I’d be going ‘but this is a really interesting predicament that I’m in, and I need to talk about it. I’m thinking about it all the time, and I’m contemplating that, to kill myself and... why would no one talk to me about this? About this psych thing, or this disappearing thing? No one would talk to me. And that’s so wrong.”

“I was very angry, I had terrible anger and I couldn’t control it and I used to want to put my hand through a glass window all the time. I used to kick things and I know I hit my partner.”

“When I’m angry it’s always at myself, never others.”

“I’m so angry at the way I was treated – all professionals, even alternative ones are arrogant.”

“I used to suddenly have very big emotional swings, but then some of them weren’t related to me, and finally I worked out that I was walking down the street and somebody on the other side was getting angry, I would suddenly start feeling really angry. So when my moods started changing, I started looking out and seeing what was going on around me. So when my housemate came home, whatever mood she was in I would immediately get it. And I was like picking up on everybody else emotions.”

“Probably mad/frustrated – that’s brain injury in a nutshell.”
“Frustrated, yerr – frustrating – not – to – be – understood.”

“I get very frustrated when I am forced to rely on others.”

“Oh God I was really frustrated.”

“It drives you to distraction... trying to make your brain work.”

“Frustrated? Were you there this morning when I was getting dressed?” (blind).

“I was depressed, and I was powerless. I was on antidepressants, and I had no power to say yes or no. The antidepressants actually made me worse, and then they put me on other ones. And I was put on so many different ones, and I didn’t have the power.”

“I’ve had my times – I was suicidal until this year.” (This person said his life was better since his brain injury – but his marriage had broken down, he’d been suicidal for years. This was an example of contradiction that occurred in many interviews.)

“It is interesting that you have a card saying “distressed” – because I would try to explain to them this isn’t depression this is a sense of loss, this is grieving, this is a sense of being overwhelmed but this isn’t depression.”

“I’m so disappointed with life – my illness wasn’t my fault.”

“I’m still sad and depressed constantly.”

“Feeling am I going mad? I think I am going mad.”

“I thought I was mad and everyone else was mad.”

“I’m going crazy. With the professionals, sometimes I felt like... are people doing this on purpose? Is this part of a stupid IQ assessment? Whether that’s a bit of paranoia or whatever...”

“I feel guilty because I can’t trust myself – I’m not dependable – with good and bad days my thinking works in stops and starts.”

“I feel bad because I’m slow and I can’t concentrate, I can’t understand things.”

“They say put the thing over there and I don’t understand – I’m lost.”
“I feel bad because people say things that I don’t understand and I feel bad - is it me or maybe the ABI just brought that out?”

“I’m sad I still suffer depression from it – it’s still a challenge.” (A third participant who said life was better now. Another contradiction.)

“I’m still sad and depressed constantly.”

“I’ve wondered. I’ve questioned, am I going crazy. Other people are telling me I’m going crazy.”

“Mad, nuts crazy – oh yes.”

Rehabilitation didn’t suit me

“Rehab has not made me better.”

“My OT was hopeless – it just didn’t fit with what I felt I needed.”

“I didn’t like anything done in groups.”

“Health professionals – anyone who has made a difference? Nup sorry.”

“Professionals from rehab centre I don’t think played a huge role in my acceptance... They focused on the physical...”

“They (professionals) don’t know what it’s like to actually experience the system.”

“...lipservice. That they didn’t even believe what they were saying themselves “We’ll say this to appease him and keep him calm”. I probably had more insight than what they had…”

“I felt it was suggested I was lazy, or my motivation damaged.”

“Integrity, that’s something about ABI.”

“I wasn’t wanting an OT and I didn’t want to do the exercises.”

“I’ve discovered that people judge you, they believed I was lazy.”

“They (professionals) didn’t find some of the injuries until some months afterwards - they didn’t even know about it, and I kept on complaining...”
“Rehab for 12 months oh poor me!”

“..bad experience in hospital and rehab, they rely on some of the first off medical stuff, and that didn’t really happen so well, not documented, it transfers the bureaucracy down the line. And they think “oh but that would have been picked up”...but it wasn’t”.

“I was told that my fatigue would be with me for as long as I lived.”

“Dealing with bureaucracy- a minefield.”

“...in the end they ended up putting me in the dementia ward because I was so bad. They didn’t know... they wanted to put me somewhere, apparently a little bit safe.” “I can remember not being able to speak at all, just speaking gibberish, and people just looking at me, not knowing where I was, what was happening...I was so frightened.”

“In rehab I felt like a meal ticket.”

“...they were just like a Nazi camp to me...”

“I wanted it to be about me. Well, all our problems were different. And I don’t like group therapy.”

“Some of those experts that I saw ... didn’t inspire ...they made it harder...”

“I thought they (professionals) didn’t know what they were talking about.”

“Rehab was a waste of time.”

“Rehab was like being in jail – I was a copper.”

“I had to do rehab – I didn’t want to do rehab – but you’ve got to do what you’ve got to do...”

“We [people with ABI] want to educate the professionals.”

“You can’t trust what they say...I was told I wouldn’t be able to do things that I’m doing now.”

“Sexually inappropriate behaviour from professional people.”

“The OT kept telling me I wasn’t trying enough. It made me mad.”
“They thought I was slow – I was now deaf – what terrible mistake to make.”

“Perhaps the professionals could treat us less like text book cases and consider us as human beings with thoughts and feelings a little more... we are not babies and do not need to be treated like we are.”

“People in rehab were blind to our ability, they just concentrate on our disability.”

“I wish staff at rehab do a bit more than what they are doing – things I want to do.”

“Pretty frustrating – I don’t think the system catered for me to a degree because of my level of fitness.”

“Remember that we may have lost some of our bodies BUT help us to work out with the remainder. Abilities NOT disabilities.”

“They told my wife that if I did live I would probably spend the rest of my life in a wheelchair in a nursing home.”

“The nurse wanted to turn off the news because she wanted to watch something else. It made me feel like a child.”

“At rehab they should have understood – if I had all the rehab people I saw in front of me now I’d just blow them away (makes a machine gun motion with his hands)– all fucking useless.”

**Trust**

“The accident - It’s all my fault – I tried to save a dog that comes onto the road - I should have gone straight I should have...”

“I can’t trust myself to say or do the right thing.”

“... maybe I am not tactful. The silly thing that’s just on the tip of your tongue you say it and suddenly you realise I shouldn’t have said that.”

“...it’s safer not to plan, not to go outside your comfort zone, it’s safer just to be where you are, not make different decisions.”
“I’m scared anxious quite a bit, scared and shaky when I feel I am going to be physically attacked – when I’m smacked by my wife.”

“I’ve had people come to me, and I can understand it to a degree, they say to me, “Oh I’ve heard you’ve had a stroke. You don’t look like you’ve had a stroke, mustn’t have been too bad at all.” And of course I feel oh yeah. Swap places with you then.”

“Unlucky? No well yes because it was bad luck.”

“I’ve never been lucky so I can’t be unlucky.” (chuckles)

“My hands didn't work properly...not only did I not know how to make a cup of coffee I couldn't carry that cup of coffee to the table.”

**Ashamed/ Guilt**

“I feel like I’m an imposter – I haven’t got it all together and things eat away at me – if I tried a bit harder I’d fix myself. I’m feeling guilty that I can’t make myself better and guilty that I’m too good - so I must be an imposter.”

“I know I have been guilty – I feel bad for my son – he’s had to deal with all of this.”

“Guilty in that how could I have avoided this?”

“I feel guilty for things I do and say but how much blame can you put on something that happened five years ago?”

“I feel like I’ve let it affect my life more than I’ve wanted it to and I feel like I don’t have any control over my life and my brain injury and I’d like to have control over it – and I put a lot of pressure on myself....”

“I should feel guilty for changing my parent’s life but I put on the “I don’t care” factor. When I’m feeling scared and crushed it’s a big factor for me - I don’t care – but it avoids all responsibility, it avoids all guilt – it tries to avoid everything – then you just get stressed because it doesn’t last forever – it’s a trap - the only way to move forward is to acknowledge and move forward and that's everyday a challenge – even if you look fine.”

“I felt bad about not knowing where I was, having to ask people it was annoying.”
“I’m seen as drunk – judged by others – difficulty explaining – stereotyped as being a looser.”

“I often get declined entry to bars – I think there is a card you can get – I show my taxi card.”

“I do or say the wrong thing and then feel bad about it.”

“Not being able to do up my buttons made me feel pretty stupid actually.”

“I feel bad because I do and say the wrong thing – I call it loss of social graces.”

“I didn’t feel bad when I said or did the wrong thing then because it was funny - but do I feel bad now? Yep. But now I don’t feel I can excuse it.”

“It’s embarrassing with strangers when I say or do the wrong thing. With people I know I’ll say “What’s your excuse? I got hit on the head!”

“I bump into walls and door frames and I feel like a bloody idiot.”

“I definitely feel terrible when I say and do the wrong thing, and I think to myself, is it because I’ve got a brain injury, or am I just stupid?”

_Afraid_

“I’m afraid that family/friends/general public and medical personal don’t understand.”

“I had no explanation so from the word go I was terrified, so the only way I ever knew to face fear was to understand it. I think some of the first words I found to say was “educate me.”

“I’m scared of everything.”

“I’m afraid it will be like this forever and ever – a millstone round my neck.”

“I’m afraid that my life is out of control, I have no power, I’m dependent on others.”

“Financial difficulties.”

“It’s very difficult – I don’t think I’ve let myself fully feel the impact yet. It doesn’t feel it’s over for me, I’m so scared I haven’t stopped really to take a breath.”

“I think everything’s scary and annoying.”
“I wish ABI wouldn’t have left me with a huge fear to commit, trust or care in individuals and so I could move on with my life.”

“Sometimes I am so happy because I’m proud of all my achievements and how far I have progressed, then something confronting comes my way, and I over-react or react completely inappropriately, and have a mental break down.”

“It’s scary dealing with bureaucracy when you’re damaged.”

“So much is scary and complicated such as tax etc.”

“It was most disturbing dealing with the X organization.”

“I was very scared it would never be light again and would never know who I was. Particularly the first two years was just constant, I was constantly terrified. When I didn’t know my name. It was such a relief when I knew my name again.”

“Early on I was scared I’d never walk again - the pain was not being able to stand up and walk – walking was on my mind 24 hours a day.”

“You don’t know what’s going to happen next, bad things happen and you don’t see them coming.”

“I am frightened of making plans as I never know what is really in store for me.”

“I don’t have the will or the energy to fight brain injury when it happens again.”

“I’m so scared - I feel I’ve lost my family because they don’t understand a bloody thing.”: “You don’t understand ABI and it’s making the person very scared, very frustrated.”

“Scared yep.. they may have explained brain injury.. but I just wanted it to go away, when was it going to go away? Maybe with the short memory thing ...it went in one ear and out the other.”

“The experts can’t fix me – why are they experts then?”

“I’m scared of not being able to do things again, of losing my job, um because I loved my job...I was scared of people’s driving.”
“If only I wouldn’t have such black and white thinking patterns and be able to see positive first rather than negative.”

“I feel like this experience is something I’ll always live with and always have to be prepared for a sudden panic attack from having seen something that I emotionally reacted to.”

“I’m scared that when things get tough my negative thinking gets overwhelming.”

“I have had to choose to have dangerous operation – even though there were risks there was something you could do – it wasn’t just live with the possibility of a big bleed which would have been worse.”

“I felt hopeless because the experts couldn’t fix me.”

“I feel scared and hopeless because no one’s sort of fixed me – yep.” (near tears).

“Tax problems were scary because I was self employed.”

“Legal ramifications – fatigue – in supreme court the QC suspended all files from X.”

“The family wanted to pursue someone (medical negligence) but I said we were going through enough. Let it go.”

“Difficulties with rules and regulations – if you applied to get a job or part time job and you didn’t come up to specifications you could lose your entitlements and pension.”

“I am in constant pain, I live on panadine forte and morphine – I’m in a dire financial situation.”

“The expense of going to hospital for 5 months (stroke) - no money left (might lose the house).”

“Every day is a new challenge.”

“My emotions are less controlled – I cry more and get angry more”

“My wife treats me like a brother and not a lover and I feel the same about her.”

“My wife has become the money manager- most of the financial decisions are hers – I received the compensation not her.”
“I have always been the provider and now that has changed.”

“I was treated like a leper.”

“I often have bouts of low self esteem and consider myself to lack intelligence.”

“I have difficulty maintaining a relationship.”

“My isolation.”

“Poor understanding and social skills.”

“Childish behaviour.”

“The loss of independence is very difficult.”

“Lonely and an infinity of feelings and emotions.”

“Poor memory and all the other deficits that came with brain injury make life frustrating.”

“Many times a day things go wrong and you just have to continue on.”

“I only live moment by moment now as planning for me is a muddle and not worth the disappointment.”

“Lonely, isolated, no one understands me I don’t understand me either.”

“An aneurism creates another problem too of course. And that is because it’s something that a lot of people consider because it’s not a collision of some sort, where you’d get sympathy...”

“They don’t understand how bad I am, I’m actually amazed at the actual reaction or lack of reaction that I’ve had.”

“I’m sort of a bit angry and just a bit disappointed as well.”
“Isolated/friends

“I felt pretty hard done by – but I’ve got new friends.”

“(my friends) I didn’t know who they were and I’d try to pretend to know them, but how I behaved, was not how the old me would have behaved. In the end, every time I saw anybody it was so traumatising for me, that I tried to avoid seeing people I think.”

“My friends I pushed them away ‘cos I realised I’m different and they’re not and I’m creating a division, very subconsciously, but it’s happened – I’ve ruined some g-oo-d friendships and I’ve some terrible terrible things, I’ve pushed them away – it’s a big problem.”

“They had their own things to do, their lives have moved on, mine hasn’t.”

“There is a bond with people with brain injury - definitely although I can’t explain it, but it seems to tie people - we understand (each other).”

“Problems with the law. When you’re sick (ABI) I think this is, we know this, people with mental illness, and brain injury is over represented in prison everywhere. But I was in and out of court for stupid things all the time, I was getting in trouble. And they were just awful things like you’d go to the chemist and the chemist would... horrible stuff and I’d get banned for the gym because I said something wrong, or... just, I was always, and the doctor I would have a fight with the doctor and I would get banned.”
7.2 Mothers and wives

Lack of understanding and guilt:

“I mean medical terms are hard enough if you don’t have a brain injury but if you have an injury it becomes like a second language because I know a lot about medical terminology because I’ve done a medical receptionist’s course but before I did it, if you look at the medical terms it is a second language to you, you don’t know unless you’ve studied it ...so imagine someone with an ABI it’s like hello, I don’t know what you’re talking about, yer...”

“...I needed information and training.”

“I had the expectation he’d ‘grow out of’ or ‘get better’ but instead it led to depression.”

“I felt thrown in the deep end.”

“But it’s mind boggling, I mean you’re there with your loved one and there’s all these UVs and everything going on and these machines beeping and you think there really needs to be a non-medical way to explain things ..”

“The hospital was not keen to suggest rehab – they felt he would just be a nursing home person –I fought to get him rehab. I think it was our perseverance (you can’t give up, you can’t give up).”

“He says ‘yes’ but next day nothing – no memory, no motivation no capacity – ...frustration needs masses of assistance...”

“..how much of this is behavioural, how much is... this tempestuous hormonal time, indecision and a bit of back answering and establishing that ‘I’ concept, if you’ve got half your memory wiped out which I didn’t comprehend then you’re back to being an adolescent again ...my son was 21 so he’d at least finished his education and we had something to build on...like he couldn’t write a check, didn’t know what a check book was for...he couldn’t add up but once introduced he remembered those things over time...”.

“M is very hard to persuade, he has an opinion it is straight down the line – not swaying either side, and sometimes in the early days he couldn’t comprehend it – it was how he saw it...his
perception of things played a big part, it he perceived things to be a certain way – that’s the way it is – so it can be quite trying...”

“Our family has had 15 years of trauma in one form or another as the physical injuries got better I began to realise there were a lot of cognitive deficits - it’s a hidden injury...”

“Another key in his life was going to hear you talk...normally he doesn’t last a whole hour..and he loved that because you said what he felt, but you said it in a humorous way, but not the whole lot but things that he could relate to with sufficient pauses..he can’t seem to absorb a lot of material without it being punctuated with pauses and I think having things to see, things to touch that’s really good...

“I didn’t know what I was doing.”

“Needed information and training.”

“Told ‘this is as good as he’s going to get.’”

“I found it frustrating being a Mum where I couldn’t pick him up, I couldn’t cuddle him – I felt helpless that there was nothing I could do for him...”

“I wasn’t advised on what I could or should do - no training about what to do with him - I tried as much as one can being the mother of an adult child and having to do lots of things for him like toileting and stuff like that for a while that to be the role of teacher with flash cards again, seemed even more demeaning.”

“I tried, and I kept thinking this is a depressed state...he’ll grow out of it...I kept asking myself is it behavioural or is it something wrong with his head? Is it going to improve?”

“When he found his brain function wasn’t returning he became incredibly frustrated and nobody knew...we lived on a farm...and he came back home after the rehab time and I guess I didn’t know what I was doing so I blamed myself...”

**Problems - things get worse – spiral out of control**

“What I’m feeling hard is convincing my son with ABI that this is real so some days he doesn’t look ill so some days he is ok.”

“Socially isolated (lost friends) isolation recipe for disaster.”
“He blew his settlement trying to buy affection and loyalty.”

“Drugs – psychosis – from then on it has been hell – he couldn’t cope - life lost all reality - Everything he used to do and his dreams were gone.”

**Giving him some independence**

“..it’s a person you live with “now come on I’ll help you..what would you like”...instead of being aware this is an adult child I’ve bought up through adolescence now back off I’ve got to give him his independence, that was a really hard juggling what do you do, how far do you go..are you interfering in their life...”

“...but perhaps I erred in giving him too much freedom too soon, difficult especially when I was still living on a farm hours away from big country town started an x degree...while waiting for him in rehab - wanted to do something completely different really enjoyed the challenge of what I was doing so he wasn’t a burden, then I’d drive him back home again but of course he was at home with mum and dad in an isolated environment where our nearest neighbour is 6 ks away so it’s been a challenge of logistics as much as anything...”

“Sometimes he’ll lose comprehension a bit of it, ah like with instructions that was initially the first couple of years just one instruction at a time.”

“I don’t think he sees himself as isolated or being disabled – he doesn’t seem to see himself.”

**Bad rehab experiences**

“There were hours and hours of doing nothing and he was introduced to some bad habits in the hospital through being inactive physically, sharing cigarettes was a very real communication – a bit like the blitz I guess...anything you can do whether you can talk or think if you can share a cigarette...light a cigarette for a mate...I guess that’s a common mateship in a way...”

“Very little rehabilitation of the mind... is this a cup or a toothbrush..but not a lot.”

“I think if they’d had some of these brain Nintendo games and stuff like that I think his eventual prognosis would have been better.”
**Difficulty of getting rehab**

“Doctors told us we were taking up acute hospital bed and that the only thing was to move him into a nursing home, he didn’t qualify for mainstream rehabilitation they weren’t going to give him any rehab, it was just horrible..from an acute bed in a hospital to a nursing home and I told them over my dead body...but that if they couldn’t offer him anything I was bringing him home and I did...I got told I was delusional, that I was insane, that nobody had done it .”

“I took him to the rehab hospital for three weeks and our private health insurance paid for it and in those three weeks I learnt to … feed him, ... to do everything and then I brought him home and he has been home...”

“As a mother it’s sad to think he’ll be on his own – no love - how do you replace that? How do you make that spark happen with someone you can live a life with?”

**Motivational problems**

“He says “yes” but next day nothing – no memory, no motivation no capacity – incredible frustration – needs masses of assistance...”

“TS Eliot - my biggest metaphor for brain injury is The Hollow Man ...between the idea and the reality, between the motion and the act is the shadow (chasm), and that for me was with my son he’d agree “I can do that yes I’ll do that” – but the next day – nothing, no memory of it, no motivation no capacity and that becomes incredibly frustrating.”

“You could get a spark of enthusiasm in the minute but then implementing was a different matter and that I reckon is still his major problem, can’t do it without masses of assistance..”

**Difficulty at school/university/training**

“He tried to go back to university, got a sort of aid but she didn’t know how...she knew how to be an aid for a disabled person but not brain injury.”

“Yeh like at school  he may remember how to do a maths problem one day but if you put it front of him again he may forget and not be able to do it and he struggles with that a little bit.”
“I know a lot of people who’ve never heard of ABI they wouldn’t have a clue...”

“Friends yes and no some of them – I think it takes situations like this to work out who your friends are – we’ve had friends that have said, we’ve had some that have had to come to court to be witnesses, and they’ve wanted to know what he was like pre accident and a lot of them said to us, not in court, they’ve said there’s nothing wrong with him. And we’ve said to them how can you say that, you’ve seen him when he’s at his worst and some of them saw him when he was at the hospital and then they see him like today and they think it has all healed up – having to explain to everyone is hard...”

“Our families have been good but like his mother, you think; like she’d understand a bit better but she doesn’t – she’s a nurse – and she’s in denial – she’ll always say ‘He’s fine’ – he might be a little bit injured but he’s fine, whereas my mother, she has no medical training at all and she can see it when he’s tired (flagging).”

“I want people to understand - more education about abi – it would even be nice to have a TV ad, they show so many ads what’s the latest one about drugs -yes something about ABI, you know.”

“All the kids came back to the class and they said Mr So and So said ‘you’re not sick you just didn’t run cause your lazy’. Comments like that were starting to come, so then this brick wall came up, and we couldn’t get him back to school... We didn’t take it any further – I regret not doing that now.”

“The aide just wouldn’t be there (to help him) – she would nick off and do photocopying for the teacher or other things the teacher needed... we just started to go through that again yesterday so we are going over to the school this afternoon...”

“At school ‘this is how we will make him do things and bugger the injury and what problems he may have’.”

“People talk about quality of life...I get really really irate about that because nobody has the right to tell what quality of life is to a person...quality of life is hearing his nephews laughing
and seeing his dog and his cat, being outside with the sun in his face ... he’s got quality of life that a lot of people would never have... I get very passionate about this ...it’s nobody else’s business how we come to be here...to know his personal background and how hard he has fought to be here... nobody has the right to speak about his quality of life…”

“It’s very difficult when the world today is all about stereotypes and it isn’t very helpful about difference...many a time I think people have said “Is your son drunk?” because he lurches and spills things...the worst moment of my life and it gave me some insight into how it must be for him was at my mother-in-laws funeral and a neighbour - a farming neighbour – small community...”you must be so embarrassed by your son.” and I thought if he’s saying that to my face and I feel that rejection, criticism, venom and stigma how on earth must he feel... and I remember walking down X street with him to get a suit for his brother’s wedding and he lurched and I try not to hold onto him, and someone said “Isn’t it disgusting, drunk at 11 o’clock in the morning” and he could hear that...so now he won’t go anywhere without a stick.”

“I’ve had so many people say to me ‘Hey your husband is not injured – he’s fine, why does he have a disability sticker?’”

“The people who employ him through X “What injury do you have? It says here you have a brain injury but we can’t see it..so...anyway at work I think 2 days and the manager actually called me in and apologized - his hours are from about 8.30 to 12 – he works 2 days doing this by about 11 o’clock they can see the brain injury, he starts to fall asleep, and he looks like he has an injury if you look at his face and he called me in and said “Yes by 11 we see that he has to slow down on his work because we can see it’s a bit much for him after a few hours.”

“..We’ve been to concerts – people say “What’s your disability?” And he say’s “I’ve got an ABI” and they say, “You’re standing up, you’re walking you’re talking, you’re fine.”

“We’ve had quite a few doctors that have said the incontinency was nothing to do with the brain injury but a X doctor actually said “Yes it does have everything to do with the brain injury. He wasn’t like that before.”

“Worst experiences – like when people tell me or to Sam himself that he’s drunk and he’s not injured – just pinpointing you don’t have a disability, there’s nothing wrong with you and we
still get that – so that’s hard – he does have a card from the brain foundation – and it helps and it doesn’t, people that don’t understand won’t regardless of the card .”

“Why should you have to explain that his is a hidden injury at certain parts of the day? You know I suppose you’ve had that too – you look all right so you’re OK and you say “Come back here at about 4pm and see if you say the same so once again.” People need to be educated that there is such a thing as brain injury.”

“What injury do you have? It says here you have a brain injury but we can’t see it.”

“We have experienced things like that “You’ve had a bit much to drink” or we’ve had an episode at the supermarket- he was a bit tired and couldn’t find what he was looking for – and asked one of the girls – who told him he’d had a bit to drink – and he has a card which says ‘I’ve got an ABI’ ...I don’t think he got an apology but... and a few times they’ve tried to short change him too because they that we’ll get away with it.”

Sadness for the future

“Your whole life changes, it’s just like that and you sort of think ‘well I’ll probably have to give up work’. You’ve got all those things and you’ve got your other kids to worry about... my husband took it quite hard and that sort of caught up with him this year.’’

“Because you’re Mum you fall into the habit of treating them as children, wanting to ‘fix’ them, and that’s really difficult not to do I constantly get reminded by my son now ‘Mum you’re doing it again’ (laughter) so I have to stop and think.’’

“As a mum it was the hardest thing.. I spoke to my husband and my son and my daughter and I spoke to them all by themselves privately....and told them to tell him how proud of him they were and if he felt he had to let go that they’d understand and that they really love him and we’d give him that choice and every one of us did that with him – they turned off the life support and he began breathing for himself...he has fought so hard to be here...”

“When you talk to mothers you get a common worry about when I’m not here that concerns me...that’s why I’m trying to put so many things in place now that he can exist..’’
“No girlfriend – no grandchildren ‘As a mother it’s sad to think he’ll be on his own – no love - how do you replace that? How do you make that spark happen with someone you can live a life with?’”

“‘My son’s had a few tries at relationships but they’ve ended in disaster so I think he’s signed off from that...’”

“‘On the love angle, we had a little granddaughter born recently...seeing my son with his brother and his nieces you could see that look ‘I’ll never have this’ and he doesn’t drive because he can’t, he’s got so many lacks in his life comparative with and I know comparisons are odious but I just wonder...’”
7.3 Professionals

The losses of ABI

“[my client] has been locked up in a secure ward in a rehab hospital for 8 years.’’

“...he forget things, he laughs, he cries.’’

“He’s a very cluey guy, and has lots of embedded knowledge (but can’t read).’’

“Recognize that there is a lot of loss - I think like they feel they’ve lost everything from relationships to especially work, driving a car, having to start all over again.’’

“Memory and fatigue are the main difficulties [of our clients].”

“They have lost the ability to know when they’ve been diddled – you know that and they just have to trust, that’s what it amounts to, by the way someone speaks to them there’s a limitation that involves trust because they no longer have those resources to alarm...’’

“Some people with brain injury may have a chip on your shoulder, but no one deals with that ‘being diddled’ feeling and the people with brain injury can’t talk about it or people will think they need some help mentally.”

People don’t understand ABI

“Medical jargon is actually useless to you in the long run...not in diagnosis but what it means for life it’s actually quite useless information to families - education much broader than just information.”

“They didn’t hear it ... they weren’t in the space where they could hear it.”

“’There can be a lot of misunderstanding, even within families.’’

“Families split up, divorce...’’

“They can’t relate to their friends because their friends have nothing to say to them and they have nothing to say to their friends.”
“The person with brain injury may have experienced many people who do not understand ABI.”

“People don’t realise how difficult brain injury is.”

“A lot of people with brain injury have had a lot of poor experience with the medical profession.”

“I’ve noticed with X over the years that he does have quite a mistrust for medical professionals and I’ve met other clients like that and that’s based on the poor relationships they’ve had whether it’s with GPs, or psychiatrists, psychologists.”

“People with brain injury fall somewhere in the cracks between the criminal justice system and the mental health act which doesn’t seem to cater for them very well either.”

“Some people have never been in the medical system - not necessarily a diagnosis of BI because they haven’t been in the health system - This is even more frightening because they are out there struggling on their own so I would see a local health practitioner based in a community health centre, promoted really well - people could easily make contact with those people at the community health centre.”

“They need advice to see a counsellor for marital problems : Carers Victoria there are six free sessions of counselling available for marital counselling but people don’t that stuff and how are they ever gunna know that stuff if someone isn’t there to tell them?”

“PWABI don’t want everything all at once – social workers like to tick boxes and you only have certain amount of time with them before they go to rehab or home the most important when they- show brain take them apart show them where damage is.”

“Once they’re discharged from the health system, unless they’ve been linked up to some other agencies before discharge they are left to sink or swim.”

“I think people can pretend very well, if it’s a small injury and they learn to compensate, but it comes out in the end when they do strange funny things because they don’t have the filter.”
Some professionals do not understand ABI

“I know lots of people, lots of GP’s who don’t understand ABI.’

“Once they’re discharged from the health system, unless they’ve been linked up to some other agencies before discharge they are left to sink or swim.”

“I’ve noticed with X over the years that he does have quite a mistrust for medical professionals and I’ve met other clients like that and that’s based on the poor relationships they’ve had whether it’s with GPs, or psychiatrists, psychologists.”

“A lot of people with brain injury have had a lot of poor experience with the medical profession.”

“I cringe for young people – parents and staff making them a child saying “good boy, good girl” – they don’t mean to put them down. They may be doing childlike things – humiliating with food all over their face everything exaggerated, lots of makeup, lots of jewellery – nothing’s subtle, 10 cigarettes within 2 hours.”

The general public doesn’t understand brain injury

“The general public don’t understand - I think that until you’ve either had a bi yourself or been close to someone - yer I don’t think you’d have a really good understanding about it at all – it’s a quite unique situation.”

“The person with brain injury may have experienced many people who do not understand ABI.”

“People don’t realise how difficult brain injury is.”

Emotional challenges

“I think it’s almost irrefutable... certainly the research shows that if you’ve got an ABI your incidence of depression and other mental illnesses is very high.”

“Isolation I relate it back to mental illness – they think they will get better and be the ‘old’ me, often in our work it is working towards a different state – I don’t think they are ever the ‘old me’. With brain injury you wouldn’t be the same again.’”
“They can have very bad weeks this makes them very fragile...emotional problems.”

“There’s the down side of getting really depressed about the problems, but there’s the up side are all the amazing things of how you cope.”

“The big issues are do I look different. How am I fitting in now? Do I look attractive anymore, women will feel it worst.”

“We have lots of trouble modulating inappropriate behaviour...he realises...then he forgets...and he says ‘ooh sorry’.”

“There can be a lot of misunderstanding, even within families.”

“Families split up, divorce...”

“They can’t relate to their friends because their friends have nothing to say to them and they have nothing to say to their friends.”

“Isolation I relate it back to mental illness – often when people have had an episode they think they will get better and be the ‘old’ me, often in our work it is working towards a different state – I don’t think they are ever the ‘old me’. With brain injury you wouldn’t be the same again.”
Summary audit trail of factors that have a positive effect on the lifeworld of the person with ABI

8.1 People with ABI

Hope

Determination

“Um, I guess I don’t use the word hope, I just think of it as bloody mindedness. Sheer determination, where I’m mad as hell and I’m not going to take this anymore.”

“I wasn’t willing to accept that I would be in a wheelchair in a nursing home for the rest of my life.”

“Hang on; I’m not going to let this beat me!”

“Proving professionals wrong – I’ve proved them wrong in a thousand ways.”

“There is nothing I can’t do I just haven’t found a way to do it.”

“Things change, you make it work. You need keys... I need to expand all the time. I joined this work (volunteering) …I was just drifting, [but] I didn’t want to sit at home and do nothing. So I joined the club.”

“.. staff therapists said to me, “I just wish that other’s had your willingness to get up and do things and try to overcome things, because if they did, this place would be a much better place to work in and we’d have a lot more people recover.”

“Going outside my comfort zone – new experiences.”

“Realising I can use ABI as an excuse to justify all my shortcomings in some way or another – relations – university. It can become a lazy reason not to put in effort because it was becoming too overwhelming for me.”
“Proving professionals wrong – I’ve proved them wrong in a thousand ways.”

“There is nothing I can’t do I just haven’t found a way to do it”

**Being Positive**

“Saying I can do something.”

“I think I’m a pretty positive person, and I think I thought this was always going to be alright. And I don’t know if there is anyone else you have interviewed has said this, but, I’m glad this happened to me. My mother is horrified when I say that. But I would say that I haven’t changed as a person, but I’ve learnt something.”

“Looking at every part of my life post the brain bleed as a bonus.”

“Focusing on the small goals that achieve bigger goals.”

“To take very small steps and be patient in returning to “normal” life.”

“It’s like I’m constantly finding new aspects of myself.”

“Apparently I was supposed to be dead – that’s how bad it was. But then I had a few broken bones, in my legs and my arms I couldn’t walk I couldn’t talk I basically had to relearn to do everything but I could breathe.” C “You’re doing pretty well!” F with the breathing part I am.” (laughter)

“The brain tumour was the worst thing that ever happened to me but because of the journey, my understanding it was also the best thing that ever happened to me too.”

“Tracking my progress and achievements.”
**Wishful thinking**

“They told mum that I’d never be able to walk again or do this or that have children – Luckily I didn’t believe them – you wouldn’t want to believe would you!” (laughter).

“The doctor was quite adamant about after two years you’ve reached your peak – it took away all my hope – I was frustrated because I thought I was going to get better….but then I thought I’m going to improve…”

**Denial**

“It just went in one ear and out the other.”

“I’ve never thought about these things.”

“I didn’t really think about anything.”

“I try not to see anybody, because I worked out not seeing any medical professionals, actually improves my life, because if I want to see these people I have to look at what’s wrong with my life. And my life is better when I think of what’s right.”

“I ignore my difficulties – other people are a problem not me I don’t think I have trouble speaking.. but people can’t understand what I’m saying.”

“I get told I don’t walk properly (lurches) but I think I do (walk properly).”

“People say to me you’re speaking a lot clearer – but I just don’t think about it.”

“People say “you’re bloody game” I think I’ve always been.”

“I don’t think I’ve got a comfort zone (comfortable taking risks).”

“I’m really lucky I can drive - I lost one eye, my memory is funny…”
“Pain you know what- it’s funny. At the moment I’ve got pain – but I usually avoid pain by doing my exercises.”

“My memory was never great but since my accident for me it’s quite normal.”

“I’m pretty good at losing things – everybody does things like that – maybe I do it a bit more I’ve done some silly things (driven off without my handbag twice) but everyone does silly things like that.”

**Religion and Metaphysical things**

“I’m only here because of my religion Jewish – very important but is God punishing me? Am I here for a purpose?”

“I think about religion, I’m a Catholic – it’s comforting.”

“Catholic my faith is important.”

“My faith.”

“My belief.”

“I did a course last year in healing and spirituality – and I read a lot and they were basically saying that people do best – people look better, feel better and behave better when they’re in that community when they’re always receiving constant support, constant encouragement…”

“I’m only here because of my religion Jewish – very important but is God punishing me? Am I here for a purpose?”

“I think about religion, I’m a Catholic – it’s comforting.”

“I turned to religion and spirituality – I was really seeking but none of it worked for me.”
**Nature brings hope and comfort**

“The sea – I can hear it from my house and it’s like the universe breathing.”

“Being at the beach – the sea,”

“Escaping to country.”

“Sunshine yep.”

“I live in the country, and that’s great.”

“Flowers and nature, those sorts of things help.”

“Seeing symbols as meaning.”

“I see ‘Streetlights’ or symbols I think “this is why I’m on the right path because I’ve found this and it means something” – to deal with a terrible thing we start seeking outside ourselves ...we need to believe whether it’s true or not is sort of irrelevant to me. Because I believe it’s true for me so that’s ok, and it helps me to believe it.”

**Love**

*The two way love of family and friends*

“The understanding of my oldest and very dear friends and their ongoing support.”

“Encouragement from my parents and siblings.”

“Love is extremely important I believe that if I didn’t have my family and husband to come home to, I wouldn’t have worked so hard – I don’t think I did it for me, I did it so they could have a life. I saw my youngest daughter would hand herself over to my life and that wasn’t the future I wanted.”

“Love is most important with the care, patience and encouragement it brings.”

“Encouragement was very important. The fact my family has held their breath when I try to do what I try to do, when I’ve completed it I say “you can breathe now” cos I hear them going
“hhh” and letting me go must have been so hard on my husband because I know it would be so much easier for him if I just stayed home.”

“My wonderful husband.”

“My family is hugely important to me.”

“Joining groups in the community.”

“Joining brain injury groups.”

“Talking to old friends.”

“Meeting new people, going to certain groups (such as drama, writing, discussion & wellbeing).”

“Finding out that other people with ABI have the same experience - I’m normal.”

“Work friends from a long time ago come and talk about the old days and it helps.”

“I have good carers – I can talk to them – do quizzes and crossword puzzles with them.”

“Friends – I’ve got new friends – more new friends than old friends.”

“Love most important.”

“Love …is… important…I just don’t think I’m any good at it.”

_The love of animals_

“I could stay in bed but I have a big black muzzle me saying get up and feed me.” “I love my animals.”

“My dog understood that I was crook and stayed by my side.”

“I think if I didn’t have my three cats who loved me unconditionally, to talk to, I wouldn’t cope at all.”

“Animals. I have lots - the cats are great, really affectionate.”

“Taking responsibility and caring for something else (my animals) - I think it is very big.”
“My cats saved my life I would have “disappeared” but for my cats.”

**Things they love doing – finding a passion**

“I love going out - I’m terrified of my arm chair.”

“I always want to be out and doing things – doing new things.”

“I love going to live shows.”

“Going out to lunch on the weekend made me feel more normal.”

“Fishing.”

“Staying in: I’ve got a big TV, writing poetry, writing – recording my thoughts, feelings and daily events a surprise, a treat – reward self after I’ve achieved something, a glass of wine perhaps (laughter), talking books, cooking, listening to music, reading the newspaper, making jewellery.”

“Writing all my thoughts down – everything...and they say stop this lunacy and I say I can’t stop...”

“Gardening yep, I love gardening.”

“Ah, gardening is a new thing I’ve taken up that I find a lot of peace, as a therapy... it’s a wonderful, wonderful thing.”

“A treat – yes – that’s part of the life process – it has to be achieved – a prize at the end of something. You’ve achieved something so now you can have a treat. Big or not so big – a cup of coffee shared with friends or family.”

“Exercise- Yes so important – I’m convinced the exercise side of things reduced the severity of the damage that was done significantly – simply having rich oxygenated blood flowing through the systems.”

“Seek things to do that you enjoy and that help you to feel good about you.”

“Going out – staying home is very very detrimental – if I get out more I feel a lot better.”
“I always want to be out and doing things – doing new things.”

“Often a cup of coffee calms me down, it’s like meditation.”

“Doing cross stitch/tapestry/knitting focused, calmed me and I felt productive. It was my security blanket and I took it everywhere.”

“Technology/ Using the computer

“Treats – but it only helps for 5 minutes.”

“Painting – art is very important (couldn’t draw before) colour gets me excited – want to touch smell the colour – another dimension.”

“Listening to audio books on my ipod.”

“Using the computer at home.”

“I do like digging out those weeds.”

“I do like to garden.”

“Appreciating friends/nature/sunshine.”

“Finding hobbies – reading, community things.”

“Writing...recording my thoughts, feelings and daily events.”

“Staying home because I don’t like being in crowds because I can’t take in so much information at any one time.”
"Seek out the local community centre for art, craft classes (and anything else of interest!) It can be therapy, rewarding and afford you the opportunity to interact (and meet) others with a similar interest. It is also terrific for building confidence."

They love to be able to help other people with ABI

“Helping people yea…”

“Being useful is absolutely necessary.”

“Volunteering.”

“I help people.”

“I volunteer to help people with disabilities ‘cos I know what it’s like to be in a wheelchair.”

“Being useful – yes that’s why I do so much – I refer to it as my sense of purpose.”

“I’m a volunteer I have a lovely lady to look after. She’s lovely, she loves me, she’s like a mum to me and I’m a mum to her”.

“Helping at home.”

“I love being useful – I go up to the country with my dad and help.”

“Helping a lady who suffered a stroke. And we got along well. We clicked. We became good friends. We phone each other.”

Learning to understand ABI and working things out:

Learning to understand ABI

“Gain as much knowledge as you can about your brain injury to help you understand…”

“It was important to understanding my condition.”

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“If I’d had the CD earlier on it would have helped me to understand that I wasn’t going mad. And it certainly would have given me another way of approaching things too. And too perhaps even ask more questions. Because if I knew that was the situation, then I could relate that to other areas.”

“What other people with ABI have done this is massive to me – peer support – my writing group.”

“What other people with brain injury have gotten up to, or survived. Um, it didn’t help to start with, because I was too interested in myself. But later on, to read stories of people who’ve survived was good.”

“Meeting you (Durham) at a conference in Sydney was another moving point for me and the rest of my life, as I feel that it is the survivors who can talk the talk to get others back on their feet after an injury, because we can walk in their shoes.”

“Brain injury information.”

“Doing Up Buttons.”

“‘Keys to the ABI Cage’ CD and sheets helped reflect about things - it did, I thought it was very helpful as far as making you sort of sit down and think about things.”

“I must say, there are a few things here on the CD that related to me, particularly on the side where, it helped me to sort of come to terms with things and sort of get along..”

“Therapists were talking about what was in your book (‘Doing Up Buttons’) and asking if I’d read it and I remembering listening (she was blind) to the first three lines (on a talking book) of your book and I had to keep replaying it because I was in so many tears and replaying wasn’t easy for me – I can assure you, trying to figure out which button to press to make it go forward, and I thought this is person.. I thought I was the only person in the world who has ever felt the way I felt. I knew nothing about brain injury – nothing about vision loss and I felt extremely ignorant.”
Things they worked out

“It is fortuitous and I need to embrace whatever this learning and this opportunity that has been provided to me.”

“Working out things I need to do.”
“I try to be the best I can at everything that I was good at before my ABI.”
“I made sure I had routine and that I was organized.”
“My short term memory is getting better and I feel that it is because I have always practiced my memory with mind games and developed strategies.”
“Order – my lists.”
“Placing my head on a wine flask so help with balance problems, broad beans, Ginkgo, avocado cashews.”
“Helping my memory I practiced with mind games and developed strategies to help my memory.”
“Remembering to use my diary.”
“A white board positioned in an obvious place is an invaluable tool to assist with everything from what’s going on in the week ahead to groceries.”
“Repetition with a new task, or learning something different - repetition is the only way to cement it until it becomes part of the fabric of your life.”
“Admitting to myself I have shortcomings (short term memory) and learning to employ strategies to assist me with coping with these shortcomings.”
“I’m not good with time so I set my watch 15 minutes early.”
“Patience.”
“Structured living, routine.”
“Minimal stress.”
“I perceive that I don’t have power over the direction that my life is going because my life is about recovering from that accident and coping. It’s not about planning for the future anymore.”
“My life is down to just the basics of existence.”
“Simplicity.”
“Routine/organization.”
“Quietness.”
“A healthy diet.”
“I try not to get impatient with myself.”
“Never be afraid to ask for help or get something wrong.”
“The more “mistakes” I made the more I learnt and recovered. Getting as much help from as many people as possible always puts you in the best position possible.”
“Exercise.”
“Whatever I’m doing gets all my attention.”
“Writing...recording my thoughts, feelings and daily events.”
“Tracking my progress/achievements.”
“Facing the fact I need to rely on my palm pilot diary”;
“Everything is “slowly slowly” and time has changed.”
“Acceptance of my lot has always been part of new life.”
“Acceptance of events in the past and coming to terms with consequential responsibilities of future.”
“Facing the fact I need a whiteboard on the wall near the doorway of my bedroom.”
“I think you’ve got to keep busy, keep your mind going, the busier you are the more you socialize with people the better things are and you don’t worry about being disabled.”
“Admitting to myself I have shortcomings (short term memory) and learning to employ strategies to assist me with coping with these shortcomings – a whiteboard on the wall near the doorway of my bedroom, my palm pilot diary.”

“Setting goals – living independently with assistance.”

*Teaching their body to work again*

“Speech therapists were great”

“My counsellor was great.”

“The psychologist – she was just wonderful.”

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“I did a lot of intensive rehab.... physio exercises at the gym. I devoted all my time to doing that, last year 6 days a week.” (man)

“... physical rehab wonderful...” (man)

“Rehab exercises was just brilliant.” (man)

“My balance is a hundred times better with a lot of hard work and physios.” (man)

“I had a lot of rehab, it was extremely helpful. But taking control of it was… better. I was so determined to get home It was this is going to take too long to do it their way. It’s a long time to sit, if you’re just in hospital.” (woman)

“Letting me do what I want, and not what they think I want/need. One of my speech therapists used that theory on me and it allowed me to surge forward in my rehabilitation.”

“Rehab was helpful.”

“Physical rehab wonderful, psychologist – she was just wonderful. They were really good.” (man with brain tumour)

“I had some great OTs – but in the end I think it’s been better for me to sort it out myself.”

**Learning to face the facts - acceptance:**

**Accepting that the person is not the same**

“Coming to terms with the fact that I’m not the same person any more.”

“Redefining who I am and where I want to head to.”

“Acceptance of events in the past and coming to terms with consequential responsibilities of future.”

“Admitting to myself I have shortcomings (short term memory) and learning to employ strategies to assist me with coping with these shortcomings.”

“I now view the word from a changed perspective.”

“I have changed careers/job to a completely different area.”

“Remember the past, live the present, hope for the future.”
Recognizing the positive things that have come because of ABI

“Changed me - learning new things.”

“Recognizing positive things from ABI experience.”

“I have a much greater understanding of life and people.”

“Learning to appreciate life.”

“Don’t take life for granted.”

“Believe in yourself.”

“Looking at every part of my life post the brain bleed as a bonus.”

“Saying I can do something.”

“Focusing on the small goals that achieve bigger goals.”

“To take very small steps and be patient in returning to “normal” life.”

“It’s like I’m constantly finding new aspects of myself.”

“Talking about things.”

The person’s sense of humour

“My sense of humour is the best thing I’ve got going for me.”

“My optimism and sense of humour.”

“My ability to find the funny side of things and to laugh.”

“I was one of the court jesters at rehab - the nurses came to visit me when they finished their shift.”

“[I was] sick of looking at the negative things – I turned things round – it’s a nice surprise to find $5 in coat pocket!”(when you’ve forgotten it’s there).
“Apparently I was supposed to be dead – that’s how bad it was.... I couldn’t walk, I couldn’t talk, I basically had to relearn to do everything - but I could breathe” C. Durham “You’re doing pretty well! S “With the breathing part I am.” (laughter).

Holding the ‘Mad/frustrated’ talk-about card commented: “Frustrated? With my ex wife – a lot of married men have been frustrated by their ex-wives. I might be wrong but I don’t think so.” (laughter)

“Turning difficult situations/people into fiction/ two-dimensional characters in my head.”

“My ability to find the funny side of things and laugh.”

My attitude

“Believe in yourself.”

“I can use ABI as an excuse to justify all my shortcomings in some way or another – relations – university as a lazy reason not to put in effort because it was becoming too overwhelming for me.”

“I was able to set up an electronic security business to keep my mind active whilst I was waiting for compensation.”

“Recognizing positive things from ABI experience.”

“I have a much greater understanding of life and people.”

“Learning to appreciate life.”

“Don’t take life for granted.”

“My word power and writing skills were mostly unaffected by the ABI and I was able to play a role in the community and with my business with those old skills.”

“Being on the ball pushing, pushing.”

“Changed me- Learning new things.”

“My recent training in the disability industry has helped me come to terms with some of the insult and pain that I have suffered the last 13 years. In fact I am doing work... I was a client/patient and now I am on the way to becoming a health professional... so there!!”

“The brain tumour was the worst thing that ever happened to me but because of the journey, my understanding it was also the best thing that ever happened to me too.”
Making progress: brain injury is not all bad

Being able to do ‘normal’ things again

“Being able to talk to people and realize that I am still a ‘normal person’”,

“Being a basketball coach and instilling some of my training into the team.”

“Knowing I am making a worthwhile contribution at work.”

“Returning to study.”

“Having a job makes you feel alive.”

“Now I’m in a job that I love more than anything I’ve done. So I think this has given me the opportunities to make those sort of decisions, and it’s been a really powerful experience.”

“Being able to revert back to old skills that could be reused in my new life.”

Freedom to be able to drive again.”

“Getting my license again was freedom!”

“Undertaking courses and passing them.”

“Knowing I am making a worthwhile contribution at work.”

Achieving hard things

“Achieving or doing hard things.”

“Doing things I was told that I wouldn’t be able to do.”

“Stretching outside my comfort zone.”

“Being able to do things at work that are beyond my fellow peers.”

“I was proud I could teach therapists a couple of things on the computer.”

“It’s interesting when you look at what is hard. It is all these million little baby steps that were hard. I practice trying to get my two feet into slippers – I’ve only been able to do that in the last year. It was wonderful when I was actually able to put my left foot straight into my slipper.”
"The survivors ‘high’"

“I feel that I have been so fortunate and I must help others who have not been so lucky to have recovered so well.”

“I am clearly meant to be in this world now and I have a responsibility to work on myself always to be living up to the best me I can possibly be.”

“I am so grateful that physically “Thank God” I am OK, my spirit has been damaged, not broken, and it’s up to me to make the most of the unpleasant challenge that has happened to me.”

“I have a desire to share my story and feelings with others so they too can appreciate the wonders of life and all the moments they have. If they had a difficult experience which challenged them, I am so happy to come talk to people and let them know they’re not alone.”

“I tell people I’m lucky to be alive, I’m lucky to have a family I’ve got – lucky now – if I’d had this 20 years ago I’d be locked away in an institution so yea...”

“I felt so lucky that I’d survived.”

“I was lucky (to have the right surgeon) I’m not scared, I should be but I’m not I should be dead but I’m not.”

“I feel I am really lucky because this has happened to me, it has given me a chance to start my life again.”

“I feel special having experienced so many unique and valuable things.”

“I have to accept that I am newer better person and I have become more aware of the environment, pollution, good friendship, humanity to mankind, volunteering, service clubs and general sharing, better sailing skills (amazing eh).”

“Actually it was a flower that told me one day that the world is really worth being in. It was a memorable experience because I was walking around the side of my house and the world had been grey for a long, long time and I saw a red tulip, the bulb I’d put in a pot, and it had
flowered red and honestly I stopped in my tracks, and it was like wow, and I’ll never forget that, and the world then had colour.”

“I’m on the right path because I’ve found this and it means something.”
“I’m meant to be here.”
“Comfort. I am clearly meant to be in this world now and I have a responsibility to work on myself always to be living up to the best me I can possibly be.”

“Desire to share my story and feelings with others so they too can appreciate the wonders of life and all the moments they have.”

“If they had a difficult experience which challenged them, I am so happy to come talk to people and let them know they’re not alone.”

**Aware of strengths and weaknesses**

“Affinity with dogs, and animals that I’ve never had before. I mean I’ve always cats, but I’d always been a bit scared of dogs and horses, and all of a sudden I have no fear, I don’t have any fear of animals. And I can commune with them. I talk with them. And I couldn’t do that before.”

“The brain injury has caused me to become highly sensitive to many things, noise, light, people, feelings etc. Whilst this magnification of sensation can be overwhelming and force me to retreat to a quiet safe place there have been some wondrous exceptions. Colors have taken on an extra dimension and are marvelously more colorful. I still have to wear earplugs most of the time but I love the way things sound after the rain and in autumn because sounds become clearer yet softer.”

“Having a brain injury is also taking me down an artistic path. Whether it was the inability to read, the increased sensitivity to color, or the desire to explore something completely new, with no possible comparison to the former me, I have surprised myself in finding within the new me.”
“My vocabulary shrank to the most basic things, and my way of combating that is trying to learn new words all the time. I’ve got an exercise book where I’ve got all these words I’ll probably never never use, but I’m really pleased, I used the word ‘impolitic’ with someone the other day.”

“What I say to them now is, there are two selves, there’s the person I was before, and no matter how much I grieve and think I’ve lost that person, I have not lost her she’s still here, she’ just been pushed back by this new self. There’s two selves, and there’s this new self, and the two of them have to learn how to get along.”

“But then my old self will have changed as I would have grown and changed anyway, so it’s a process of negotiating myself and getting to know myself, and not putting it in such final terms, is the only way I can deal with it, otherwise I may as well shoot myself.”

Feel older and wiser

“It’s been a really powerful experience.”

“I think I’m more real, I haven’t got time or patience, to waste on niceties. So I cannot be as nice, but that’s ok – I get to the point. I like that.”

“I have to accept that I am newer better person and I have become more aware of the environment, pollution, good friendship, humanity to mankind, volunteering, service clubs and general sharing, better sailing skills (amazing eh)!”

“...and I don’t know if there is anyone else you have interviewed has said this, but, I’m glad this happened to me. My mother is horrified when I say that. But I would say that I haven’t changed as a person, but I’ve learnt something.”

“Brain injury is the worst thing and the best thing that has happened to me.”

“Yes, yes, I had a lightning bolt moment, an epiphany – in rehab I was in the ABI unit, surrounded by others – you start comparing yourself and you say “I’m not as bad as them,” and my family was saying “Oh my God, she isn’t really quite with it!” and I knew I could sit back and do nothing, and let people look after me and pamper me for the rest of my life, or I could take another road and have a life that I felt I had achievement in. I felt I was at the
crossroads that it was up to me – one was the hard slog the other was the easy road but I don’t think I’ve ever taken the easy road.”

“I guess the secret to me, is to decide that this doesn’t have to be permanent, that it doesn’t have to be fully incapacitating, and there’s a lot I can do about it and to never give up...and to try anything and everything.”

“I was told all through my rehab and from other doctors, that the brain will only heal in the first two years, and after that there’s not much healing that happens. And I refuse to believe that and I feel very lucky that I refused. So that really helped me to think I could keep getting better. I still believe it.”

“Believing the brain is a muscle – today the new term is neuro-plastic, but I was told all through my rehab and from other doctors, that the brain will only heal in the first two years.... That would be the one big change I would like to see in rehab or ABI treatment. I went for 10 years and I saw people who believed it – it was heartbreaking.”
8.2 Mothers and wives - Factors that have a positive effect on the lifeworld of people with ABI

Love

People who love them and people they love

“The [family’s] love is important.”
“He says ‘my family – if I didn’t have my family I couldn’t...’”

“What got him going? I think a lot was having a daughter – that was something to live for of course when we married we didn’t have her, but he always loved about having a family – and when we had her he thought she’s someone I’ve got to live for...and she’s only six but we’ve tried to explain to her that some of daddy’s brain doesn’t work, he saw so many doctors in his rehabilitation process and they’ve always said what kept you going and he’s always said – my family – if I didn’t have my family I couldn’t...”

“I think it’s more the family, the understanding of the family and just showing him a lot of love and support and also having this pottery now is really working for him now."

Things they love to do

“Being in the country – some freedom”

“To come down to the township with his big brother to escape home.”

“Fishing.”

“Reading local paper – with all the town gossip.”

“[I] try to make life as normal as possible – take him out to friends place in wheelchair...”

“Activities to fill his week; hobbies.”

“Using his sense of humour: He has a very dry sense of humour.”

“Getting out and about: he likes to be in on the action – staying home he gets bored a bit.”
Pets

“His dog on his bed...”

“He loves his animals.”

“The cat is always on his bed.”

“The bird.”

Understanding – getting the ‘right’ information:

Information I could understand, he could understand and for others

“Information and not just give you a whole bunch of booklets – probably 5 months after his injury I started to read through some of these – my husband wouldn’t. Reading them sort of throws you because you think ‘Oh my God is he going to be like this – like that? Is he going to end up that way? So it sort of makes you worry more – on the internet – much the same information it’s sort of repeated.”

“I’ve had great support from friends – but I don’t think even my closest friends understand ABI or me – some days I’m just ragged; I need info for friends.”

“Hearing [about ABI in a way like ‘Keys to the ABI Cage’ CD talk] – he needs to have ABI told in a humorous way – things he can relate to – things he can see and touch.”

“[He] accepts it’s good to talk to someone else with ABI.”

“Information the family can understand.”

“We want people to understand - more education about ABI – it would even be nice to have a TV ad, they show so many ads what’s the latest one about drugs -yes something about ABI, you know.”

Accept assistance

“He has developed some insight: He accepts assistance.”

“He accepts he needs to use his mobile phone.”
**Hearing from others with brain injury**

“[He] accepts it’s good to talk to someone else with ABI.”

**Developing some quality of life**

**Finding ‘good’ people to help - Proper treatment, Suitable housing etc**

“Find good people.”

“We got a psychologist who came to see him and she was very helpful.”

“Get help with transition from hospital to home.”

“.got onto proper medication ,for depression ...Housing that suits the young person is important.”

“A guardian to oversee his life – he liked the guardian – she understood ABI - tests and treatment - If she hadn’t intervened he’d be dead.”

“At first he was very frustrated and angry with the world very angry with the people who ran him off the road because we caught them, we had a solicitor and she tracked them down and they were in court facing us and that was very difficult for him we got a psychologist who came to see him and she was very helpful.”

**Development of confidence/self esteem**

“...learning by his own mistakes, but not on tight leash ...but supported and shadowed.”

“He works 16 hours a week; Sympathetic understanding work is important.”

You should see him on the phone “I’m an artist now”. Has helped his self esteem - he feels like he’s out there and contributing to society and he’s made friends with others who have ABI, [with] similar injuries to himself,[it’s] easier when people understand.”
Some independence/happiness

“He’s got his mind and memory; I think he values what he’s got – he doesn’t think about what he hasn’t got.”

“My son said “Now ‘I’m perfectly happy.””

Whiteboard/signs/mobile phones

“Whiteboards, he’s only just started to use a diary, he couldn’t before, he tried but he wouldn’t know what day it was but now.”

“When he’s tired he might forget where the toilet is so not just for him it’s for others, there’s signs toilet this way.”

“...he lives with a mobile phone ringing ...we just program it in and it rings and tells him what he does at a particular time.”

Attitudes

“We’re lucky to still have him.”

“Appreciate the small gains and events.”

“I think you’ve got to you just have to take one day at a time.”

“Just think you’re lucky.”

“Every little thing is a gift.”
8.3 Professionals - Factors that have a positive effect on the lifeworld of clients

*Group X: The professional fills the gap after the person leaves rehabilitation:*

**Professionals walk beside families**

“To walk beside families once they’re discharged from the health system because they can feel like they are being left to sink or swim - discharge planning actually caters for a way of being followed up.”

“People with brain injury need help with not the medical needs but follow up needs - I think none of the current models work well that’s why they often struggle and their families struggle because the health bit ends at whatever point they think that your rehab is finished...”

“The needs of the family surrounding that person often are not looked at or managed.”

**Professionals keep an eye on providers**

“Someone keeping an eye on providers and making them a bit accountable for the decisions they’ve made.”

**Training for families**

“What we need to start saying is rehab doesn’t start till 2 years or 5 years post injury but we have this system where things have to be very set and very structured, again if you don’t fit the pigeonhole you don’t get...”

“We need regularly training for family carers. Current training is often just for the professional and service providers.”
Group Y: The person’s hope, acceptance and attitude is important:

Hope, love and dreams

“People with brain injury need hope – when the doctor says you’re going to be a vegetable, or that you’re only going to improve for 2 years or 5 yrs... people need to have hope.”

“People really want to connect and if it’s an animal – the primary thing is people want to connect and love and be loved – because it’s lonely having ABI – you think you’re mad and all of those things ...”

“His self worth – there’s a light inside him it may be masking other issues but it’s still a form of self esteem.”

“He has hope that he’ll improve – constantly.”

“I absolutely have no doubt that you can improve..that cells regenerate and that you’re learning like all of us can go on for ever...I do not believe at all that there is a limit, I’ve seen evidence of this in my work. In my work I see the contrary to that (that people only improve for the first two/five years).”

“If they get the basic and primary health care that they need and once you provide situations for people to thrive in, they will do that, and I’m always amazed that how far that can go.”

“I want to temper my comments because even when I think ‘oh my god, you don’t get (understand) this at all’ in fact I am often surprised with people given the right sorts of circumstances...”

“He’s got a highly developed sense of humour.”

“A sense of humour is important for people working with people with brain injury.”

Understanding

“Medical jargon is actually useless to you in the long run...not in diagnosis but what it means for life it’s actually quite useless information to families - education much broader than just information.”
“An important hurdle for them is having an understanding of the impact of the ABI on themselves.”

“What I’ve been really working with, employment skills and studies, so they have some foundations for whatever they chose to do next. It’s slow work.”

“They have information but they can’t absorb it. I think somehow they need to look at this and say, ok, I’d like to improve on this part, and this is how I’m going to do it. And I’ve been trying to work on the thinking part, and I think what you’ve got with the hand (Handy Thinking) would be just fabulous to incorporate into...”

“I really want to get them thinking what are the alternatives to watching television.”

“Palm pilots and a lot of mobile phones - they’ll use them like alarms, and also as sending themselves messages to remember things.”

“We need regularly training for family carers. Current training is often just for the professional and service providers. Carers aren’t comfortable because (to go to these training sessions) they think “I don’t want to be the only family carer amongst say 40 professionals.”

“They need things that have relevance - to maintain connection with their family, friends, community and workplace – we’re essentially tribal beings – people get isolated in acute hospitals, in rehab and back at home so the whole thing is about connection.”

**A sense of purpose**

“Help with the creation of purpose - purpose I think is an absolute key to everything we’re doing.”

“The “switch” to get people going again It’s the same things that everybody else does – their kids, their partners, their work it’s all those things that we all value – what makes me feel good? What makes me get out of bed every day and come to work?”

“There’s something about recreation that I think it’s important for a long time for people to be involved, but I think, the sense of purpose is so enormous in human beings, that to have lots of time, and nothing to do with it, no sense of purpose, is worse... it’s torture.”

“Socialization to him is the key it is the very centre of his world.”
“He could talk a leg off a table.”

**ABI can be an opportunity**

“There are some people who embrace the difficulties and others who fight them ... the embracing gets you further in the end... I guess there’s people who would have a view of the world that has happened for a reason, it is fortuitous and I need to embrace whatever this learning and this opportunity that has been provided to me.”

“Some people might see it as a wakeup call. Like some people may lose their jobs would lose their self esteem and would despair, and other people would say I get to spend extra time with my children and I think some people see it as that.”

“It [ABI] can bring you to despair, or it can help you to refocus your life and priorities and there’s something about your belief and faith or serendipity or whatever it happens to be... I’ve spoken to people for example, who say I can’t rush around so much, so I am able to listen more and that has opened huge opportunities for me.”