

**Strategies people use to participate in everyday occupations  
when experiencing persistent symptoms following a mild  
traumatic brain injury: A qualitative descriptive study**

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partial fulfilment of the degree of Master of Health Science (MHSc).

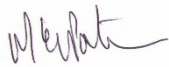
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## **Attestation of Authorship**

I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person (except where explicitly defined in the acknowledgements), nor material which to a substantial extent has been submitted for the award of any other degree or diploma of a university or other institution of higher learning.

A handwritten signature in dark ink, appearing to read 'M Paterson', is written on a light-colored rectangular background.

Maree Paterson

19.10.2016

“The ultimate paradox is that qualitative inquiry is impossible – both conceptually and practically – yet it still goes on. It must do so if the professions ... are to advance”  
(Elliott & Williams, 2001, p. 181)

## **Acknowledgements**

There were numerous times I questioned the value of writing a thesis. I kept coming back to my work as an occupational therapist, and the participants who so willingly shared their experiences. The thought that our combined insights may be useful to others, kept me engaged in this endeavour. Without the participants and their detailed and thoughtful descriptions, the research question would not have been answered. I will always be grateful for the opportunity to listen to the recovery journeys shared with me by the participants in this study.

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## Abstract

This exploratory study investigated the strategies that eight New Zealanders with persisting symptoms following a mild traumatic brain injury (mTBI) use to enable participation in day-to-day occupations that they need or want to do, in their homes, at work and in the community. The types of strategies that this group of people successfully use to mitigate against persisting symptoms is largely unreported in the literature.

This study utilised a qualitative descriptive methodology to investigate the question: “What strategies do people with persistent symptoms post mTBI use to manage everyday occupations?” This study had three purposes. First, to fill a gap in the literature and document specific strategies that people who do not make a full recovery from a mTBI use to manage their participation in everyday occupations. Second, to examine any patterns in the strategies adopted, which might indicate that the strategies used by this small sample of participants may benefit other clients to participate more fully in their everyday routines. Third, to determine if an occupational perspective could offer new insights and fruitful suggestions for further research.

Semi-structured interviews were held with eight people who volunteered to participate in this study after being approached by a third party. A conventional thematic analysis resulted in a nuanced account of developing strategies in direct response to unresolved mTBI symptomology and experiences, as the participants endeavoured to resume participation in previously familiar domestic, community and work related occupations.

In presenting the findings, the strategies were initially divided into two categories reflecting if they were deployed in the early stages of recovery (1-12 weeks post injury), or later in the recovery process. For the strategies deployed in the early stages of recovery, three themes emerged. These were taking off the load, relearning how to do things, and making things easier. In the later stages of recovery, further strategies were developed to manage the trifecta of symptoms that persisted post mTBI, categorised as matching occupational demands with available energy, achieving emotional control and managing the persistent changes in cognitive capacities, which were further broken down into subthemes.

The findings demonstrated a reoccurring pattern in the recovery process which may be useful for developing into intervention programmes to meet the needs of people who do not experience a timely recovery from a mTBI. In particular, there was a relationship between

capacity changes, fatigue, and the triggering of a stress response when routine occupations were unable to be executed, in same way prior to the injury. Three phases to the recovery process were identified. Phase one was characterised by taking off the cognitive load and reconfiguring simplified routines to meet essential self-care and productivity demands. The second phase required “recalibrating” the motor and cognitive components of problematic occupations, together with deploying compensation strategies, so occupational routines could be reliably performed. The final phase of the successful development of occupational functioning was accepting the changes in the way occupations were performed and stopping the struggle to get better.

The insights demonstrated in this research reinforce the complexity of learning how to manage simultaneously alterations in energy levels, emotional regulation and processing capacities. The occupational perspective shows how occupations which were routinely performed prior to the mTBI can be reconfigured and a satisfying balance between productively, leisure and play attained.

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# **Chapter 1 – Introduction to the Study**

This qualitative descriptive study explores the views of eight people who had experienced a mild traumatic brain injury (mTBI) and failed to make a full recovery within three months of their injury. Specifically, participants were asked about the changes to their routines post mTBI, and the special efforts they and others around them made to manage the challenges experienced in their everyday life. This enquiry was developed to answer the research question “What strategies do people with persistent symptoms post mTBI use to manage everyday occupations?”

Within the New Zealand guidelines for the management of concussions (New Zealand Guidelines Group [NZGG], 2007) there is no information on how to manage persistent symptoms post mTBI, reflecting the dearth of information in the literature. Learning more about how people engage in their everyday occupations in real life contexts when they do not make the expected timely recovery post mTBI provided the impetus for conducting this research project.

A qualitative descriptive methodology was selected as it offers a framework for understanding complex experiences that are embedded within the human context (Sullivan-Bolyai, Bova, & Harper, 2005). This methodology is a form of naturalistic enquiry, using low inference interpretations, and everyday language to present the facts (Sandelowski, 2000). Analytic strategies, as outlined by Miles and Huberman (1994), are used to; code data from transcribed interviews, identify commonalities and differences, develop generalisations pertaining to the data, and to examine these generalisations in relation to what is known in the literature.

In the remainder of this chapter, I will firstly define the terminology pertaining to my study. Next, I will provide a conceptual overview followed by an outline of the significance of the study. Thirdly, I will provide the context for this research topic by briefly discussing the management of mTBI within New Zealand, and describing my own interest in this topic. Finally, I will outline my responsibilities as a researcher acknowledging the assumptions I made at the commencement of this project.

## **Defining Concepts**

### **Mild traumatic brain injury**

Although a universally accepted definition of mTBI is lacking (Pertab, James, & Bigler, 2009; Ruff, Iverson, Barth, Bush, & Broshek, 2009), the widely used American Medical Associations’ grading system for brain injuries (Kay, Harrington, & Adams, 1993) has been adopted in this study and utilised when discussing the literature. Thus mTBI is defined as a closed head injury resulting in

a traumatically induced physiological disruption of brain function with at least one of the following three features: 1) any loss of memory for events immediately before or after the accident, 2) any alteration in mental state at the time of the accident e.g., feeling dazed, disoriented, or confused, 3) neurological deficits which may or may not be transient. In addition, the score on the Glasgow Coma Scale is between 13-15 points thirty minutes after the injury, and any post-traumatic amnesia has a duration of less than 24 hours. As few people suffering a mTBI receive an immediate medical assessment, or have a Glasgow Coma scale administered within 30 minutes of their injury, I have accepted participants for this study who generally fit the above description with a period of post traumatic amnesia lasting less than 24 hours.

### **Persistent symptoms**

A cluster of symptoms have been demonstrated in approximately half of the people experiencing a mTBI (Kraus & Nourjah, 1988). These symptoms are; headaches, dizziness, fatigue, irritability, reduced concentration, sleep disturbance, memory dysfunction, sensitivity to light or noise, double or blurred vision, frustration, restlessness, anxiety, depression and sensitivity to alcohol. Many people recover quickly from a mTBI with a predictable clinical course of recovery within a few days to a few weeks following injury (Bigler, 2008). An estimated five to 15% of people post mTBI were thought to experience permanent symptoms (Binder, Rohling, & Larrabee, 1997; Cassidy et al., 2014; Grant, 2005). However, a longitudinal study based in provincial New Zealand, demonstrated that almost 50% of participants were suffering four or more symptoms relating to a mTBI, one year post injury (Theadom et al., 2016). This recent finding suggests that many people do not attend a hospital at the time of their injury, hence the number of people with a complex recovery post mTBI, may have been underestimated in past epidemiology studies. Thus, the number of people experiencing permanent symptoms post mTBI may also be underestimated.

In my study any combination of symptoms associated with a mTBI lasting longer than three months post injury is referred to as persistent symptoms. Participants were considered for selection if they experienced persistent symptoms for at least three months, to clearly differentiate them from the group who make an early full recovery. This timeframe was expected to be sufficient for the impact of changes in capacity post mTBI to be identified and for coping strategies to be initiated. The ongoing process of developing and applying strategies to enable successful engagement in everyday occupations was not expected to be completed for all participants.

The nature of persisting symptoms post mTBI is poorly understood (Bigler, 2008; Lishman, 1988). A debate spanning 150 years, on whether or not neuro-cognitive or neurobehavioral sequelae

best explain the persistent symptoms, remains unresolved (Bigler, 2008; Evans, Iverson, Yatham, & Lam, 2014). For example, Kashluba et al., (2004), demonstrated that most people experience a dramatic reduction in symptom severity one month following a mTBI, with relatively few differences between matched controls and people with a mTBI three months post injury. Kashlubas' study is part of the evidence used by McCrea (2008) directing us to understand persistent symptoms post mTBI as a "neuropsychological disorder maintained by a combination of psychological and social factors in the overwhelming majority of cases" (p. 118). An occupational perspective is lacking in this debate.

## **Occupation**

Central to an occupational perspective are concepts of occupation, occupational loss and adaptation. Occupational therapists have long believed that participation in occupation influences health (Reilly, 1984; Wilcock, 1993). Engaging in meaningful occupation allows basic human needs to be met, capacities to be exercised, and for meaning about one's life to be experienced (Wilcock, 1993). Very simply, occupations are activities that engage one's attention interest and/or expectation e.g., sailing a yacht, reading a novel, cooking a meal, writing a report, completing a business quote. In order to maintain daily routines, repetitive patterns of occupations are performed in sequence and in conjunction with other occupations (Erlandsson & Eklund, 2001). Other occupations occur less frequently e.g., taking a vacation or redecorating one's home, or reappear in one's repertoire with seasonal changes. Furthermore, involvement in everyday life implies broken patterns (Erlandsson, Rognvaldsson, & Eklund, 2004) which may reflect unpredictable events and irresolvable conflicts, or be irrational or duplicitous (Felski, 2000). The expected focus on occupation in my study is on ordinary and familiar things that people do every day. At times in the thesis, occupation is interchanged with activity or task, to reflect the terminology used by the author or participant whom I am discussing.

## **Occupational loss**

Occupational loss can occur when a person's capacities are altered or impaired (Townsend & Polatajko, 2013). Impairment refers to any problem with normal psychological or physiological function or with a body structure or organ (World Health Organisation [WHO], 2001). Impairments may disrupt occupational patterns and make chosen occupations difficult or impossible to perform (Townsend & Polatajko, 2013). Typically post mTBI, the disrupted occupational patterns occurring in complex environments provide people with the most potent information on altered capacity (Gilworth, Eyres, Carey, Bhakta, & Tennant, 2008; Nilsson, 2011).

Losing occupations, even temporarily, can impact deeply on a person's sense of identity and self-worth, causing emotional distress, depression, and periods of sadness (Townsend & Polatajko, 2013). People with persistent symptoms post mTBI express difficulties with everyday occupations, demonstrate reduced attendance at work or school, and experience low levels of life satisfaction (Stålnacke, 2007).

## **Occupational adaptation**

Occupational adaptation or the process of "learning to live well with an impairment in the context of one's own environment" (Hammell, 2006, p. 8) is fundamental to the practice of occupational therapy. My study is aimed at developing a better understanding of how disrupted patterns of occupations are managed, when people fail to make a timely recovery after mTBI.

At the most basic level, occupational adaptation refers to the "special efforts" and "changes in doing" (Klinger, 2005, p. 9) that occur in response to internal or external stressors, which permit successful participation in occupation. Schkade and Schultz's (1992) theory of occupation adaptation integrates concepts associated with the internal psychic processes associated with humans' overwhelming desire to be engaged in meaningful occupation, with the process of striving for and achieving mastery. If someone experiences a sudden life change, his or her ability to adapt can become overwhelmed, resulting in an experience of dysfunction. Conversely, success can be experienced if a person adapts well enough to satisfy him or herself and society. The small number of studies (Blijlevens, 2005; Gooder, 2001), exploring the relationship between occupation impairment and health, supports Schkade and Schultz's theory that the presence of an impairment may or may not undermine wellbeing (Hocking, 2009).

A small study by Nilsson (2011) suggests that, following a mTBI, people experience occupational adaptation. Participants reported an initial emphasis on struggling to be the person they were before their injury. Repeated performance failures along with fatigue and dysphoria led to an awareness that the 'capable person' had gone. Gradually the process of challenging themselves in important occupations enabled new strategies to emerge to manage everyday situations. The participants who adjusted to living well with their impairments reported that they stopped trying to get better, were more relaxed with who they had become, and could generate strategies to overcome everyday problems. The strategies people utilised were not recorded in this study.

## **Strategy**

A strategy is defined as a practical plan of action used to overcome impairments or reduce the impact of any barriers encountered. Thus a strategy can be conceived as the “doing” part of managing an impairment.

As discussed by Dodd et al., (2001) people will select a strategy to use if the difficulty they face is bothersome. In identifying the strategies people are using, I can gain knowledge about the bothersome impairments that are impacting everyday occupations. I am interested in identifying what strategies people start using and how these change over time.

## **Conceptual Overview of Study**

The occupational perspective in my study takes into account both the symptoms and impairments associated with the mTBI, and the impact this has on everyday occupations. A closer look at Kashluba et al., (2004) study, reveals three significant persisting symptoms, experienced by 60% of the mTBI group. These are; doing things more slowly, fatiguing more quickly, and experiencing subtle balance problems. Personal experience suggests that these three difficulties impact on everyday occupations and, in contrast to suggestions by McCrea (2008) and others, may not be “minimal” in their impact. For example, an electrician with subtle balance problems might need to use two hands to remain steady while climbing a ladder and may experience dizziness and nausea in cramped spaces with poor light. Carrying equipment becomes problematic when two hands are needed to steady oneself and working in confined spaces may not be avoided. The distress this can cause if the worker tries to cover up these difficulties, is suspected of malingering, and/or experiences sanctions for decreased productivity, can be considerable not only for the person concerned, but also for their colleagues and family. What little we know about the impact of symptoms on everyday occupations, following an mTBI, will be explored in the literature review in chapter two.

In asking people who sustained a mTBI about the strategies or special efforts they needed to make to engage in everyday life, I aim to better understand the occupational challenges pertaining to everyday life and gain knowledge about how these challenges were mitigated. By identifying a “data bank” of strategies which have been used in real life, it may be possible to promote dissemination and wider use of these strategies reducing the impact of persistent symptoms on everyday life after a mTBI.

The value of taking an occupational perspective is demonstrated in a study (Jackson et al., 2010), that investigated the development of advanced pressure sores, occurring in 95% of adults following a spinal cord injury. This high rate of ulcers has persisted despite intense research and

comprehensive education about the known risks. The analysis of everyday occupations, which were occurring around the times the pressure areas developed, revealed eight patterns of behaviour and environmental circumstances which were not previously known. For example, changing care givers resulted in disruptions to well-rehearsed routines, when the “taken for granted” sequences for dressing and toileting were not translated into skilled applications with the new caregiver. Another danger period was engaging in spontaneous opportunities for adventure, when the usual attention to skin care was forgone in the moment of having fun. Identifying these patterns enabled the development of preventative interventions for implementation at critical junctions throughout a person’s life.

In addition, when older people were asked about their experiences with everyday occupations (Hocking, Murphy, & Reed, 2011), a range of strategies not previously utilised by the health professionals, who were working to minimise the impact of disability and aging, were revealed. Together these studies reinforce the value in exploring the perspectives of the people who are the recipients of rehabilitation services and involving them in the research.

## **Significance of the Study**

The importance of developing an understanding of how to live well with the persisting sequelae associated with mTBI is threefold. First, the incidence of mTBI is high, with an estimated 750 cases per 100,000 per year in New Zealand (Feigin et al., 2013). The conservative estimate of 5-15% of people experiencing permanent difficulties equates to 15,000 - 45,000 additional New Zealanders learning to live with long term effects of a mTBI each year. Hence, there is nothing “mild” regarding the impact of mTBI in our society. Second, the burden associated with persistent symptoms following an mTBI is significant for both society and the individual concerned and their families. International research suggests that approximately 35% of people with persistent symptoms post mTBI fail to return to work (Fraser, Machamer, Temkin, Dikmen, & Doctor, 2006), with a threefold increase in the development of a mental disorder after a mTBI (Mooney & Speed, 2001). Finally, the available literature and guidelines for interventions for people with a mTBI focus predominantly on early interventions designed to prevent the development of persisting symptoms (Snell, Surgenor, Hay-Smith, & Siegert, 2009). The question of how best to support people with long term impairments has been largely ignored.

In addition to an improved understanding of how disrupted occupational patterns might be mitigated, this study may offer new insights into understanding the impact of persistent symptoms on everyday occupations and offer fruitful avenues for further research.



## **Context of the Study**

### **Management of mTBI in New Zealand**

The New Zealand Accident Compensation Corporation (ACC) provides a comprehensive, no blame cover for all people who sustain an injury in New Zealand as the result of an accident. In 2006 guidelines for the management of traumatic brain injuries including concussions were released (New Zealand Guidelines Group, 2006), which continue to provide a comprehensive synthesis of the literature which underpin best practice recommendations for early interventions. In 2010, a Concussion Service Contract was released for early intervention following a mild or moderate brain injury (Accident Compensation Corporation [ACC], 2010), which was updated in 2015 (ACC, 2015). This initiative allows access to early education, with access to a multi-disciplinary team as required and support to return to paid employment if the person was employed prior to injury. Importantly for my study, however, there were no guidelines for the management of persistent symptoms, perhaps reflecting the assumption that timely early interventions will prevent chronicity.

### **My interest in this area of research**

In 2002, I began working in brain injury rehabilitation with a company who did not have an early intervention clinic. My initial mTBI work was with people who did not receive timely early interventions, or had not made a successful return to pre-injury employment. I assumed that people who failed to recover had missed a window of opportunity to benefit from early education and support, received less than optimal early interventions, and/or experienced environmental or personality factors which limited progress. When I started working with people immediately after their mTBI, it became apparent that, despite best efforts, some clients with supportive families who were clearly motivated to make a timely recovery were not achieving a full recovery.

Consequently, I enrolled in training courses to better understand the cognitive, visual, vestibular, and balance problems pertaining to mTBI. I developed contacts with optometrists and physiotherapists, who had postgraduate training in visual and vestibular difficulties, and commenced supervision with a neuropsychologist. Despite offering a comprehensive range of early interventions, a proportion of clients continued to experience persistent symptoms post mTBI.

A review of the literature revealed two studies which resonated with me. The first was a case study by Bootes and Chapparo (2010), which challenged my reliance on neuropsychology assessments to identify occupational performance difficulties in real life settings. The second

was a large randomised controlled study by Andersson, Emanuelson, Björklund, and Stålhammar (2007) demonstrating that tailored early interventions did not lead to improved outcomes for people with uncomplicated mTBI. These studies prompted me to review my involvement in early intervention clinics, challenging me to develop a better understanding of the experience of living with impairments post mTBI.

## **Responsibilities as Researcher**

Engaging in qualitative research requires the researcher to demonstrate an understanding of reflexivity, or awareness that all knowledge is affected by the social conditions under which it is produced (Hesse-Biber & Leavy, 2011). In denoting one's attitudes and values at the beginning of the research process, the researcher begins the process of contrasting the complexity of one's own world view with others, guarding against introducing personal biases that shape the research findings.

At the onset of this study, a presupposition's interview was conducted with an experienced researcher. Transcripts of this interview were made available to both my supervisors, and plans were made to revisit this information during the data collection and data analysis stage of the research process.

Originally I negotiated to have a second supervisor who did not have a background in occupational science or occupational therapy. I felt this could help expose some of the taken for granted assumptions embedded in my discipline, thus improving the depth of my analysis. Prior to data collection, this supervisor left the university and for pragmatic reasons was replaced with another occupational scientist. I quickly learned that as a novice researcher there was plenty of scope to develop sound analytical skills utilising resources within my discipline, thus challenging one of my preconceptions.

The final part of this chapter provides an overview of my thesis, which is presented in eight chapters.

## **Overview of Thesis**

The first chapter has outlined the focus of my study, and outlined my interest in identifying the strategies that people use to manage complicated sequelae post mTBI. The salient facts as to why this topic is relevant to the practise of occupational therapy in the New Zealand context have been presented. Chapter two reviews the literature pertaining to the research question. The unresolved controversy surrounding the nature of persisting difficulties post mTBI is presented together with what is known about strategy training with this group of people. In the third chapter the rationale for selecting a qualitative descriptive methodology to guide this

research project is presented. Details of how the study was conducted permits the reader to understand the processes deployed to recruit and select participants, maintain ethical standards, collect and analyse the data and ensure rigour. Chapter four briefly introduces the participants and orientates the reader to the occupational nature of the challenges facing participants when they do not make a timely recovery from a mTBI.

Chapters five to seven present the research findings. The fifth chapter describes how participants recognised occupational performance difficulties post mTBI and identifies common problems that were experienced. The initial strategies that were adopted to cope with disrupted occupational patterns are presented. In chapter six the reality of participants when they do not make the expected full recovery is explored in three parts. First, the readers are orientated to the complexity of learning to live with altered capacities for regulating energy levels, managing emotional responses and processing complex information, which simultaneously impact on occupational performance. Second, the deployment of strategies to regulate energy levels, and manage persistent periods of fatigue are identified and discussed. The third section focuses on the strategies utilised to regulate emotional responses, which support participation in everyday occupations and help maintain effective relationships with others. Chapter seven identifies strategies deployed to compensate for changes in cognition and processing speed and gives some examples of how persisting difficulties were remediated.

Finally, in chapter eight, a synopsis of the research findings is present and situated in the relevant literature. Implications for practice are developed and recommendations for further research are presented. The study's strengths and limitations are identified and a conclusion is formulated.

## **Summary**

The aim of this qualitative descriptive study is to fill a gap in the current research, by identifying the strategies that are utilised to support participation in everyday occupations after mTBI. The specific question I have used to frame this research is "What strategies do people with persistent symptoms post mTBI use to manage everyday occupations?" In asking this question, I want to gain insight into the occupational performance difficulties that are experienced when the expected full recovery post mTBI does not occur. I envisaged exploring the aspects of occupational performance, which proved problematic post mTBI and how these difficulties were managed to minimise disruption to important life roles. I wanted to determine if there were consistent patterns to the dysfunction, which could be addressed in the early stages of rehabilitation. The research findings are expected to form evidenced based knowledge which may be useful for others to facilitate increased participation in everyday life, when the expected

full recovery does not occur in the first few weeks after a mTBI. Furthermore, this information may be useful for service providers to help identify areas in the provision of services that need to be strengthened and for researchers to open new lines of enquiry.

## Chapter 2 – Literature Review

As stated in chapter one, a small proportion of people post mTBI fail to make a full recovery. A review of 23 clinical practise guidelines (Berrigan, Marshall, McCullagh, Velikonja, & Bayley, 2011) demonstrated that the guidance on treatment and management for this group of people is “severely lacking” (p. 750). Al Sayegh (2010) responded to the multiple inconsistencies in the literature pertaining to mTBI by stating that “perhaps the only area that clinicians do agree on is that there is a lack of clear, evidence-based treatment strategies to guide our clinical management of such patients” (p. 1128). Similarly, Chen and D'Esposito (2010) reflected that “unfortunately, most tests of cognitive functioning, including neuropsychological tests and most cognitive science neuroscience, are not designed to reflect the complexities and low structure of settings in the real world” (p13), while Bigler (2008) concluded that “we have reached a level in the investigation of mTBI sequelae where the entire role of traditional neuropsychological methods in mTBI needs refinement” (p. 198). Together these statements suggest that; the sequelae of a mTBI are poorly understood, traditional assessment processes are inadequate, and a better understanding of difficulties, as they occur in the real world, is necessary.

A detailed review of the vast amount of conflicting literature pertaining to mTBI, is beyond the scope of this study. I have therefore summarised what *is* known about the acute symptoms following mTBI and briefly outlined the contentious issues in determining the nature of persistent difficulties. I then focus on the studies offering insights into the functional difficulties post mTBI and their management. In reading across the literature, research studies pertaining to interventions generally fell into one of three categories; preventing chronicity, addressing the psychological mechanisms thought to underpin the maintenance of chronic symptoms, and addressing cognitive difficulties. For ease of presentation, I have utilised these categories in presenting information from the literature base, adding a further section on mTBI and occupation. Prior to discussing the content of the literature, I outline my search strategy.

### Conducting a Literature Search

In investigating the strategies adults use to manage persistent difficulties post mTBI, the key concepts of post-concussion symptoms, everyday occupations, and rehabilitation were adopted. These concepts were searched on Scopus, Medline, CINAHL, Sports Discus, Cochrane, and AMED search engines, using combinations of the following words; mild traumatic brain injury, post-concussion syndrome, mild head trauma, rehabilitation, manage, adjust, intervene, adapt, daily living, occupation, work, and daily life, for a 10-year period from 2000 to 2014. The

literature search was updated in 2016. Papers gathered in the course of prior learning, pertaining to executive functioning, visual, vestibular and balance difficulties, together with occupational performance research were also utilised. Review articles were sourced to update knowledge in these areas and reference lists utilised to locate details of relevant studies not previously cited.

Only peer reviewed journals and articles available in English were considered. Unless otherwise stated, papers were excluded if;

- multiple levels of brain injury severity were included and the cohort with a mTBI could not be differentiated in the findings;
- multiple age groups were reported, and the adults could not be differentiated from those under 16 years old;
- the quality of the research paper was poor with insufficient detail to support the findings;
- the description of sports injuries and return to competitive play guidelines did not have direct references for understanding difficulties in other domains of everyday occupations;
- the mTBI was sustained by military personnel in combat, with research findings relevant for war zones rather than civilian populations.

### **Acute Symptoms Following mTBI**

It is generally accepted within the literature that four features dominate acute symptoms, post mTBI (Bigler, 2008). First, a brief alteration in consciousness or neurological function with at least an acute decrease in processing speed is experienced. Next, physical symptoms of headaches, dizziness and/or vertigo and increased fatigability commonly occur. Third, impairments in short term memory, attention and concentration, particularly for multi-tasking, impede processing capabilities, and last, there is an increased likelihood for changes in mood and emotional functioning. In addition to the concussed brain, there is often damage to the eye, face, neck, vestibular apparatus and internal organs (Bigler, 2008). Thus common symptoms and underlying pathology can be summarised as; 1) damage to the peripheral vestibular apparatus with symptoms of vertigo, dizziness, tinnitus, and ocular disturbance, 2) neck injuries with whiplash symptoms and cervicogenic dizziness, 3) post traumatic pain which is known to change the structure and functioning of the brain, 4) fatigue which remains poorly understood, 5) slowed information processing speed and cognitive difficulties, which can impact on dual task capabilities, 6) production of stress hormones which has an effect on all people involved in

trauma and can co-occur with symptoms of post-traumatic stress syndrome, anxiety and depression, 7) pituitary dysfunction, and/or subtle abnormalities in stretched blood vessels potentially contributing to poor regulation of blood flow, persisting headaches and dizziness, and 8) an increased risk for chronicity for those people with pre morbid factors, including drug and alcohol misuse or a prior psychiatric illness.

There is good evidence that abnormal neurophysiology is the predominant cause of symptoms immediately after a mTBI (Barkhoudarian, Hovda, & Giza, 2016; Grant, 2005). Animal studies demonstrate a complex cascade of biochemical events resulting in a harmful range of physiological stress responses and disruption to the intracellular processes (Giza & Hovda, 2001). Functional imaging with single photon emission computed tomography (SPECT), show metabolic changes and perfusion abnormalities (McAllister, Sparling, Flashman, & Saykin, 2001), and biomechanical studies inform us that a loss of consciousness is more likely to occur if there is some rotational force present (Viano et al., 2005; Vorst, 2007). Neuropsychological testing confirms impairments of speed of information processing, attention and or memory in the first few days after injury (Carroll et al., 2014). What remains contentious are the reasons that 10% to 50% (Alexander, Shelton, Fairhall, & McNaughton, 2007; Binder, 1986; Theadom et al., 2016) of people experience persistent symptoms for more than three months post mTBI.

### **Nature of Persistent Symptoms post mTBI**

For some, it is assumed that the adaptive nature of brain function combined with neural plasticity mitigates against any lasting neurological sequelae resulting from a transient concussion resulting from a mTBI (Iverson, 2005). Studies using computed tomography (CT), or magnetic resonance imaging (MRI), seldom detect any neuropathology (Bigler & Snyder, 1995), and traditional gold star neuropsychological testing concurs indisputably that the vast majority of people return to pre-injury base line functioning within weeks of their injury (Larrabee & Rohling, 2013).

The complex array of persisting symptoms that some experience (dizziness, fatigue, headaches, impairments in short term memory, attention and comprehension, and changes in mood and emotional functioning) are not specific to mTBI and are commonly reported in psychiatric disorders (Edmed & Sullivan, 2012; Iverson, 2006; Moore, Terryberry-Spohr, & Hope, 2006), medical illnesses (Gunstad & Suhr, 2004; Lees-Haley, Fox, & Courtney, 2001), pain conditions (Iverson & McCracken, 1997; Radanov, Dvoak, & Valach, 1992) and even in healthy individuals (Fear et al., 2009; Iverson & Lange, 2003; Wang, Chan, & Deng, 2006). Similarly for athletes who do not make a timely full recovery from on field concussions, persisting symptoms become vague and ill-defined, characterised by complaints of persistent headaches and descriptions

such as; “feeling slowed down”, “feeling like in a fog”, “fatigued or low in energy”, and “difficulty concentrating” (McCrory et al., 2013). A meta-analysis of emotional symptoms post mTBI, concluded that only minimal effects on psychological and psychosocial symptom reporting were directly attributable to the mTBI (Panayiotou, Jackson, & Crowe, 2010). This finding supports consideration for factors, other than the brain injury, to improve the understanding of mTBI sequelae.

The increase in conscious effort that is required to concentrate and complete even simple tasks, in the acute stage of recovery post mTBI, was described by van Zomeren and van den Burg (1985). This sustained effort can lead to fatigue, headaches, and anxiety, which in turn can exacerbate information processing difficulties. Negative expectations regarding cognitive performance can develop and create additional stress. This can lead to avoidance of anxiety provoking situations, including those tasks requiring optimal cognitive abilities, which in turn, can lead to a loss of confidence and self-esteem, and contribute to the development of psychiatric disorders such as anxiety or depression.

These “vicious cycles” of maladaptive behaviour are integral to the various multi-dimensional models seeking to explain the maintenance of persistent symptoms post mTBI (Kay, Newman, Cavallo, Ezrachi, & Resnick, 1992; Lishman, 1988; Montgomery, 1995). For example, Lishman’s (1988) influential model differentiated between the ‘physiogenesis’ and ‘psychogenesis’ of symptomatology post mTBI, observing that the complex interplay between the organic and non-organic contributions is time dependent. Central to Lishman’s hypothesis is that the organic symptoms, apparent at the onset of the injury, resolve fairly rapidly for most people. Over time psychological factors emerge and strengthen, hampering both symptomatic and functional recovery. Iverson and Lange (2011) offered an updated biopsychosocial conceptualisation of the factors contributing to both the development and maintenance of persistent symptoms post mTBI. This model suggests that structural or microstructural damage to the brain is not necessary to either cause or maintain symptoms post mTBI. Thus there are many factors that could singularly or in combination be the underlying cause of these symptoms. For example;

If a person is deconditioned, anxious, depressed, drinking too much alcohol, and sleeping poorly, it is very likely that he or she would feel cognitively impaired and have trouble functioning at work and in daily life, due to a diverse range of symptoms (e.g., headaches, fatigue, and emotional instability). As such treatment can be focused on specific symptom target areas, such as improving sleep hygiene and reducing alcohol use.” (Silverberg and Iverson, 2013, p. 362).



The strong voice within neuropsychology suggests that, for most people, there is no known long-term brain damage underpinning persistent symptoms post mTBI, is reflected in the evidenced-based best practice guidelines (NZGG, 2006), underpinning the provision of rehabilitation services for mTBI (ACC, 2015). Management and rehabilitation in the post-acute recovery period of mTBI, is offered on a pragmatic basis, providing reassurance and advice for managing persisting symptoms, with acknowledgement that there are no published trials of high quality studies to guide management.

Embracing the uncertain aetiology of persistent symptoms post mTBI, a self-management programme was developed (Kendrick, Silverberg, Barlow, Miller, & Moffat, 2012), to weaken the link between symptoms and disability, and support participants to more fully engage in valued activities. Interventions were provided by occupational therapists, in a variety of environments, and by clinical psychologists via 30-minute telephone conversations. By targeting emotional consequences of health conditions and developing strategies to more efficiently participate in occupations, there were significant gains ( $p < 0.0001$ ) in both participation (75% of participants) and satisfaction (85% of participants). These gains were maintained, and sometimes improved on, at the 9-month follow-up point, supporting further development of this approach. Unfortunately, the occupational challenges and successful strategies employed by participants were not specified.

Others postulate that microscopic damage resulting from a mTBI, simultaneously occurring in neural, vascular, and dural tissue *across* brain networks, can prevent a full restoration of homeostasis (Bigler, 2008; Cohen et al., 2007; Ellis, Leddy, & Willer, 2015), directly causing most of the physical, cognitive and emotional sequelae post mTBI. Emotional changes may represent an indirect psychological reaction to the trauma, and/or occur as a direct consequence of damage to the emotional regulation system (Draper & Ponsford, 2008). The following is a good example of how damage in the vestibular system may simultaneously impact on balance, ocular-motor performance, post-traumatic stress and problem solving abilities.

While the mechanisms are not fully understood, the highly integrated systems for postural control and balance would logically be affected by a slowing of signal processing. This suggests that some vestibular features related to the integration of the vestibular-ocular reflex (VOR) and the vestibulospinal tract (VST) with the brain stem and the cerebellum also interacts with the frontal lobe circuits mediating judgement, decision making, and anticipation. In addition, to the extent that anxiety, response to threat, post-traumatic stress disorder, and/or loss of emotional control

become an issue, these can further aggravate functional balance. (Fife & Kalra, 2015, p. 99)

Biomechanical studies (Bayly et al., 2005; Viano et al., 2005) demonstrate the vulnerability of the upper brain stem, hypothalamic-pituitary axis, medial temporal lobe, along with the basal forebrain and long-coursing white matter fibres involving the corpus callosum and fornix, in mild brain injuries. Histology studies of people suffering a mTBI, but dying of other causes, show neural related damage (Omalu et al., 2005), and human and animal studies have shown outward appearance of recovery but continued metabolic derangement (Johnson, Stewart, & Smith, 2013).

With the advancement of diffusion tensor imaging (DTI), the analysis of specific neural connections has been possible, showing white matter microstructure not seen on conventional CT and MRI imaging (Bigler, 2013). Damage to the long white matter tracts of the brain (Messé et al., 2011), with implications for efficient functioning of attentional and working memory networks, have been demonstrated. Likewise tracts in the inferior frontal, frontotemporal and limbic systems are commonly damaged after a brain injury, including mTBI (Levine et al., 2008), which has implications for understanding alterations in motivation and drive (Pardini, Krueger, Raymont, & Grafman, 2010). For example, in a study of American retired national football league players, a relationship between depressive symptoms and damage to white matter integrity, in pathways known to participate in emotional control, executive function, attention, working memory, and language was shown (Strain et al., 2013).

Advanced magnetic resonance technology is sensitive to multiple types of pathophysiologic neural networks, and is advancing knowledge on how neuropathological processes disrupt or damage different networks, and how the brain responds or adapts to the injury (Bigler, 2013). For example, experimental work in the development of algorithms for interpreting scan results (Lui et al., 2014) suggests that measures of thalamic integrity (located in the upper brain stem) are key elements for differentiating between the control group and those with a mTBI. As stated by (Bigler, 2013), “even subtle impairment at the thalamic level or integrated thalamocortical or corticothalamic tracts may disrupt the cortical organisation of a variety of cognitive and neurobehavioral functions sufficient to result in many of the symptoms frequently associated with mTBI” (p. 2).

Combining what is known about cranial nerve damage, co-occurring with mTBI, with central nervous system and vascular pathology, Ellis et al., (2015) developed a novel framework for diagnosing and managing persistent symptoms. These researchers suggested that, for the

majority with symptoms persisting three weeks or more post mTBI, pathology in one or more of the following three subsystems is evident; 1) global metabolic systems, 2) vestibular-ocular systems and 3) cervical spine and somatosensory systems. The fourth cluster describes the very small, albeit significant number of people presenting with predominantly affective disorders of depression, anxiety, and disrupted sleep. Studies to correlate patient symptoms with specific organic impairments are underway using advanced neuroimaging techniques.

Proponents of the view that mTBI disrupts neural networks, suggest that pathophysiology underpins most of the persistent symptoms arising from the mTBI and should be ruled out before considering psychological responses, illness behaviour and malingering to explain persistent symptoms (Bigler, 2008). This view implies that specific patterns of behaviour occur in response to the neuropathology. Mitigating symptoms will occur by either advancing new ways to stimulate homeostasis and/or by supporting behavioural changes, which progressively occur over time, as people adapt to the subtle changes in their neurological functioning and improve their functioning.

In summary, there is no consensus on the nature of persistent symptoms post mTBI, and no agreed diagnostic framework exists to predict outcome and guide therapeutic decisions for people post mTBI. Perhaps more important than the “sterile debate concerning the psychological vs organic origins of symptoms” (Wood, 2004, p. 1135), is the degree in which impaired functioning can be improved by a particular intervention.

## **Early Interventions**

### **Balancing rest and activity**

Supporting a graduated return to usual activities, ‘as symptoms permit’ appears in many contemporary guidelines for managing mTBI (Silverberg & Iverson, 2013). Although this recommendation makes good intuitive sense, it is difficult to apply due to the different mechanisms and severity of injuries underpinning a mTBI, and the wide range of pre, peri and post injury biopsychosocial factors, potentially impacting on recovery (Alla, Sullivan, & McCrory, 2012).

Importantly, there is no clinical research proving that rest enhances recovery or diminishes the long term sequelae associated with mTBI (Wells, Goodkin, & Griesbach, 2016). In a randomised control study examining early versus later mobilisation (de Kruijk, Leffers, Meerhoff, Rutten, & Twijnstra, 2002), adult participants were assigned to a tapering rest schedule over five days. One half of the trial population commenced graded activities, day one of their mTBI, after 4 hours of

bed rest, resuming usual activities on day five. The other participants had 6 days of bed rest followed by the same activation programme over five days. Two weeks post injury, the group with extended bed rest demonstrated decreased dizziness, and a trend for a further 13 symptoms to decrease in intensity. At six months post injury the benefits had disappeared and in some instances reversed. It is not known if cognitive restrictions were in place while the participants were on initial bed rest, however participants in the control group found it difficult to maintain bed rest and reported a greater use of analgesics.

Another small prospective study (Moser, Glatts, & Schatz, 2012) reported that high school and college students benefitted from a week of “comprehensive rest”, regardless if the rest occurred immediately following the mTBI, or weeks or months after the injury. A study by Majerske et al., (2008), showed that those participating in a moderate amount of activity performed better than those who stayed home doing very little, and better than those who engaged in a full schedule of study and competitive sports. Furthermore 60 adolescents and adults who had an atypical recovery from a mTBI, were referred for an aerobic exercise programme (Baker, Freitas, Leddy, Kozlowski, & Willer, 2012). Two-thirds of the subjects experienced an exacerbation of symptoms during exercise, and more had headaches and fatigue at rest. Although the study sample was small, it was demonstrated that any exacerbation of symptoms occurring during exercise was temporary, with no lasting effects recorded for any of the research participants.

Deciding on the timing for graduations in returning to usual work and play activities is compounded by the “double edged sword” associated with exercise (Griesbach, 2011). Animal and human studies show that voluntary exercise in the post-acute recovery of mTBI is linked with improved neural plasticity and cognitive and emotional wellbeing (Kozlowski, Graham, Leddy, Devinney-Boymel, & Willer, 2013). Conversely, rigorous exercise appears counterproductive, if commenced in the acute period post mTBI, while the brain’s energy consumption is thought to be directed to neuronal repair and homeostasis (Griesbach, Hovda, Tio, & Taylor, 2011). In animal studies the length of the window where exercise fails to be therapeutic, differs depending on the severity of the injury, and hasn’t been determined in humans (Griesbach, Gomez-Pinilla, & Hovda, 2007). Finally different forms of exercise regimes involve distinct motivation and fatigue characteristics, eliciting different stress responses (Griesbach, Hovda, Tio, & Taylor, 2011). A hyper-response to stress correlates with strong increases in glucocorticoids, which suppress the production of proteins required for neuroplasticity.

It remains unclear if physical or mental exertion, sufficient to exacerbate post mTBI symptoms at any stage of recovery, has negative long term consequences. Silverberg and Iverson (2013)

found no evidence that bed rest, lasting longer than three days post injury enhanced recovery, and concluded that post mTBI, a combination of physical inactivity, avoidance behaviours, and limited mastery opportunities while resting, may contribute to the cognitive distortions and misattributions that prolong recovery, and contribute to the development of serious mental illnesses. A pilot study by Leddy et al., (2010) enrolled six athletes and six non athletes, with an atypical recovery, in an exercise programme using a standard treadmill protocol. After five weeks all participants were able to exercise at or near to their age related heart rate maximum, and reported a decrease in post injury symptoms. At the three month follow-up period, 10 out of the 12 participants had returned to athletics, school and/or work; however, it is not known if the participants were performing at their pre-injury level of functioning at work or school. Larger studies are required before determining the extent that physical exercise programmes can reduce misattributions about the severity of persisting symptoms, and reduce avoidance and emotional disturbances.

Finally, although there are recommendations to commence occupation as symptoms permit, no studies are available to guide a return to competitive paid employment. Expert opinion such as the review by Anderson, Heitger, and Macleod (2006), suggests that a forced return to normal functioning, and a premature return to paid employment, can trigger an “explosive resurgence” of acute symptoms, with adverse psychological consequences. A failed return to work may result in a reappraisal of the seriousness of the mTBI, setting off a trajectory of poor coping responses.

Thus, the ideal timing to implement graduations for a full return of normal occupation is likely to be different for each individual and is difficult to standardise given the wide range of contributing factors and a lack of objective markers to determine recovery status. For example, there may not be any advantage for a self-employed person, fretting about the viability of their business, to have a period off work to recuperate.

### **Early education and targeted symptom management**

A plausible intervention to prevent misattributions about the seriousness of acute symptoms post mTBI, and therefore prevent chronicity, is to offer early education and encourage a graduated return to usual occupations as symptoms permit. Single education sessions and/or providing advice in the form of a booklet or targeted phone calls may reduce the severity of post injury symptoms (Mittenberg, DiGiulio, Perrin, & Bass, 1992; Ponsford et al., 2002). Bell et al., (2015) conducted a randomised control study, studying the efficacy of five telephone consultations, providing education, reassurance and support for reactivation, in the first three months after a mTBI. There was a significant reduction in symptoms at six months post injury

and better engagement with daily occupations including work and leisure, but no difference in general health outcomes. A large subsequent study did not confirm these findings (Matuseviciene, Borg, Stålnacke, Ulfarsson, & de Boussard, 2013). Over a four-year period there was a progressive shift in advice generated by systematic reviews. These changed from “patient educational approaches may be beneficial if they are initiated in the early period following injury” (Snell et al., 2009, p. 30-31), to “information, education or reassurance alone may not be as beneficial as previously thought” (Amal Al, 2010, p. 1134), to “no intervention initiated acutely has been clearly associated with a positive outcome for patients who sustain mTBI” (Gravel et al., 2013, p. 10).

### **Addressing psychological mechanisms**

Included in the above systematic reviews are two randomised control studies (Andersson et al., 2007; Ghaffar, McCullagh, Ouchterlony, & Feinstein, 2006) offering extended individualised follow-up post mTBI, with access to a multidisciplinary team as required. Both these studies demonstrated no overall benefits for the group receiving targeted interventions compared to the control group. As discussed in chapter one, the range of interventions offered in these studies were routinely provided in clinics where I had previously worked.

Most studies exclude people with comorbid difficulties. For example, Anderssons’ (2007) study excluded people with a psychiatric diagnosis and those with drug and alcohol misuse issues. The intervention group in Anderssons’ study received a medical assessment and were referred for individually tailored interventions’ including pharmacotherapy and counselling for pain, depression and sleep disturbances, as required. Most often a referral was made to an occupational therapist for reassurance that most symptoms would resolve in two-three months and for assistance to manage the temporary disruptions to daily occupations. The occupational therapy interventions included teaching compensatory strategies such as the use of written schedules, use of a diary, fatigue management and relaxation. Furthermore, home visits and work/school based interventions were implemented, as required, to support a graduated return to usual occupations. One year post mTBI, no improvements were evident in terms of a reduction of persistent symptoms, improved life satisfaction, health-related quality of life, and community integration in the domains of home and family life, vocational, social, and leisure activities. No details were provided of the participants’ responses to the interventions or the types of occupational difficulties which persisted.

A study similarly targeting psychological and psychiatric interventions, along with medical assessment, reassurance and symptom management, did include participants with a prior psychiatric diagnosis Ghaffar et al., (2006). Interestingly, the cohort with an mTBI plus a previous

psychiatric diagnosis, benefitted from the psychological therapy, despite no statistical benefits for the group as a whole. It is not known if the psychological interventions offered in Gaffers' study addressed a previously unmet need, in the cohort with a psychiatric illness prior to their mTBI. Developing a better understanding of the impact of persistent symptoms on everyday functioning, for all people with persisting symptoms post mTBI is clearly indicated, given the limited benefits of early intervention and support to resume usual occupations in a timely manner.

Another plausible intervention is to address the psychological mechanisms thought to play a role in the maintenance of post acute symptoms post mTBI. The overlap in persistent symptoms with depression, anxiety disorders, panic, health anxiety, chronic fatigue, and medically unexplained symptoms, offer a starting point for developing suitable psychological interventions (Potter & Brown, 2012). In particular Potter and Brown recommend that cognitive behavioural therapy (CBT) interventions are indicated, given their efficacy in targeting the vicious cycles or dysfunctional feedback loops, hypothesised to be maintained and exacerbated by anxious and fearful responses. These CBT interventions target the vicious cycle or dysfunctional cognitive loops. Intervention starts with validating a sense of self along with examining the symptoms the individual is experiencing, and progresses to a functional analysis of the dysfunction. A positive sense of self is re-established by gaining control over the symptoms through the use of compensatory strategies and modification of emotional responses. Conversely repeated failure has been linked to major depression (Potter & Brown 2012).

Major depression is estimated to affect 10-20% of people post mTBI (Deb & Lyons, 1999; Rapoport, Kiss, & Feinstein, 2006) and is the most frequently investigated psychiatric consequence following a brain injury. Small studies with a test, retest design suggest benefits for receiving CBT (Bradbury et al., 2008; Tiersky et al., 2005), however it is unclear if participants were experiencing a recognised clinical threshold for depression, at the time of their recruitment to the study by Tiersky. When these studies were included in a meta-analysis alongside larger randomised controlled studies, (Barker-Collo, Starkey, & Theadom, 2013) it was concluded that active treatments are no more beneficial than placebo, and currently there is insufficient evidence to recommend any particular type of psychological or pharmacological intervention, to treat depression post mTBI.

Similarly, anxiety and avoidance of anxiety provoking situations is commonly associated with the maintenance of persistent symptoms post mTBI, with estimates that 23% of people develop a first occurrence of an anxiety disorder post mTBI (Mooney & Speed, 2001). All types of anxiety disorders (generalised anxiety, post-traumatic stress disorder, obsessive compulsive disorder,

panic disorder, specific phobia, and social phobia) have been documented after mTBI. Making sense of the available data were difficult due to the variations in methodology, failing to differentiate the cohort with a mTBI from the wider group with more serious brain injuries, and conflicting results between studies (Bay & Liberzon, 2009; Moore et al., 2006). However, it does seem that for those experiencing vestibular disorders, motion induced dizziness and imbalance will be distressing to most people. Avoidance of activities requiring head movements can contribute to the maintenance of anxiety and limit central nervous system adaptation and symptom resolution (Gurley, Hujsak, & Kelly, 2013; Yardley & Redfern, 2001).

A small number of case studies and underpowered studies suggest CBT approaches may be useful to alleviate aspects of anxiety post mTBI (Panayiotou et al., 2010). For example, Bryant, Moulds, and Nixon (2003) provided a five week CBT group programme, targeting acute stress reactions and compared outcomes against a control group receiving non-directed supportive counselling. At six months follow-up there was no difference between the treated group and control group in the incidence of generalised anxiety, but fewer people developed post-traumatic stress disorder in the group receiving CBT. However Soo and Tate (2007) concluded that there were insufficient studies to compare results between studies or conduct a meta-analysis, and I have been unable to locate further studies that would reverse this finding.

### **Addressing cognitive difficulties post mTBI**

The third plausible set of interventions is to address the cognitive impairments persisting after a mTBI. Although “gold star” evidence, for persisting cognitive impairments resulting from a mTBI the evidence remains inconclusive (Carroll et al., 2014), the number of studies demonstrating cognitive impairments, 12 or more months after a mTBI is growing (e.g., Barker-Collo et al., 2015; Dean & Sterr, 2013; Konrad et al., 2011).

The argument for the potential efficacy for cognitive rehabilitation post mTBI is derived from studies which include brain injuries of moderate and severe intensity (Tsaousides & Gordon, 2009). However, it is not known if these training programmes are effective for people post mTBI. Before I summarise the findings of studies which include a mTBI sample, I first address the difficulties defining executive functioning problems and secondly discuss the limitations using traditional cognitive testing to identify cognitive difficulties post mTBI.

#### *Defining executive functioning*

Whilst an agreed construct of executive functioning remains elusive (Jurado & Rosselli, 2007), there is a general acceptance that executive functions are not restricted to prefrontal lobe functioning but are distributed over a wide cerebral network (Gonsalves & Cohen, 2010).



Executive functioning is the umbrella term for functions such as planning, working memory, sustained attention, inhibition, mental flexibility, as well as regulating social behaviour and emotions (Chan, Shum, Touloupoulou, & Chen, 2008). As discussed by Schutz and Wanlass (2009), executive functioning is not a continual process, and these higher level cognitive functions are most likely activated during novel and/or complex tasks and when a person recognises that routine strategies are not effective in minimising errors. As there are considerable individual differences for determining what is sufficiently challenging and motivating to recruit higher level executive functions, no one task can be considered inherently executive in nature. Thus defining executive impairments requires multiple measures that examine functioning in a range of situations of varied executive demand, which are almost impossible to achieve in a clinic setting (Bigler, 2013; Manchester, Priestley, & Jackson, 2004; Sbordone, 2014).

In my previous experience in brain injury rehabilitation, it was not unusual that both the client and their employer dismissed specific performance errors as “usual mistakes that everybody makes”, only to revise their initial appraisals over time. The insights into the process of altering self-concepts after injury provided by Charmaz (2002), give additional insights into the adjustment process following a brain injury, such as an understanding that clients may resist therapy interventions if these are at odds with habitual behaviour patterns and self-concepts. Thus persisting with pre-morbid behaviours even when these are ineffective in solving post injury difficulties, needs to be considered alongside the cognitive and emotional changes following a brain injury.

The difficulties defining what is or is not executive dysfunction is also apparent when interpreting results from standard cognitive testing.

### *mTBI and cognitive testing*

As mentioned in chapter one, the study by Bootes and Chapparo (2010) resonated with experiences in the field, prompting me to question my reliance on neuropsychological testing for predicting functional difficulties after a mTBI. Boots and Sharpes provided an example of how a person can make a rapid transition through rehabilitation with no (apparent) lasting physical, sensorimotor or emotional impairments. The currently regarded “gold-star” neuropsychology assessment demonstrated that cognition was minimally affected, and a comprehensive work assessment indicated that the client could independently perform each component of pre injury work tasks. However, six months after returning to full time work, the client remained unable to conceptualise a “meta plan” for the day’s work, or remain on-target without significant support, with the employer expressing serious concerns about the post accident work performance capabilities. Similarly others have commented that, cognitive limitations became apparent only

after a person has attempted to return to complex environments such as work (Anderson et al., 2006; Dodson, 2010; Gilworth et al., 2008; Wolf, Morrison, & Matheson, 2008).

The specificity of traditional neuropsychological testing, to identify subtle cognitive impairments post mTBI, continues to be raised as a concern (Bigler et al., 2013; Manchester et al., 2004; Sbordone, 2014). For example, Manchester et al., (2004) reviewed cases in their medico legal practice, when executive dysfunction had been ruled out on the basis of normal performance on standardised office based neuropsychological tests. Conclusions were made that a lack of understanding on how executive dysfunction presents in everyday life, combined with a misunderstanding of the statistical properties of these standardised tests has contributed to a higher emphasis being placed on the outcome of these tests than is warranted. Tests completed in a quiet office, free from distractions, with a clinician explaining the rules and regulating behaviour precludes the assessment of many executive functioning skills such as noticing whether or not a task needs to be done, inhibiting responses when emotionally aroused, and maintaining goal focused behaviour over time. Accordingly, Manchester et al., suggested that behavioural observations should carry a greater weight when attempting to predict real world behaviour.

Assessing executive functioning errors in real world situations is also problematic. In a cross-sectional study (Bottari & Dawson, 2011), 90 occupational therapists and neuropsychologists with an average of 10.2 years clinical experience in neurology, were asked to analyse 27 short video clips of performance errors made by both patients with moderate to severe brain injuries and healthy controls, while performing the Multiple Errands Test (Knight, Alderman, & Burgess, 2002), in a real world shopping mall. Together these therapists attributed 55.5% of observed behaviours, at a rate higher than chance, to the correct population, with no statistical differences between the scoring of the occupational therapists compared with the neuropsychologists. This research clearly demonstrates the difficulties experienced practitioners have in reaching agreement over the nature of performance errors and brings to attention the subjectivity of observers in differentiating between impaired performance and the usual range of errors people make when performing new tasks.

With difficulties defining and measuring subtle cognitive dysfunction post mTBI, it is perhaps unsurprising that there are no agreed outcomes from studies designed to address post mTBI cognitive functioning.

### *mTBI and cognitive retraining programmes*

The efficacy of cognitive retraining and functional compensation is well summarised (Tsaousides & Gordon, 2009), utilising the constructs of general intellectual functioning, memory and learning, psychomotor function, processing speed, attention, language, and executive functioning. Acknowledgement is made that few studies identify the cohort with an mTBI in their findings, and the contribution of individual components in training programmes is not known.

The first randomised control study offering a combined cognitive remediation and CBT programme was designed (Tiersky et al., 2005) for people with mild to moderate brain injuries 1-20 years post injury. Following an intensive three month programme, participants in the intervention group experienced a lower number of anxiety and depression symptoms and improved performance on one measure of divided attention but no improvements in functional outcome.

Two systematic reviews found insufficient evidence to either support or refute cognitive rehabilitation post mTBI (Comper, Bisschop, Carnide, & Tricco, 2005; Snell, Surgenor, Hay-Smith, & Siegert, 2009) and another systematic review found insufficient evidence to recommend GMT as a stand-alone intervention (Krasny-Pacini, Chevignard, & Evans, 2014). Snell et al., (2009) remarks that the cost of providing intense neurocognitive retraining programmes may not be justified, given the limited support for this approach for people with a mTBI.

Overall, the multifaceted nature of executive functioning and the interdependence of cognitive functions and emotions suggests that multimodal treatment programmes are required to facilitate functional change in multiple domains (Flanagan, Cantor, & Ashman, 2008). The two traditional approaches to remediate cognitive impairments are first, cognitive and emotional regulation retraining aimed at restoring impaired functioning, and second, functional compensation, whereby compensatory strategies are taught to enhance functioning.

The executive plus model (Gordon, Cantor, Ashman, & Brown, 2006) combines information from theories of cerebral function and organisation with cognitive-behavioural and learning theories. The remediation of attention deficits in the early stages of rehabilitation is hypothesised to provide a foundation on which more complex learning can be developed. One study utilising this model, included a cohort of people who sustained a mTBI six months to 16 years previously (Cantor et al., 2014). The participants reported positive changes in their ability to solve problems and engage in efficacious, goal-directed behaviour, but did not demonstrate any changes in attention or emotional regulation on standardised tests. The functional improvements were not specified, making it difficult to establish the real world benefits of these intensive interventions provided during three months. For example, consistently using a planner to remember

appointments reflects an improvement in metacognition, but it may not be sufficient for an engineer who needs to analyse complex computer designs; and, simultaneously in conjunction with others, develop cost effective strategies for workshop production in a noisy office.

Emerging evidence from case studies and qualitative studies (Dawson, Binns, Hunt, Lemsky, & Polatajko, 2013; Nilsson, 2011; Ownsworth, 2010) suggests that teaching meta-cognitive strategies, while engaging in motivating complex activities in real world environments, is a key component for facilitating behavioural changes following a brain injury. However, in the above studies, neither the complexity of the occupations or the successful strategies that were deployed were specified. Thus it was difficult for readers to judge what type of difficulties the meta-cognitive strategies were effective in resolving.

Another variation in cognitive remediation is goal management training (GMT), aimed at improving planning, prospective memory, and cognitive control to improve executive functioning in everyday life (Krasny-Pacini et al., 2014). A lack of generalisation of the skills acquired in GMT training, into real world environments, was demonstrated in a study with 10 veterans, with executive functioning difficulties after mTBI (Waid-Ebbs et al., 2014). Opportunities to identify changes in functioning in complex environments such as paid employment, did not occur prior to the above meta-cognitive skills training programmes, perhaps making it difficult for participants to recognise the extent of their difficulties and the value of the training.

Despite the lack of clarity about the nature and impact of executive functioning problems, several small studies suggest that executive functioning problems may contribute to difficulties in returning to complex work environments post mild to moderate brain injury. At a work capacity test centre, 70% of the mTBI cohort displayed executive functioning difficulties (Matheson, 2010). Difficulties with working memory, shifting tasks, task monitoring, and organisation of materials, were the impairments most often identified. Similarly, Erez, Rothschild, Katz, Tuchner, and Hartman-Maeir (2009) tested executive functioning in 13 patients five months post mTBI, with additional tests to identify awareness deficits. Although no awareness impairments were identified, 84% of participants demonstrated aspects of executive dysfunction with difficulties planning and shifting attention. Two qualitative studies suggest that performance failures at work provided the research participants with the most potent information on altered capacity (Gilworth et al., 2008; Nilsson, 2011). This suggests that executive functioning and other cognitive difficulties may not be immediately apparent in the post-acute phase of recovery. The fact that impairments are recognised only after a breakdown

in occupational performance in the work environment raises concerns about the utility of post injury interventions.

Absent from the above multimodal neuro-cognitive retraining programmes, are exercises aimed at remediating the lower level networks that underpin aspects of upper level neurological processes. For example, disturbances in the ocular motor processes are commonly disrupted after a mTBI (Ciuffreda, Ying, Kapoor, & Ficarra, 2006) and are thought to contribute to many of the difficulties performing everyday occupations after a mTBI, such as reading. Efficient reading requires precise coordination of ocular motor functioning (version, accommodation, and vergence), with higher level (attention, linguistic, cognitive and memory components) neurological processes (Rayner, Pollatsek, & Reichle, 2003). In a recent cross over design study, the reading rate was improved by 25%, for participants with a mTBI, following nine hours of remediation exercises in the three ocular motor subsystems (Thiagarajan & Ciuffreda, 2014). Reading comprehension remained unaffected from base scores, suggesting that improvements in ocular motor functions, were contributing to the improved comfort and reading rate. Visual attention significantly improved, suggesting less effort was required to process the low-level reading components. With an increased understanding that impairments post mTBI, are more likely to be demonstrated with dual or multitask demands (Scherer, Weightman, Radomski, Davidson, & McCulloch, 2013; Sosnoff, Broglio, & Ferrara, 2008), numerous possible combinations, for integrating lower and higher level cognitive and motor demands into novel retraining programmes, have yet to be explored.

#### *Addressing cognitive difficulties before returning to paid employment*

Few studies are available to inform return to work processes post mTBI (Cancelliere et al., 2014), with a paucity of data informing work sustainability post mTBI. Specifically, it is not known what proportion of people retain the same job, reduce hours to sustain employment, move to a less demanding job, or retrain for different employment. Nor is it known what changes people are making to their work routines and environments to maintain employment. Several studies demonstrate that about 75% of participants with mTBI return to employment within 3-6 months, (Kristman et al., 2010; Stulemeijer, van der Werf, Borm, & Vos, 2008; Wäljas et al., 2014), with one study showing less than 50% of participants returned to work within 9 months of a mTBI following a motor vehicle accident (Friedland & Dawson, 2001). An analysis of the types of tasks that people post mTBI find challenging when returning to work is not available. However, Walker, Marwitz, Kreutzer, Hart, and Novack (2006) found a significantly higher rate of returning to work for the participants post mTBI, who had decision-making latitude, and independence with planning their time. Thus student, homemaker, professional/semi-

professional, and managerial occupations had higher returns to work compared with clerical, sales and service, manual labour, and skilled crafts and trades occupations, where opportunities for autonomy were limited.

A model specific to the vocational rehabilitation of high-functioning employees after a mild brain injury, has been proposed by Dodson (2010). This model draws together data pertaining to; 1) injury related changes to both psychosocial functioning and executive functioning, 2) secondary alterations to perceptions of competency and capacity, 3) assessment of the workplace ecology to identify the main factors in the social environment, which enable or inhibit integration back into the work environment, 4) identification of the cognitive loading on the essential job functions and the clients' perspective on their readiness to resume these tasks and 5) recommendations for liaison with management to commence a return to work and/or negotiating workplace changes to assist in this process. While this model provides a framework for identifying and addressing critical factors that impact on a successful return to work, details on how to weight these complex factors and identify difficulties *before* there is a breakdown in task performance remains elusive. In addition, guidance to sustain work roles over time, are lacking, reflecting the dearth of information in the literature.

## **Summary**

In summary, there is a paucity of robust data to guide recovery after a mTBI, with no clear evidence that timely psychological or cognitive interventions can prevent symptoms from persisting, in the minority of people who do not make a full spontaneous recovery. In 2004, The WHO task force on mTBI (Carroll et al., 2014), concluded that "mTBI research is of varying quality and casual inferences are often mistakenly drawn from cross sectional studies" (p. 84). Sadly these shortcomings have persisted (Carroll et al., 2014) and recommendations from Bigler (2008) for large unbiased prospective studies, using ecologically sound cognitive assessment protocols, which include an understanding of the attempts people make to establish preinjury level of function, have not yet occurred. Together with an expectation that additional support for the minority who do not make a full recovery post mTBI will prevent chronicity, little emphasis has been placed on increasing participation in everyday occupations which remain difficult to perform post mTBI. In the final section of the literature review I will discuss, what is known on the impact of persistent symptoms on everyday functioning.

## **mTBI, Persistent Symptoms and Occupational Performance**

With a lack of convincing studies on the long term sequelae of mTBI, it is not known if the contribution of psychological factors increase over time, as proposed by (Lishman, 1988), or if

there is a more consistent presentation of chronic symptoms which people learn to manage. Two studies provide preliminary evidence that symptoms may be consistent over time. King and Kirwilliam (2013), documented symptom profiles of 26 people with persistent difficulties up to 7 years post mTBI, ranking the symptoms from most common to least common. These rankings were compared with profiles derived from participants in earlier studies, performed at intervals of ten days and six months post mTBI. Results showed similarities with the most frequently experienced symptoms (fatigue, poor concentration, sleep disturbance, taking longer to think, and irritability) and the least frequently experienced symptoms (blurred/double vision, photophobia, nausea, headache and dizziness), at each of the three time intervals, ten days, six months and up to seven years post mTBI. Andersson, Bedics, and Falkmer (2011), in a 10-year follow-up to their earlier study, suggested that the cohort that did not recover spontaneously after 2-8 weeks, did not recover after a year, and had a similar symptom profile 10 years post injury. Interestingly sick leave decreased significantly after one year, and remained relatively stable, suggesting a possibility that people learn to manage their symptoms over time, and maintain employment.

Few studies are designed to illuminate how the phenomena under question impacts on actual participation in everyday occupations. For example Sveen, Bautz-Holter, Sandvik, Alvsåker, and Røe (2010) examined the relationships between problems with daily activities, brain injury severity and demographic factors, at three months and one year after a traumatic brain injury. In the cohort with mTBI (n=63), persisting symptoms at 3 months, was a significant predictor of self-reported problems, impacting on participation in a diverse range of everyday occupations. Of the 63 respondents, 43 reported interpersonal/emotional difficulties, 37 reported cognitive difficulties and 21 reported difficulties with instrumental activities of daily living. Environmental factors such as contact with immediate family, health professionals, and work colleagues, were equally endorsed as both barriers and facilitators. However, without an understanding of the context in which participants experienced challenges in everyday life, it is difficult to grasp how the reported impairments and environmental factors impact on participation.

With participation described as a central goal of rehabilitation (Cardol, De Jong, & Ward, 2002; Cicerone, 2004), qualitatively exploring experiences from the perspective of the individual concerned is vital in developing a practice responsive to an individual's needs (Häggström & Lund, 2008). The complexity of participation was explored by Hemmingsson and Jonsson (2005), who identified the subjective characteristics of participation as being essential to the understanding of the strategies people employ to bring about changes in their occupational performance. This need for a qualitative exploration was reiterated by Cantor et al., (2008), after

finding that persistent fatigue post mTBI did not limit the quantity or frequency of participation in everyday occupations, despite an impact on quality of life and well-being. Thus, it is possible that people participate in the same number of occupations across the various life domains, but experience these occupations as being more difficult to complete with less rewarding results. Alternatively, if fatigue resulted in reducing participation in some activities, but there was no consistency across people as to which activities were affected, a “wash out” effect could be reflected in the statistics giving a false impression that fatigue post mTBI does not reduce the range of occupations a person engages in. Further research focusing on the relationship between fatigue and the quality of participation is needed to identify how people are managing persistent fatigue in their everyday lives.

A meta synthesis of qualitative research investigating the beliefs, perceptions and experiences that adults with a traumatic brain injury deemed important for their rehabilitation revealed themes associated with the disconnection with a person’s pre injury identity, and the impact of emotional and social problems (Levack, Kayes, & Fadyl, 2010). Support for these themes post mTBI is provided by (Nilsson, 2011), who described participants’ experiences and dysphoria after they realised the capable person had gone, that they were not performing well in work roles, and the changes in relationships with friends and family were persisting. Adjusting to these changes involved recognising the impact fatigue and loss of energy was having on all of their life roles, and adopting compensatory strategies to speed up the process of change. Gaining knowledge about brain injury and developing ideas on how to move forward were identified by Nilsson’, as providing a shortcut for successful adjustment. These short cuts were generated between group members, as well as being provided by the occupational therapist, neuropsychologist and physiotherapist. Unfortunately, specific strategies that were deemed useful were not identified.

Another approach, compensatory strategy training is identified an important component of CBT (Potter & Brown, 2012), cognitive retraining programmes (Tsaousides & Gordon, 2009) and self-management of chronic health conditions with unknown aetiologies (Kendrick et al., 2012). Various strategies have been described to clients to support participation in everyday functioning as symptoms of mTBI continue to resolve (Radomski, Davidson, Voydetich, & Erickson, 2009). Included are cognitive energy saving techniques such as using a planner rather than remembering a list of tasks and addressing attentional deficits by completing a single task at a time. In addition, initiating the removal of visual or auditory distractions, performing challenging tasks during high-energy times of the day, pacing, planning breaks, self-monitoring of fatigue and attention levels, and using an "ideas log" so that clients can capture good ideas



that come to mind but are to be addressed later have been suggested (Radomski et al., 2009). Furthermore, instructions in the use of memory aids and internal memory strategies, together with training in the use of problem solving and organization strategies, are thought to assist with applications to increase participation in everyday life. Examples include establishing a daily routine, using weekly planners, breaking multistep or complex tasks into step-by-step checklists, and using a problem-solving mnemonic to proactively and systematically think through many aspects of a problem before initiating action. However these strategies have not been systematically investigated (Vasterling, Bryant, & Keane, 2012), raising unanswered questions as to their effectiveness.

Concerns have been mooted that teaching compensatory strategies may inadvertently train “safety behaviours” that are maintained through heightened self-focus (Veale, 2003). Thus, the reinforcement of a subjective sense of impaired abilities may interfere with evidence that might help rebuild confidence. These iatrogenic effects of clinical interactions have been discussed in the literature pertaining to mTBI (Iverson, Lange, & Franzen, 2005; Suhr & Gunstad, 2005), with some studies showing unhelpful outcomes for those receiving interventions (Snell, Hay-Smith, Surgenor, & Siegert, 2013). In addition, it has been suggested that decreasing light exposure through the use of tinted glasses may alleviate immediate discomfort but prevent long term neural adaptation (Truong, Ciuffreda, Han, & Suchoff, 2014). This has implications for delaying the use of compensatory strategies to enhance neuroplasticity and restore functional pathways within the brain. Without an understanding of why people are experiencing occupational dysfunction, and the contexts in which the dysfunction is occurring, it is difficult to determine what type of interventions would be most useful to pursue.

A review of the literature detailing changes in occupational performance post mTBI suggests that many life roles are disrupted post mTBI, with reoccurring themes that capacity is altered, interpersonal relations are disrupted and learning to live with chronic fatigue and lower energy levels is required. While strategies targeting improved participation have been suggested as helpful, it is not known what strategies people are consistently using in their everyday lives, if the occupational performance difficulties resolve over time, or if people continue their participation in valued roles with more difficulty and less satisfaction.

## **Summary**

The extent to which impairments in brain functioning are responsible for persisting symptoms after mTBI is unknown. There are no high quality studies providing clear evidence that interventions can improve outcomes post mTBI, and questions remain about what techniques

or intervention components may work, how they work and for whom and when they are most effective. Whilst there is an assumption that an inability to fully participate in valued occupation post mTBI is detrimental to health and wellbeing, there have been no studies to capture the range of strategies people are using to manage the constellation of persistent symptoms or enhance their participation in everyday environments.

In conducting a qualitative research project asking the question “What strategies do people with persistent symptoms post mTBI use to manage everyday occupations?”, I hope to gain knowledge from the cohort of people who have experienced persistent symptoms post mTBI, as to what they found useful to increase their participation in everyday occupations post mTBI. Answers to this question may guide health professionals, in providing pragmatic advice for clients who do not make the expected full recovery within three months of their injury. An occupational perspective may also reveal fruitful lines for further research, for the cohort of people with persisting symptoms post mTBI who are not well-served in conventional rehabilitation practises.

## Chapter 3 – Methodology

This study employed a qualitative descriptive methodology to examine the question “What strategies do people with persistent symptoms post mTBI use to manage everyday occupations?” First, in this chapter, considerations for researching practice based questions, and positioning my research as qualitative are presented. Second, I explain my research design in terms of four key interrelated dimensions: ontology, epistemology, methodology and methods. This includes; aligning my research with a congruent paradigm, elucidating the underlying philosophical assumptions, explaining the rationale for selecting a qualitative-descriptive methodology, and discussing the methods I planned to use to collect and analyse data. Third, I describe how the study was actually conducted, including the ethical considerations, and finally I outline the strategies that were used to ensure rigour.

### Researching Practice Based Questions

Within practice-based disciplines in health, such as occupational therapy, tensions exist between the delivery of practitioner-centred evidence based services and client centred practices (Hammell, 2006). This is not surprising given that the evidenced-based movement has assigned “gold star” status to the evidence generated from randomised control trials, thus influencing the type of research that has attracted funding (Carpenter & Suto, 2008). However, reliance on findings of experimental or quantitative research to inform practice via fixed designs, probability sampling, highly structured and closed-ended modes of data collection and statistical analyses, has restricted the sorts of questions which have been asked, and the sorts of issues it has been possible to investigate (Hyde, 2004).

By favouring studies that demonstrate cause and effect relationships, the meanings that are constructed via human interaction or between humans and objects are overlooked. For example, surveys are very good at finding out characteristics about a phenomenon, but to get at the “lived experiences,” the researcher needs to dig deeper into the goings on of persons’ daily experiences, using strategies other than closed ended questions. Hesse-Biber & Leavy, (2011) demonstrated that discussing solutions to the statistically significant trend for increased binge-drinking at their university, without understanding *why* the trend was occurring, was akin to grasping at straws. In addition, the large randomised controlled study by Andersson et al., (2007) demonstrated that an individualised multi-disciplinary programme failed to increase the percentage of people making a full recovery from a mTBI, but was not able (or designed) to identify why the interventions were not successful. These shortcomings demonstrate that to provide optimal intervention choices that help clients resolve their problems, different types of

knowledge and clinical reasoning are required (Carpenter & Suto, 2008). Qualitative research designs allow the social meanings people attribute to their experiences, circumstances and situations to become known (Hesse-Biber & Leavy, 2011).

To help fill the knowledge gap identified in the literature review, I wanted to identify what people - whose symptoms have not resolved three months after sustaining a mTBI - do to make it possible to engage in their everyday routines. The aim is to determine the ways of doing things that are empowering and enabling. As stated by Thorne (2014),

...those of us who fulfil professional roles in the healthcare system engage with patients and their families in ways that can range from empowering and healing to terrifying and soul destroying. These are naturally complex, dynamic, fluid and messy concepts to be studying...which defy measurement. (p. 100)

Thus, in the context of wanting to build knowledge that will facilitate engagement in everyday activities for people who do not make a full recovery from a mTBI, I needed a research methodology that allows exploration of a complex phenomenon, from a perspective different to the dominant biomedical perspective. My thinking was influenced by Dilthey's argument that to understand human behaviour, subjectivity needs to be understood (Gimbel, 2016). Whilst phenomena in the natural sciences can be explained in terms of cause and effect, knowledge in the human sciences needs to be understood in terms of the relations of the part and the whole. To bracket or eliminate subjective understanding in the social world is akin to "mutilate historical reality to accommodate it to concepts and methods of the natural world" (Dilthey, as cited by Gimbol 2016, p. 73).

Qualitative research is the umbrella term for a diverse set of perspectives and practices used by researchers in social and behavioural sciences for generating knowledge. In contrast to quantitative research, qualitative research employs inductive reasoning processes to develop an understanding of the social processes that people engage in, and the meanings they create from their experiences (Carpenter & Suto, 2008). Typically, qualitative research focuses on human experiences in naturalistic settings and goes behind the statistics to understand the problem or phenomena being studied (Creswell, 2014; Lincoln & Guba, 1985). Qualitative inquiries are well suited to research problems that need an exploratory approach in order to learn from people's experiences and to make visible the taken for granted practices in the world (Carpenter & Suto, 2008). As I was interested to learn from participants about the changes they made in engaging in everyday occupations in their usual or natural environments after a mTBI, a qualitative inquiry was adopted.

Within the field of qualitative research, different methodologies have developed to reflect the different ways of viewing the world and to address different types of research questions (Carpenter & Suto, 2008). In the health sciences, scholars have moved beyond adherence to the traditional methodologies of phenomenology, grounded theory and ethnography in their efforts to be responsive to practice based questions (Thorne, Kirkham, & O'Flynn-Magee, 2004). For example, qualitative descriptive methodology has been employed to provide a rich description of the informant's perception and experience of the world, which has relevance to policy makers and practitioners (Neergaard, Olesen, Andersen, & Sondergaard, 2009; Sandelowski, 2000). This approach differs from ethnography which documents how people make sense of how their world is being structured, from grounded theory - which develops a new theory - and from phenomenology - which produces an interpretive description of the essential elements of a human experience (Sandelowski, 2000; Thorne et al., 2004).

Within occupational science and occupational therapy, concerns have been raised that many published qualitative studies do not explicate the methodology clearly (Frank & Polkinghorne, 2010; Nayar & Stanley, 2015). Furthermore, incongruences between theory and described methods of data collection and analysis suggest that some authors have a limited understanding of epistemology and how that plays out in the conduct of the study. This makes it difficult to establish the quality of the research findings, posing problems for health practitioners who use these findings to inform their practice, and undermining the credibility of the discipline publishing such research. Thus, the core philosophies of science that are embedded within the different research approaches and traditions need to be understood, if the scientific pursuit for generating credible knowledge is to be attained (Hesse-Biber & Leavy, 2011).

## **Research Design**

Within the social sciences, a common approach to elucidating the complexity of a research design is to position the study within a research paradigm. Denzin and Lincoln (2011) defined a paradigm as "the net that contains the researcher's epistemological, ontological and methodological premises" (p. 13). Articulating a paradigm suitable for qualitative descriptive research is difficult, due to lack of commentary in research texts that aligns qualitative-descriptive approaches within established paradigms (Stanley & Nayar, 2014). In addition, the tendency for practice based disciplines to align themselves with credible social science designs, even when their research does not reflect an accurate alignment with these methodologies, remains problematic (Sandelowski, 2000; Stanley & Nayar, 2014; Thorne, 2016). Despite the controversies within and between research paradigms, they "remain a useful tool for novice researchers who are learning to think about their methodology" (Kramer-Kile, 2012, p. 25). As

there are numerous different paradigmatic schema introduced in the literature, I have taken Ponterotto's (2005) advice to review the various options and operate from the one that I find most comprehensible. Thus I have situated my study in the interpretive-constructivist paradigm, as defined by Denzin and Lincoln (2011). In a nutshell, the interpretive-constructivist paradigm assumes a relativist ontology, a subjectivist epistemology and naturalistic set of methodological procedures.

To explain my research, I address in turn four interrelated dimensions which together make up the research design. These are ontology, epistemology, methodology and methods. As discussed by Hesse-Biber & Leavy, (2011), these dimensions impact on how the research is conceptualised and implemented. For example, the ontological and epistemological positions form the philosophical basis of the project and provide a sense of what kind of information can be generated from the research. Congruency between methodology and the methods utilised to collect and analyse data were one important requirement to produce credible findings.

## **Ontology**

Ontology is a philosophical belief system about the nature of reality i.e., what exists or what there is to know. Within research designs, the most common ontological question concerns the nature of reality (Creswell, 2014). At one end of the spectrum is realism, which presumes the existence of an external world that can be described, analysed, explained, and predicted. Reality is therefore perceived as universal truths which are objective. At the other end of the spectrum is the relativist position which posits that human experiences can only be understood in the contexts within which they are embedded (Creswell, 2014). Thus reality is constructed through social interactions, relationships and experiences and many realities can exist simultaneously. An ontology of relativism underpins the interpretive-constructive paradigm (Denzin & Lincoln, 2011), and my construction of qualitative descriptive methodology.

The concept of multiple realities is neatly captured in the following extract from the Personal Narratives Group 1989, cited by (Carpenter & Suto, 2008).

When talking with people about their lives, people lie sometimes, forget a lot, exaggerate, become confused, and get things wrong. Yet they are revealing truths. These truths don't reveal the past 'as it actually was' aspiring to a standard of objectivity. They give us instead truths of our experiences. They aren't the result of empirical research or the logic of mathematical deductions. Unlike the reassuring Truth of the scientific ideal, the truths of personal narratives are neither open to truth nor self-evident.

We come to understand them only through interpretation, paying careful attention to the contexts that shape their creation and the worldviews that inform them. (p. 29)

In seeking to uncover the realities of people who do not make a timely recovery following a mTBI, I am not expecting research participants to give factually accurate and objective explanations of the strategies they adopted. Rather, I accept that all they can offer are their accounts of what they do, how they do it and why. Different people will have different experiences and potentially will provide opposing views about the strategies they adopted and their utility in enabling participation in daily occupations. By comparing and contrasting participants' experiences, commonalities and differences can be conceptualised. It is these conceptualisations that can be used within the practice disciplines to inform practice.

The key ontological assumptions underpinning my study are: that multiple realities are best studied holistically in the context where they occur and that an enquiry into multiple realities will inevitably diverge so that prediction and control are unlikely outcomes (Lincoln & Guba, 1985).

## **Epistemology**

Arising from ontology, epistemology or the theory of knowledge, lays down the foundation for the knowledge building process in qualitative research. Epistemology is concerned with explaining how reality can be known, the relationship between the knower and what is known, and the reliability of processes being shared and repeated by others to produce the same truths (Vasilachis de Gialdino, 2009).

The epistemology underpinning the interpretive-constructionist paradigm is transactional and subjectivist (Creswell, 2014). This means that knowledge comes into being through the subjective experiences of people. Key philosophical assumptions of naturalistic enquires (Lincoln & Guba, 1985), which have been adapted for smaller scale practice based research questions by Thorne, (2008), form the epistemological basis of my research. This means my study will; 1) explicitly attend to the value of subjective and experiential knowledge as a fundamental source of clinical insight, 2) acknowledge a socially constructed element to human experience that cannot be separated from its essential nature, 3) acknowledge that the relationship between the knower and the known cannot be separated, such that the enquirer and the "object" of the inquiry interact to influence each other, 4) capitalise on human commonalities as well as individual expressions of variance within a shared focus of interest, and 5) accept that no *a priori*

theory could possibly encompass the multiple realities that are likely to be encountered; rather, patterns and themes that emerge will be grounded in the data.

## **Methodology**

Building on the ontological and epistemological assumptions, methodology aligns the philosophical and theoretical base with the research question, data collection and data analysis. This creates a comprehensive and cohesive research design (Hesse-Biber & Leavy, 2011). By building a bridge between the ideas (theory) and doing (methods), methodology provides the rationale for the choices that are made for generating knowledge (Kramer-Kile, 2012).

Following a review of the different exploratory perspectives pertaining to qualitative research, a qualitative descriptive methodology was selected for two reasons. First, qualitative descriptive is well suited to answering “what” type questions in areas where little is known (Magilvy & Thomas, 2009; Neergaard et al., 2009; Sandelowski, 2000). In asking the question “What strategies do people with persistent symptoms post mTBI use to manage everyday occupations?”, I am seeking to develop a rich description about the strategies participants are using to mitigate symptoms that they experienced post mTBI, so they can successfully engage in their daily occupations. I can then draw on participants’ combined wisdom and experience to inform practice.

I considered utilising a phenomenological enquiry to study the meaning of what it was like to fail to make the expected full recovery from a mTBI. Despite personal appeal, I rejected that approach in favour of identifying strategies people use to manage chronic symptoms. This reflected a greater perceived need for my discipline to be proactive in developing practices that address the neglected area of what to do when the expected full recovery has not occurred post mTBI. While a phenomenological approach would have revealed the essential components of what it means to fail to make a full recovery, the profession would still be left with a paucity of findings to guide the process of managing mTBI sequelae, a priority area for my research. I also considered a grounded theory study, to develop a theory about the process of generating strategies and the influences that promote deployment of these strategies. However, as I wanted to generate new knowledge that was immediately and directly useful, I adopted a qualitative descriptive methodology, which would allow me to identify the specific strategies people utilise to manage their occupational demands. Generating new perspectives that could be the basis for further research is a recognised benefit for using a qualitative descriptive methodology (Neergaard et al., 2009; Sandelowski, 2000).



Second, the qualitative descriptive methodology uses low level inferences and presents findings in an uncomplicated format using everyday language which is easily understood (Magilvy & Thomas, 2009; Neergaard et al., 2009; Sandelowski, 2000). Given the paucity of knowledge pertaining to the management of chronic symptoms following a mTBI, communicating the study's findings to a diverse range of health professionals, who each have their own language and understanding of the world (McCallin & McCallin 2009), was deemed important. For example, general practitioners, psychologists and physiotherapists may find it helpful to discuss management strategies with clients, when adherence to early management protocols have not resulted in a timely recovery post mTBI. Individuals reading the findings of a descriptive project do not need to understand complex jargon or agree with each other's world view to understand the implications of the research findings.

Having explained the rationale for selecting a qualitative descriptive methodology, I will continue the discussion on the study's design by discussing the methods I planned to employ to collect and analyse data.

## **Methods**

Research methods are the tools and techniques employed to collect and analyse the data (Carpenter & Suto, 2008) that allow us to learn about social realities. Qualitative descriptive methodology supports a diversity of sampling and data collection methods (Sandelowski, 2010). In my study, I selected maximum variation as the optimal sampling strategy, and aimed to conduct semi-structured interviews with 8-12 participants. A thematic analysis was adopted to analyse and interpret the data. The rationale for selecting these methods is described prior to describing how the research was conducted.

### *Sampling*

Purposeful sampling is a strength of qualitative research. According to Patton (2002), "the logic and power of purposeful sampling lies in selecting information-rich cases for study in depth. Information-rich cases are those from which one can learn a great deal about issues of central importance to the purpose of the inquiry" (p. 230).

Patton (2002) described 15 purposeful sampling strategies. Maximum variation is the sampling strategy of choice for my research, as it mitigates the inherent difficulties associated with small sample sizes and considerable individual differences by applying the following logic: "Any common problems that emerge from great variation are of particular interest and value in capturing the core experiences and central, shared dimensions of a setting or phenomenon" (p. 235). I planned to gather and compile demographic data from each participant, including age,

gender, work roles, number and age of dependent children, along with a symptom profile, so the degree of variation between participants could be described.

I also heeded Thorne's (2008) advice that "we must assume that every voice we will encounter in trying to expand knowledge about a human experience will have an explicit interest or bias to bring to our attention" (p. 88). I planned to give consideration to the participants' exposure to advice given by health professionals. As New Zealand offers a no fault, fully funded comprehensive service for all residents following an accident or injury, it was expected that participants would have engaged in education and/or rehabilitation programmes. It was therefore anticipated that their relationships with both the insurance case manager and the health professionals could influence participants' experiences of re-engaging in their everyday occupations. To reduce the possibility that advice given by a particular health professional might dominate the data, I planned to recruit participants from different services and geographical areas, and at different stages of their recovery.

The required sample size was difficult to predict when designing my project. As stated by Sandelowski (1995), "too few may risk inadequate depth and breadth, but too many may produce superficial or unwieldy volumes of data" (p. 179). I agreed with Thorne (2008) that collection strategies such as saturation and redundancy seem antithetical to the epistemological foundations of practice knowledge. With assumptions that there are infinite variations in relation to people's experiences, it therefore would not be possible to keep recruiting participants until *all* variations on adapting to a mTBI were accounted for. In addition, there were several unknowns such as the calibre of my interviewing skills as a novel researcher and the ability of participants to reflect on complex processes post mTBI, which might have impacted on what data could legitimately be used.

It was decided that the final number of participants would be determined according to the quality of the data being produced, and in collaboration with the project supervisors. Advice from experienced researchers suggested 8-12 participants would be needed for a small scale project such as mine. A similar study (Murphy, Hocking, & Reed, 2008) found that data from eight participants was sufficient to generate new knowledge about the strategies that older people used to participate in everyday occupations.

### *Semi-Structured Interviews*

In keeping with an epistemological perspective that data emerges from a mutually coordinated relationship between the researcher and informants (Lincoln & Guba, 1985), semi-structured interviews were selected to access information about what people do after a mTBI to engage in their usual occupations. I anticipated that some strategies participants described might be new

to me and/or difficult to communicate in a verbal discussion. Built into my research proposal was the possibility of viewing these strategies “in action” to understand fully what the participant was trying to convey, should this be necessary. The use of open-ended questions was adopted in order to understand the world as seen by the respondents without predetermining those points of view through prior selection of questionnaire categories (Patton, 2002). Care was taken to minimise the use of leading questions, which might limit opportunities for participants to tell their own story.

Consideration was also given to the extent of disclosure that the researcher would provide to participants about her own interest in the research topic. Thorne (2008) suggested that if a researcher shares his or her personal experience, the study participant is more likely to assume a shared understanding and be disinclined to go into depth on what might be key elements of the phenomenon under question. In addition, the temptation to “compare notes” may convey that there is a “right way” to have experienced the post-acute recovery period. A decision was made to emphasise my enthusiasm for the opportunity to learn from the participants and to defer any direct questioning on my personal views to a conversation at the end of the interview, should this be necessary to maintain an open honest approach with the interviewee. I found this strategy useful especially when participants assumed that I knew how difficult it was explaining mTBI to others, and coping with a combination of symptoms and depressed mood. By emphasising my objective of not making assumptions and wanting to learn from the people in the study, the participants put extra effort into explaining the “difficult to discuss” aspects of a brain injury, providing me with thoughtful insights I was not always expecting.

### *Thematic Analysis*

The qualitative descriptive methodology requires analytical methods to generate conceptualisations, to provide the reader with a better understanding of another’s perspective (Sandelowski, 2000). Both content and thematic analysis are suitable analytical tools for examining narrative materials from participants’ experiences (Stanley & Nayar, 2014; Vaismoradi, Turunen, & Bondas, 2013). Differentiating between these methods is problematic as there is no shared understanding as to what a content analysis is. I adopted the stance described by Stanley and Nayar (2014), that content analysis uses codes that were predetermined by researchers who have anticipated what they will find in the data, while a thematic analysis is inductive and works through a process of coding in layers of abstraction and interpretation. I selected a thematic analysis as described by Graneheim and Lundman, (2004) for use in my research as it allows for both visible and obvious strategies to be identified

(manifest content) as well as an interpretation of the underlying meaning associated with using the strategy (latent content).

The four sequential cognitive processes of data analysis as described by Morse (1994), and elaborated on by Thorne (2008) provide guidelines on the interpretation process in a thematic analysis. The first process is comprehending, whereby one learns everything one can about the setting and experiences of the study participants, holding judgements in abeyance and passively absorbing as much information as possible. To assist in describing the experiences, I designed a participant demographic sheet and symptom checklist (See Appendix 1). Comprehending starts with data collection and proceeds through to coding, allowing numerous new questions to be generated that uncover deeper layers of understanding about the experience being studied. The second process is synthesising, whereby events are merged to describe the typical patterns contained in the data. The researcher decontextualizes the processes from the individual instances of them, extracting common features and systematically discarding possibilities. The third process is theorising and occurs when the researcher develops “best guesses” about the information. This includes formulating questions arising from the data in relation to other insights from theoretical and empirical sources. Lastly re-contextualising occurs when the researcher permits a full appreciation for the implications for the new knowledge and discusses applicability to other settings. These cognitive processes clearly emphasise that it is the researcher and not the recipe that drives the interpretive process.

Having described the study’s design, I will now outline how the study was conducted, with sufficient detail to render my work open for analysis, critique and replication, guarding against “picking and choosing available information to bolster a particular bias or preconceived opinion” (Thorne, 2008, p. 124).

## **Conducting the Study**

Ethics exist within a social context and are demonstrated by following the rules which have been developed to prevent a repetition of the atrocities enacted by past researchers (Carpenter & Suto, 2008; Hesse-Biber & Leavy, 2011). However ethical rules cannot account for all the myriad of possibilities that can be encountered conducting social research. As stated by Patton (2002),

You cannot achieve ethical research by following a set of pre-established procedures that will always be correct. Yet, the requirement to behave ethically is just as strong in qualitative interviewing as in other types of research on humans – maybe even stronger. You must build ethical routines into your work. You should carefully study codes of ethics and cases on

unethical behaviour to sensitise yourself to situations in which ethical commitments become particularly salient. Throughout your research, keep thinking and adjudging what are your ethical obligations. (p. 411)

In my study, I repeatedly reflected on the presupposition interview described in chapter one, and I kept notes detailing my responses to the various stages of data collection, differentiating between what the participant actually said and my interpretations. I sought opportunities with my supervisors to discuss personal likes and dislikes, emotions, values and motivations, with the aim of being both realistic and fair to all concerned. Occasionally, during my interviews, I needed to think about how hard I would push for information. For example, I stopped pursuing data on emotional regulation, after learning therapy sessions were scheduled to start in the following week, for one participant. In another instance I checked with a participant if he wanted to continue discussing a sensitive issue before elaborating on the topic. I also became aware from one of the participants that her spouse worked at the same hospital department as myself, albeit in a different division. I therefore checked with both the participant and my primary supervisor before confirming that the interview could proceed.

### **Ethics approval**

Full ethics approval (See Appendix 2) was received from the Auckland University of Technology's Ethics Committee (AUTEC). Part of the application process involved submitting my proposal for peer review by Dr Sutton at the Department of Occupational Science and Therapy at Auckland University of Technology (AUT). In addition, my research and indicative questions were discussed with Mr Hori Ahomiro, a family and whanau advisor at Mental Health and Addiction Services in Tauranga, who was also completing his own Masters project.

In achieving ethical approval, a familiarity with and understanding of the legislation associated with ethical research was acknowledged. The mandates contained within the Health Information Privacy Code 1994 (Privacy Commissioner, 2008), Code of Health and Disability Services Consumers' Rights 1996 (Health and Disabilities. Commissioner, 2009) and the Guidelines for Researchers on Health Research Involving Māori (Health Research Council, 2010), together with the principles of ethical research as discussed by (Tolich & Davidson, 1999), underpin the ethics of this research. Thus the rights of research participants were protected in three important ways. First, by ensuring the participants were fully informed about the study and gave voluntary consent; second, that potential harm was minimised with respect and dignity preserved for both the people expressing an interest in the research and for the participants; and third, that confidentiality was maintained.

## **Voluntary participation and informed consent**

To ensure participants were not treated as mere objects to achieve the purposes of my study (Gabard & Martin, 2011), I adhered to the principles of voluntary participation and informed consent (Health and Disability Commissioner, 2009; Tollich & Davidson 1999).

Third parties, known to the researcher from local concussion clinics and previous work environments agreed to make the details of this research project known to adults who had not made a timely recovery from a mTBI. Interested participants were recruited without the use of coercion or deceit and were provided with a full disclosure of the research aims and expectations for voluntary participation and provided with an explanation of the research (See Appendix 3 for a copy of this disclosure). Potential participants either contacted me directly or provided their consent for the third party to pass their contact details on to me (See Appendix 4 for agreement with third party). Confidentiality between the researcher and third parties was made explicit, formalising assurances that no information regarding their cases from the third party or from ACC were passed on to me.

As expected, the majority of the population I was interested in interviewing were no longer receiving active treatment at the concussion clinics. Recruiting former clients from third parties did not occur as anticipated, due to time pressure and a reluctance from company directors to allow subcontractors to alert former clients to the study. A submission was therefore made to AUTEC, for Auckland University of Technology research officers to extend invitations to suitable people who had indicated they were willing to be contacted for future research. Approval for this to occur was received on 15 June 2015 (See Appendix 5 for an amendment to the ethics approval), and invitations sent to suitable people on 21 August 2015, via a research officer at the Health and Rehabilitation Research Institute at AUT.

A cool down period of 14 days occurred before I contacted potential participants to discuss the research in a telephone conversation. A full disclosure of the research occurred along with a discussion on the rationale for the inclusion and exclusion criteria for people responding to the research invitation. This provided me an opportunity to ascertain if there were risks needing further consideration and to answer questions. In the course of this conversation all people expressing an interest met the project requirements and accepted an invitation to be interviewed. All participants were reminded that they could withdraw from the project at any stage prior to submitting my work to AUT, without providing a reason for doing so.

A further opportunity to reiterate voluntary participation and discuss informed consent occurred prior to interviewing, when I formalised the verbal agreement with a written consent

(see Appendix 6 for a copy of the consent form).

### **Minimisation of harm and maintenance of dignity**

All research participants have the right to be treated with respect and in a manner that preserves their dignity and safety (Health and Disability Commissioner, 2009). This right also extends beyond respect for an individual's cultural beliefs and values to include being made fully aware of potential risks or adverse side effects that may occur as a consequence of their involvement.

Participants were alerted to the possibility that some may experience distress when recalling some of their experiences, and/or find that their brain injury symptoms are impacting on their ability to communicate. I also indicated that I would be sensitive to any cognitive difficulties, pain, fatigue or emotional lability which might have occurred and that I would provide adequate time for participants to express ideas and for rest breaks to occur.

Strategies to maintain dignity were considered prior to interviews. For example, I sometimes used humour to convey perspective and relieve tension when participants were describing awkward or embarrassing events. On other occasions I switched topics when a participant appeared to be struggling to follow a train of thought, when my probes were not effective. Opportunities to regain composure when a participant became tearful were offered. This included providing reassurance, turning off the tape recorder, and checking with the participant that he or she was comfortable to proceed. In all cases the participants wanted to continue with the interview and all elected not to have the topic that triggered distress wiped from the recording device(s).

It was anticipated that unresolved health problems or an unexpected psychological reaction could be triggered during or after the interview process. Prior to starting the interview, participants were made aware that safety issues, such as suicidal ideation with intent or revelations of significant assault, would be addressed and an appropriate agency contacted. In all other instances, resources to resolve the unresolved health and/or safety concern, would be identified, but the decision to follow through with these suggestions would be left to the participant's discretion. In addition, participants were alerted to the possibility of triggering distressing emotions when they reflected on the interview. They were encouraged to use the free telephone number to contact the researcher to discuss any aspect of the interview, or to contact the project supervisors if they preferred to discuss their experience with a third person.

Two participants revealed unresolved health and disability issues. At the end of the interview, information on how to access further rehabilitation advice was provided, and - in keeping with the ethical obligations - I made no further attempt to see if this advice was implemented. There

were no safety issues and, to my knowledge, no participants contacted a third person or myself to discuss the interview content or their responses.

### **Confidentiality**

In undertaking this research, I adhered to strategies to ensure confidentiality (Tolich & Davidson, 1999), as mandated by Health and Disability Commissioner (2009), and Privacy Commissioner (2008). This included; securely storing all forms of data in locked cabinets or in password protected computer files, assigning and using pseudonyms in the transcripts, removing or altering personal data from transcripts which had the potential to identify participants, and limiting access - to field notes and transcripts - to myself and my university-based supervisors. A locked briefcase held the data carried between interview sites and supervisors' offices.

Participants were advised that if they withdrew from the research project all their data would be immediately destroyed. No participants withdrew from the study. In all instances the audio-recordings were deleted, once the transcripts were completed. Copies of transcripts and consent forms were forwarded to the primary supervisor to be held in secure facilities at the Faculty of Health and Environmental Sciences at Auckland University of Technology, for a minimum of six years.

### **Honouring the Treaty of Waitangi**

This research considered the principles of partnership, participation and protection (Māori Health Research Council, 2010), which underpin the New Zealand Treaty of Waitangi operating between the Crown and Māori. In addition, I drew on previous experiences of living and working in geographical areas with a high Māori population, including Te Puia Mental Health Services on the East Coast of the North Island, to inform my understanding of cultural practices and individual variation. Partnership principles were discussed with Mr Hori Ahomiro, together with my research objectives and interview protocols, to ensure their suitability for Māori participants. The design of my research was sufficiently flexible to allow participants to be interviewed in a location of their choice and to bring support person(s) to the interview. Protection was ensured through the informed consent process and by the constant monitoring of the research ethics by the supervisors associated with this project. Māori participants were offered an opportunity to say a Karakia or prayer at the beginning and end of the interview process. The one participant identifying as a New Zealand Māori took up this opportunity and blessed our dialogue at the beginning and end of the interview.



## **Selection processes and recruitment of participants**

At the outset of the study it was estimated, in consultation with my supervisors, that 8-12 participants, who experienced prolonged symptomology after a mTBI, would be required to explore the research topic. Maximum variation was the preferred recruitment strategy.

Recruitment of research participants occurred in two ways. An invitation was sent via a third party to clients and former clients of rehabilitation centres in Tauranga and Hamilton, inviting them to consider participating in a research project. In addition, an invitation was sent to people who had agreed to participate in future research from AUT, asking if they would like to participate in a further research project.

All people volunteering to find out more information about the research project agreed to be interviewed. A suitable time was organised and venue arranged. Seven people consented to be interviewed in their own homes and one person agreed to meet in a nearby office. One participant had unexpected visitors and requested to proceed with the interview at a local coffee shop, rather than reschedule the interview. No participants organised to have a support person present at the interview.

Due to the difficulties experienced in recruiting participants within the allotted budget and timeframe, my preferred strategy of maximum variation was compromised. I converted to purposive sampling, described by Teddlie and Yu (2007) as the deliberate selection of individuals, groups of individuals or institutions based on their importance to the research question. There was agreement between my supervisors and myself that the data collected from the eight participants was sufficiently rich and varied, so that further recruitment was not necessary to complete this project satisfactorily.

## **Data collection**

Demographic data was collected, and the Rivermead Symptom checklist (Eyres, Carey, Gilworth, Neumann, & Tennant, 2005) administrated, prior to the interview being conducted (see appendix 1). This was used to; 1) orientate me to the unique situation of each participant, 2) prepare for potential difficulties such as emotional dysregulation and 3) assist in the development of questions pertaining to everyday occupations relevant to the particular participant 4) ascertain the sample variably and 5) help determine if strategies were linked with specific clusters of symptoms.

The majority of the research data was acquired during semi-structured interviews. As discussed by Hesse-Biber and Leavy (2011), in-depth interviews are a meaning-making partnership

between the interviewers and their respondents. As such researchers need to ensure the relationship between the researcher and the participant is reciprocal and that the interviewee is seen as the *expert* on the topic of their lived experience. Thus special attention was given to the process of rapport building, and facilitating each participant to feel at ease, by employing the full range of active listening skills (Carpenter & Suto, 2008).

All interviews followed a similar pattern, inquiring about occupations pertaining to the participant's main roles. Variations of the prepared indicative questions (See Appendix 7 for indicative questions) were used, allowing the participant to tell their story in their own way with as few interruptions as possible. At strategic times during the interviews, the material presented by the participant was summarised, providing an opportunity for him or her to agree or to correct these impressions.

Reviewing interviews soon after they were recorded enabled me to improve on my ability to pick up on markers, or the passing references to important events or feeling states (Hesse-Biber & Leavy, 2011), with more targeted use of probing and clarifying questions in subsequent interviews. I was also able to determine that there was one strategy pertaining to use of a scheduling system on which I wanted more information, and I made arrangements with one participant to view the application on his cell phone that he was using to organise his schedule.

Within a week of interviewing each participant, the interview was transcribed. I chose to proceed without using a transcription service, to "fully immerse myself" in the data. The benefits of transcribing one's own work (Thorne, 2008), became apparent after I started the transcription process. I recognised that spending time paying attention to the way participants emphasised words and spoke with hesitation or confidence, was providing important cues for understanding the latent content of their experiences.

Recording my reflections and interpretations of events pertaining to the specific participant and the overall project occurred initially without analysis. Reflecting on these writings, I was then able to formulate my impressions and bring these for discussion at supervision.

## **Data analysis**

There is no prescriptive approach to analysing data, and it behoves the researcher to match the analysis to the selected methodology (Green & Thorogood, 2009). With a relativist ontology, it is assumed that reality can be interpreted in different ways and that all text will involve some degree of interpretation (Graneheim & Lundman, 2004; Lincoln & Guba, 1985), with different methodologies requiring different levels of inference. For example, qualitative descriptive

methodology does not have the degree of theory building that characterises grounded theory, or the level of interpretation from the multiple meanings in a discourse analysis, or the narrative of the lived experience extracted in a phenomenology study (Green & Thorogood, 2009).

Congruent with qualitative-descriptive methodology, I selected an inductive approach which seeks to find the core meanings in a text that are relevant to the research objectives and then organise these into categories which can be described in a straight forward way (Neergaard et al., 2009; Sandelowski, 2000). Underlying a qualitative analysis are three main tasks (Miles & Huberman, 1994). These are data reduction, data display and conclusion drawing. In implementing these principles, I initially planned to follow the processes outlined by Graneheim and Lundman (2004), whose conceptual model starts with the unit of analysis, and proceeds with developing a meaning unit. This meaning unit is condensed, then abstracted into a content area, code, category and theme.

I however deviated from this continuum when I was unable to fit the data into discrete entities in the first analysis and build from a sub-category to a category. For example, rest was a useful strategy to manage fatigue in the early stages of recovery, but it was of limited benefit for managing fatigue and increasing participation in everyday occupations in the longer term. I therefore grouped the content areas into the strategies that were deployed in the early stages of recovery and those deployed in the later stages. I was then able to make further refinements and develop the sub-categories. Thus I was able to remain open to new ways of seeing and understanding the phenomenon (Thorne, 2014), rather than trying to fit the data into a prescribed pattern.

In analysing the data, first I selected each interview as a unit for analysis. Thus the unit was large enough to be considered a whole but small enough to keep in mind as the context for extracting smaller meaning units (Graneheim & Lundman, 2004). To familiarise myself with the content of each participant, I typed a verbatim transcript of the recorded interview and then read through the interview several times. I then transferred the entire interview into a table. The next step was selecting a meaning unit, which consisted of words, sentences or paragraphs containing aspects which related to each other through their content and context. These meaning units were then condensed into a shortened piece of text, whilst preserving the core meaning. These shortened pieces of text were extracted and placed in a column adjacent to the interview, colour coded for each participant.

The third process, labelled abstraction, grouped together related units (Graneheim & Lundman, 2004), initially with little interpretation, from the first two interviews. Thus I was able to begin shedding light on specific areas of content, and I began developing a rough structure for the

development of categories and subcategories. Similar to Murphy et al., (2008), I found that the strategies that participants deployed did not fit neatly into occupational categories. Similar occupational performance difficulties were managed differently, reflecting individual variations in values and interests. For example, messy handwriting post mTBI was problematic for the teacher aide but passed off as a minor inconvenience by others. In addition, the same participant might manage persistent symptoms differently in different contexts. Hence a different set of strategies were developed to manage a propensity for tears in a home environment, compared with a work environment.

I therefore needed to consider the participant's reasons for deploying a specific strategy and went back to the interview data, combining data about the occupational performance difficulties with the reason for deploying the strategy.

A further review of the interviews revealed I had sufficient data to differentiate between strategies that were deployed in the early stages of recovery with those strategies that were introduced three months or longer post mTBI. After dividing the strategies into two groups, based on whether or not the strategies were deployed in the early or later recovery period, I was able to start developing categories and subcategories. I have attached a copy of the first page of the grid I developed to account for the strategies used by the first two participants (See Appendix 8).

The process of creating categories continued to evolve, as I added the data from further participants. This included the creation of new categories and subcategories and re-organising data as a new sense was made of data placed in exiting categories. Owing to the intertwined nature of human experience (Graneheim & Lundman, 2004), together with multiple symptoms of mTBI impacting simultaneously on occupational performance, it was not always possible to create mutually exclusive categories. For example, chronic fatigue impacted on attention, concentration and irritability, however successful fatigue management did not eliminate persisting difficulties with emotional dysregulation, or processing impairments. In deciding how to code strategies that potentially could have been placed in more than one category, I considered the reason why the strategy was deployed and allocated it to the category with the strongest association. Care was taken to ensure all of the strategies were accounted for and that no data was excluded due to the lack of suitable categories (see Appendix 9 for an example of refined categories).

Once I had completed a refinement and revision process, I placed all of the strategies on a grid, colour coded for each participant, with a reference to the text supporting the strategy. I was then able to make use of this data when writing the synopsis, allowing me to test the data

against the description as well as accounting for the alternative and contradictory points of view. What emerged was a nuanced account of developing strategies in direct response to unresolved mTBI symptomology experienced as the participants endeavoured to resume participation in previously familiar domestic, community and work related occupations. The thesis findings will be presented in chapters four to seven, with a synopsis of these findings presented in chapter eight.

In the remainder of this chapter, I will identify the strategies incorporated into the design and execution of this project to enhance rigor and assist readers to judge if the findings deserve a place within the scholarly and professional knowledge base.

## **Rigour**

To support my intentions of producing new information suitable for use in practice, I have first utilised the concepts of credibility, transferability, dependability, and confirmability (Lincoln & Guba, 1985), which have been widely adopted as the “gold standard” for evaluating quality in enquiries with a relativist ontology and subjectivist epistemology (Carpenter & Suto, 2008). I also address Thorne’s (2008) considerations for evaluating the suitability of the research findings to inform practice using portals of moral defensibility, disciplinary relevance and pragmatic obligation, which influenced the data analysis.

## **Credibility**

Credibility or authenticity are the strategies and meticulous efforts the researcher adopts to establish confidence that the integrity of the data analysis and interpretive findings can be trusted (Carpenter & Suto, 2008). I have detailed the rationale for the design-logic decisions in the first part of this chapter, attempting to demonstrate consistency between the research question and the epistemological view point, together with a logical flow between the philosophical foundations, and the methodology. However, it is not sufficient to merely produce a technically sound piece of work with adherence to the methodological guidelines. For findings to be judged as credible, the much more complex question of what *meaning* can be made of the findings needs to be addressed (Thorne, 2008). As discussed by Miles and Huberman (1994), research findings that are interesting, evocative, and illuminating can also be erroneous, reflecting findings that cannot be substantiated and/or are reflective only of researcher bias and agenda.

Credibility is based on the constructionist assumption that multiple realities are constructed by people in their own contexts with requirements that these representations are authentic and seen as plausible by the participants (Carpenter & Suto, 2008). I addressed this requirement in

four ways. First, by making audiotapes of each interview, I demonstrated authenticity of the participants' stories, and proof that I checked with participants, as the interview progressed, that my understandings of their stories were accurate. Second, by forming an audit trail (Ryan-Nicholls & Will, 2009), I was able to track my processes and thoughts documenting the development of categories. Third, by reporting the participants' words alongside my interpretations, I permit the reader to view the type of text that was coded into categories. Finally, I communicated frequently with both of my supervisors, presented copies of my transcripts for critique, and kept written records of supervision sessions.

### **Dependability**

Dependability is both the minimisation of idiosyncrasies when interpreting multiple realities (Baxter & Eyles, 1997), and demonstrating the compatibility of the research findings with the data that has been derived from the study (Carpenter & Suto, 2008). Strategies I used to demonstrate dependability included the use of audio taped and verbatim transcriptions of interviews, low level inference descriptors, peer examination, the use of an audit trail and an examination of cases that did not fit so well within developing understandings. I colour coded each participant's interview transcript, and therefore was able to contrast similarities and differences between participants, providing an indication of the strength of the knowledge findings and/or the significance of one-off differences.

### **Confirmability**

Confirmability refers to the extent that the research findings are based on the experiences of the participants rather than the perceptions of the researcher, which potentially can influence the data analysis process and the findings (Carpenter & Suto, 2008). To reduce the extent that my views biased data collection and interpretation, I engaged in a presuppositions interview (Chenail, 2011). This involved being interviewed and audio-taped by a researcher with sufficient understanding of my research project to elicit a wide range of feelings regarding the proposed project. The results of the interview were used to refine the proposed interview schedule and as a teaching tool to be perceptive to the views and feelings of others. Additional strategies to demonstrate confirmability included keeping a grid on how each interview was coded and how coded information was linked to the development of categories and subcategories. In addition, the quotes used to support the development of the categories were recorded on the grid and can be linked to each participant's interview.

## **Moral defensibility and disciplinary relevance**

As discussed by Thorne (2014), the qualitative tradition that simply describes a thing has relatively little relevance to practising in the health field. Since all knowledge generated in the applied disciplines has potential to affect the people whom we serve, some attention to any claims which may have population relevance needs to be considered. In chapter one I clearly identified why the research question had been selected and the relevance this may have for people with mTBI sequelae. I was not trying to develop knowledge for the sake of developing knowledge but to expand the repertoire of options for informing the complex considerations that are required in brain injury rehabilitation. Thus, in identifying the variations in how strategies are applied, I was reducing the possibility of misinterpretations of the data. I have also used my knowledge as a practitioner to inform the research design. As I have worked with the data iteratively, I have tried to bring forward the new insights and possibilities for understanding which in turn can be considered, further illuminated and expanded. Thus I did not expect to uncover any truth as such, but to identify processes that might better and more effectively provide guidance for those who do not make a timely recovery from a mTBI. The aim of the study was to be able to generate a set of conclusions that follows logically throughout the research process and is credible to others with experience of mTBI.

In selecting the above strategies to demonstrate rigour in my qualitative descriptive study, I needed to be able to communicate these effectively in the research findings. Finlay (2006) described ways of moving beyond solely establishing procedural rigour and advocated the use of ethical, literary and creative dimensions that “seek to reflect the potential power of qualitative research” (p. 322). I endeavoured to use Findlay’s five dimensions; clarity, credibility, contribution, communicative resonance, and caring to assess my written work and improve my ability to produce research which can be viewed as clear, thoughtful, and reflexive. The reflexive strategies incorporated throughout the research process will be further discussed in chapter eight.

## **Summary**

In chapter three, the theoretical scaffolding which underpins my qualitative-descriptive research project is outlined by utilising congruent methodology and methods, which are ethically sound. I demonstrated how I intended to generate knowledge to answer the question “What strategies do people with persistent symptoms post mTBI use to manage everyday occupations?” The strategies to ensure rigour have been described to assist the reader in determining the value of the research findings.

In chapters four to seven the research findings are presented, with the categories that were developed presented together with examples which support the research findings.



## Chapter 4 - Introduction to the Findings and Participants

The research findings from eight participants' experiences post mTBI, shared in one-on-one interviews, are presented and discussed. To allow the viewpoint of those with persisting difficulties post mTBI to be heard, collateral information pertaining to pre-morbid characteristics and results of therapeutic interventions were not sought. Despite a wide range of differences in social economic status, available supports and pre-injury educational attainments, the accounts shared had many similarities.

Chapter four sets the scene for understanding the research findings. First, the reader is orientated to the occupational nature of the challenges facing participants when they do not make a timely recovery post mTBI. Secondly the participants are introduced, and readers are orientated to post mTBI symptoms and the impact these had on employment. Together, this information provides the context for understanding the strategies that were developed to manage the sequelae of mTBI.

### Managing Occupational Performance post mTBI

Changes in occupational functioning were described in terms of perceived difficulty and the context where the occupation occurred. Impacting on performance, all participants described post mTBI changes in energy levels, emotional functioning and cognitive processing skills. Strategies deployed depended on the performance demands of the occupation and the context where the occupation was being deployed. A succinct example is provided by Robin.

*They had a big farewell for me last week, and I thought 'Oh god no, there will be speeches and I'll be blubbing all over the place.' ...but I had a little plan. I didn't go to work on Friday, I stayed home in the morning. We went in the afternoon, I had a nap, so I wasn't tired at all. And I thought through what I wanted to say. Put a bit of humour into it, that lightens things up a bit, so doing that helps me avoid getting into that emotional type of situation.... Going through life you learn things, you learn coping mechanisms, like years ago. Really, I had to fall back on those methods of doing things, with respect to the situation. So not a difficult thing, but even your speech has to be planned out.*

Crucial to the successful deployment of strategies is knowing what to expect. Robin knew that when he delivered a speech he would have word finding difficulties (as described earlier in the interview), and there would be moments when he was vulnerable to becoming tearful. He knew that he was more emotional when he was tired, and that the use of humour altered his mood state and reduced his chances of becoming tearful. He utilised past knowledge on how to write a speech and deliver jokes, and he knew that if he planned what he was going to say, he would

find it easier to speak fluently. Thus prepared, he anticipated completing the occupational sequence successfully.

Despite having developed strategies and drawing on previous experience, however some occupations were perceived as too hard to continue post mTBI. Caroline provides an example of relinquishing complex occupations associated with staff development.

*Staff management can be difficult in its own way. Having to deal with people that are not working the way you want them to work, and making judgement calls on quite subtle stuff. I'd miss cues and things, and me being very aware, that I then get frustrated and have a temper, and I don't want to do that. If you end up with adversity or anything it is really emotionally draining on yourself, but also it then stuffs up your working relationship with other people....and I'd forget stuff... that's one thing they said as well [when I was assistant manager]. And it's yes, I believe you, but I don't actually know I am forgetting them... That is the nature of having a brain injury.*

In this scenario the altered capacities contributing to occupational loss can be identified as attention and working memory deficits, judgement errors, and decreased frustration tolerance, all of which contributed to occupational loss. Perhaps more important, Caroline was still learning how working memory deficits were impacting on her occupational performance five years after her mTBI, well after rehabilitation interventions had ended.

These two examples demonstrate the reality of managing occupational performance deficits, post mTBI. The effect of multiple impairments simultaneously impacting on occupational functioning, requires a combination of strategies deployed at strategic moments to influence occupational functioning. The specifics of the strategies that participants developed to manage the sequelae of mTBI are presented in chapters five to seven.

Before proceeding, however a brief synopsis of the participants involved in this study is presented, permitting the readers to put the findings into context.

## **Introduction to the Participants**

### **Demographic and injury data**

The background contextual information is compiled from the demographic data and symptom checklist completed by participants at the time of their interview, together with relevant information presented in each participant's interview.

The participants were three women and five men between the ages of 39 and 67 who sustained a mTBI, eight months to ten years prior to recruitment to this study. One participant identified as a New Zealand Māori, five described themselves as New Zealand European, and two as European immigrants. Six of the eight participants were living with a spouse at the time of their accident and remained in these relationships at the time of their interview. Three participants had dependent school age children. One participant had been working part time at the time of her accident, so she could be available for her children after school. Two participants were living alone at the time of their injury.

Three participants sustained their injuries in sporting accidents (basketball, horse riding, and mountain biking), and two were involved in vehicle accidents (motor vehicle and bicycle). One person was assaulted by an unknown intruder, one slipped on a slippery surface at work, and the other fell off a ladder while repairing a domestic property.

### **Overview of the participants**

The following section briefly introduces each of the participants in terms of their main occupations, to provide a context against which to understand the strategies deployed during their recovery. All participants were allocated a pseudonym and some details have been changed to protect identities.

Barry was a teacher aide at the time of his accident, with talents in music and art. Post injury, he continued his involvement with all aspects of family life, and as an active member of his church with responsibilities for youth development. Barry persevered with his employment for eight months after his injury, before recognising the impact that cognitive changes, post-traumatic stress, fatigue, anger and depression were having on his functioning. Following two separate periods of counselling, Barry resumed part time employment as a teacher aide.

Prior to her mTBI, Bronnie lived alone and enjoyed a varied social life. She owned her own horse and enjoyed the freedom of driving to places of interest in her spare time. Post mTBI, Bronnie coped largely by withdrawing from occupations and social contacts that were exhausting and confusing. She adopted a coping style of accepting what can't be changed, and getting on with what she could still do, without making a fuss. Post injury, Bronnie invited her elderly mother to live with her.

At the time of her injury, Caroline was working shift work, consisting of four, 11.5 hour days, and then four days off work. She had many interests including learning French as a second language, mountain biking, competing in triathlons, farming and photography. Post mTBI, Caroline had

difficulty retaining necessary information, and executing complex sequences “*on the spot*”. Conflict resolution and forward planning was also difficult.

Doug was working unsociable hours managing a recreational sporting venue. He rated the adjustment period post mTBI as difficult, with further emotional distress when his rehabilitation was cancelled, without warning, by ACC. With excellent support from his family, Doug continued to develop effective coping strategies, and learned to manage his sleep disturbance, post injury anxiety, emotional lability, and noise intolerance. He eventually retrained as a school teacher, and is currently enjoying travelling in the school holidays, with closer contact with his wife and extended family.

The main roles Leigh identified were those of an engineer, parent and sport coach. Prior to the mTBI, Leigh was working 25 hours per week and was the parent responsible for getting their children to and from school. One year post injury, Leigh had built up to 20 hours per week at work, but she was struggling with fatigue and managing conflict.

Nigel, a husband and father, worked in community development. He experienced a cascade of symptoms, and the onset of migraine headaches, the week after his mTBI. He initially was unable to process complex verbal and written data, developing a hesitation, and fumbling over words, interfering with his capacity to converse with others and speak publicly. Six months post injury, Nigel felt helpless and depressed with his lack of progress and stated that the health professionals working with him mooted that a full recovery might not be possible. However, with coordinated support from his family, therapists, and his wider community, Nigel was one of two participants who had been able to achieve full time work in their pre-injury employment.

Robin, also an engineer, lived away from the family home Monday to Thursdays and was responsible for 25 staff, designing and producing goods, mainly for overseas markets. Robin relinquished employment ten months post injury, citing an exacerbation of symptoms when sustaining concentration and an inability to keep track of the production sequences when working part time. Robin also revealed symptoms compatible to post traumatic stress, which he anticipated addressing in the near future.

Gerald described himself as being hyperactive with a curiosity of how the world worked. Following the mTBI, Gerard reported difficulties filtering out extraneous thoughts and structuring his ideas. In addition, he had problems developing a sense of what he was meant to be doing each day. He was unable to return to his consultancy business, and he declined ACC’s offer of a job trial selling “educational” toys which Gerald considered had no educational value. At 67 years old, Gerald had reluctantly given up on the idea of formal employment. However, he was combining his long-term interest in foreign travel, with his love of art and architecture,

and was experimenting with purchasing art pieces to sell at décor shops. He was also enjoying spending time with his grandchildren who lived close by.

### **Symptom Characteristics**

Comparing the different impact specific symptoms had on the occupational performance between participants was not possible, nor was it the goal of this study. Rather than comparative understandings, the emphasis of this study was on understanding what strategies participants used, and the reasons particular strategies were deployed. That knowledge underpins the categorisation utilised in the following chapters.

The data contained in Table 1 gives an overview of the extent to which persistent symptoms participants reported, impacted their everyday lives, at the time of interview. Most participants commented that the symptoms have a greater impact when new learning is required and/or there are multiple pieces of information requiring synthesis. As persisting symptoms were not continuously impacting on occupational performance, I instructed participants to comment on the symptoms that continue to have an impact on their everyday life, rather than reflecting on just the past week.

Table 4.1: Symptoms and estimated impact on current functioning (c.f. preinjury functioning)

Symptom	Leigh	John	Nigel	Bronnie	Gerald	Caroline	Doug	Barry
Headaches/migraines	0	3	2	2	3	3	2	3
Dizziness	2	2	0	1	2	0	0	3
Nausea/vomiting	2	1	0	0	3	0	1	0
Noise sensitivity	2	1	1	3	3	2	3	3
Sleep disturbance	3	1	1	4	3	2	3	3
Fatigue	3	3	1	4	2	2	2	4
Irritability/anger	4	2	1	3	2	2	2	3
Depressed/tearful	2	2	1	2	2	1	1	2
Frustrated/impatient	4	0	1	4	3	2	2	3
Forgetfulness	3	0	1	3	3	3	1	3
Poor concentration	2	3	1	4	2	2	1	3
Taking longer to think	2	2	1	3	4	1	0	3
Blurred vision	0	2	0	0	1	0	0	2
Light sensitivity	3	2	0	2	3	0	2	3
Double vision	0	0	0	0	1	0	0	2
Restlessness	0	0	1	3	2	2	1	3
Temperature regulation	0	0	0	0	3	0	0	0
Emotional incontinence (not depression)	0	0	0	0	0	0	4	0

Key: 0 = never a problem    1= problematic post injury but now resolved    2 = mild problem  
 3 = moderate problem    4 = severe problem

This data demonstrates that, for most participants, acute symptoms following a mTBI continue to have an impact on their everyday occupations. Bronnie, the only participant to experience a continuing severe impact of more than one symptom a year post mTBI, did not receive any rehabilitation. Gerald and Barry described a higher symptom load, which persisted post injury, despite rehabilitation from a multidisciplinary team. Nigel recorded that apart from the occasional migraine all other symptoms had resolved. However, during my interview, it was

apparent that Nigel had successfully deployed strategies to prevent persistent symptoms from negatively impacting on everyday occupations, rather than experiencing a complete resolution of all persistent symptoms.

## Work Trajectory post mTBI

Despite accessing a medical assessment at the time of their injury, no participant reported a smooth transition back into the workplace. All participants placed a high value on employment, and had spent considerable time and resources redeveloping their work roles. As employment status is reported as an important determinant of capacity in many studies, I have provided a brief synopsis of the participants' experiences of paid employment post mTBI. The timeframes and outcomes of participants' first experience of returning to paid employment is available in

Table 4.2: Outcome of first attempt to return to paid employment

Employment Details	No. of Participants	Data not available
Returned to work within one week of injury	6	
Sustained recommended hours/duties at first attempt to return to paid employment	0	
Achieved preinjury level of employment within 0-6 months of injury	0	
Achieved preinjury employment within 6-12 months of mTBI,	1*	
Achieved preinjury employment and hours of work 12+ months post mTBI	2	2**
Lost job or resigned 1-6 months post injury (attributed to symptoms related to brain injury)	2	1
Lost job or resigned 7-12 months after injury (attributed to symptoms related to brain injury)	3	
Lost job or resigned 13+ months after injury (attributed to symptoms related to brain injury)	2	
Did not attempt competitive work within 12 months of accident	1***	

### Key:

\*Continued to feel anxious and at risk for another work injury. This anxiety contributed to a decision five years post injury to resign, and retrain

\*\* long term outcomes not known, as mTBI sustained 8-12 months prior to interview.

\*\*\*Unable to return to pre-injury employment. Had sufficient resources to live on, and declined ACC suggestions of alternative work which was of low intrinsic interest.

All six participants who returned to full time work within a few days of injury, recognised that all was not well. Three of them sought additional medical support via their general practitioner and were referred to the concussion clinic. One further participant was referred to the concussion

clinic after the neurologist attending the same night class recognised the post injury symptoms and arranged further assessment. Another participant, who was on unpaid leave at the time of her accident, was advised she was not eligible for ACC workers compensation and assumed she was also ineligible for rehabilitation services, so did not seek assistance. The other participant was fearful of losing his employment and struggled on at work for eight months before resigning and accessing additional support.

Of the two participants placed on an extended period of sick leave immediately following the mTBI, one became frustrated at his inability to work. He spontaneously arranged to continue some work at home, while pushing for an early return to work date. The other participant, who was unable to return to his pre-injury work, declined ACC's suggestions of alternative work, which was incompatible with his values.

Two of the eight participants returned to their pre-injury employment at full time hours, 6-18 months post injury. Another was working part time, in her usual employment, one year post mTBI. A fourth participant resigned after eight months of work but returned to similar employment, two years later, on a part-time basis.

The four participants who were unable to sustain their pre-injury work, all had different levels of professional support, and all attempted various strategies to try and remain in their pre-injury employment. At one end of the spectrum was Bronnie, who did not receive any rehabilitation. She quickly resigned after experiencing debilitating fatigue and an inability to enter data correctly on the computer. Citing a love of driving, and an opportunity to work at her own speed, Bonnie found alternative work as a salesperson. As Bronnie eloquently expressed;

*It was the driving but I didn't know at the time. I'd get to my destination and I'd be exhausted and I couldn't talk to anyone. I'd get to the part when I had to do my job [sales rep] – and I didn't want to face it. I'd force my way through – not spend as much time with people as I probably should have – and thinking, gosh, I have to get all the way home again - three or four days to recover. I couldn't do anything for the next day at all. I'd sleep all day and slowly come right after three or four days – and then do another day's work...*

After a redundancy from the above job, Bonnie found employment at an animal shelter. She enjoyed this job, but reluctantly resigned, as the accumulating fatigue made it unsafe to drive home at the end of the day. She gained similar employment closer to home, but was dismissed, one week into the three-month trial period, as the employer didn't understand her need to overlearn new sequences. At the time of my interview, Bronnie was receiving a sickness benefit and was contemplating what other employment she could consider.



At the other end of the spectrum, Caroline spent two years trying to build up her work hours. During these two years, she received rehabilitation input from a clinical psychologist, physiotherapist and vocational occupational therapist. In an effort to improve her ability to keep working, Caroline terminated her managerial responsibilities and arranged a voluntary cut in pay, so she could spend time increasing her physical fitness. After six months, improved fitness did not increase her overall stamina, so Caroline relinquished all “extracurricular” occupations to concentrate on building up her work hours, before reluctantly accepting the redundancy package advocated by her employer.

Following her redundancy, Caroline gained full time employment, from Monday to Friday, albeit with fewer cognitive demands compared to her previous employment. After restoring confidence in her role as a worker, she secured employment more in keeping with pre-injury interests and skills. However, sustaining the higher cognitive load and longer work hours was not possible. After 12 months Caroline resigned, exhausted. Following a month’s holiday and successfully utilising strategies learned earlier in her recovery, Caroline moved towards setting up a lifestyle block with her new partner, gaining part-time paid employment.

These synopses of Bronnie and Caroline’s attempts to resume to paid employment post mTBI, demonstrate the enduring difficulties experienced by participants in this study. Early interventions were not restorative, and sustained effort over time was required to address the disruptions in occupational performance.

## **Summary**

This chapter sets the scene for reporting what strategies were deployed to restore occupational functioning when participants recognised they were not making a quick spontaneous recovery after their mTBI. In chapter five, the strategies that emerged when participants first began managing the sequelae of mTBI are presented and discussed.

## **Chapter 5 - Managing the Acute Sequelae of mTBI**

Chapter five describes how occupational performance difficulties were recognised and identifies the coping strategies deployed to manage these difficulties, both at home and at work. Participants often described their initial efforts at engaging in everyday occupations post mTBI as weird or confusing, as if they were learning things for the first time. Without the “filters” working properly, participants described feeling overloaded and not knowing what they should be doing, requiring cues to guide them on what to do next. Everyday occupations were no longer routine. Tasks took longer to perform and fatigue set in quickly, requiring new schedules to be developed. Too much occupation triggered headaches and, for some, periods of nausea and dizziness. In addition, noise and light sensitivities made concentrating difficult and explosive angry outbursts were commonly experienced if things did not go according to plan, making it difficult to resolve conflict situations.

The emphasis in this chapter is the persisting disruptions to occupational performance and the effectiveness or otherwise of the initial coping strategies. The findings are presented in three sections. The first section presents the different ways that participants identified that their usual style of resuming everyday occupations was unsustainable, and what they did when they came to this realisation. This is called acknowledging the recovery trajectory is not proceeding as expected. The next section, called balancing rest and recuperation with participation demands, depicts how participants implemented early advice to rest and reduce the cognitive demands on the brain, while learning to perform at a minimal level. Lastly the third section, making a start and doing things a bit at a time without pressure, identifies the early strategies that were deployed by participants to commence plotting a course to recovery.

### **Acknowledging the Recovery Trajectory is Not Proceeding as Expected**

Differentiating between normal recovery and recognising the need for a more strategic plan to facilitate recovery was not a straight forward process for most participants. Three different ways of recognising all was not well were identified. These were; a rapid deterioration in functioning, uncharacteristic explosive angry outbursts, and feedback from others. The easiest for participants to recognise was a deterioration in functioning after sustaining a mTBI.

## A rapid deterioration in functioning

One way participants recognised that they were unable to persist with their usual routines was an escalation in mTBI symptoms and a rapid decline in functioning within the first two weeks of their injury. Nigel, whose job as a community worker demanded concentrated listening, counselling and preparing public presentations, provides an example of progressively becoming less able to manage the demands of everyday life.

*So I had the accident on the Tuesday, it didn't look that big at the time. But the concussive injury progressed over the week, and I was less able to concentrate and manage complexity, to organise things.... I couldn't cope with any kind of complexity in a sentence, I couldn't cope with the phone, couldn't deal with prolonged conversation. The frustration about not being able to do what I was normally doing, made me angry, but then those spirals of anger that got, not out of control or violent, but I became verbally frustrated and kind of couldn't cope with kids, with home, with my job ... and then there was a crisis moment, just under a week later ... so [I spent] the next day, completely in bed, not really doing anything.... then I saw the doctor and was signed off [work] for a month. And that eventually became 19 months.*

Nigel reports not understanding what was happening, and becoming frustrated that he could not do the things he normally did. It took a crisis before he stopped pushing himself to perform his usual occupations, which then became the precursor for requesting additional advice from his general practitioner. This contact with the general practitioner resulted in a referral to the hospital for further investigation and another referral to the concussion clinic for expert advice.

In contrast to a gradual deterioration in capacity over a week, Leigh provides an example of a more sudden deterioration in capacity, when she was participating in a sporting tournament ten days after her mTBI.

*I actually played in a tournament two weeks after I was concussed, as I was still trying to convince myself that I was fine ... [after] the doctor had given me three days off work. I had the head injury, and then 10 days after that I played in the tournament.... I threw a ball to my teammate, thought it was a perfect pass, but it was a good metre above her head, ... and then, watching the ball thinking, 'Why isn't it dropping into the hoop?' .... then I looked at my fingers and they were doing that (shaking), so that was when I took myself to the doctor...*

Leigh's comment that "she was still trying to convince herself that she was fine", suggests she was experiencing subtle difficulties performing everyday occupations, but was not entirely convinced she had made the expected full recovery. She recognised something was wrong when she repeatedly failed to judge depth and distances, part way through a sport tournament.

Typical of participants in this study, was her waiting until there was indisputable evidence before seeking further help. Leigh's doctor referred her to the concussion clinic for further follow-up.

A second reason for recognising that all was not well was explosive angry outbursts which frightened the person with the mTBI, as well as those around them.

### **Uncharacteristic explosive angry outbursts**

Most often, explosive angry outbursts, which frightened both the persons with the mTBI and those around them, were a potent indicator that all was not well. Bronnie elected to complete a training course, immediately after her mTBI, and provides a typical example of failing to deploy executive control.

*This girl had been annoying me ... we were doing a test and she just kept looking at my work, and the tutor noticed and he asked her to move. When she moved she just kept staring at me, so I just picked up my book and threw it at her and said, 'here have my work if you want to copy off me'.... That's just not me - like I wouldn't say something at the time, I'd let things go on and on until I couldn't handle it any more. I never used to get upset and cry over things, and that made me feel angry because I shouldn't be getting upset.*

Bronnie describes an uncharacteristic delay in deploying strategies to diffuse the conflict situation, followed by an impulsive outburst of anger. Typically, such incidents also triggered shame or anger directed at oneself for losing control.

Others described impulsive behaviour, which placed them in danger.

*We had a fight up the road here – this guy had a machete and an axe and all that. I went up there and got involved. And I learned something from all of that; when I came away I realised that, umm, I didn't have that sense of danger in my head. It is only when I walked away and thought about it - that I thought I could have been hurt, or killed or something like that. So yeah, every day has been a learning curve from that accident. Barry*

Despite the temporary loss of executive control, most participants deployed strategies to mitigate the fallout from the uncharacteristic emotional outbursts and initially carried on with their usual routines. For example, Bronnie accepted help from her tutor to diffuse the situation, after she had thrown a book at her peer, whom she thought was cheating in a test.

*I said to my tutor, no one will like me anymore, I don't know why I did it. He was good, he took me into his house and sat me down, [and said] come back tomorrow. I didn't want to come back, no one will like me anymore, everyone will hate me. But no it was fine. I went back; I was so nervous, but it was fine.*

Nigel describes a typical response of calming down, apologising for his inappropriate behaviour before moving on with his daily routine.

*...at that moment I was unhinged.... And I phoned the next day and said, 'I spoke to someone yesterday, and I was really out of order. So please apologise on my behalf'. Nobody deserves to be spoken to like that, regardless of what they had done...*

It often took a crisis incident, before accepting that the impulse control issues needed to be managed differently. In Barry's case, this occurred about eight months after the mTBI.

*In my mind as a male I thought I was doing the right thing, trying to keep my job and earn the money, and all that ...but boy, it was a struggle. So I think it all hit rock bottom in October, when the depression from it, and struggling was just too much...The reason for the counselling was I had rage and got violent. And I'm not a violent man, and my kids know that; my wife knows that, and I got violent and angry towards my oldest son who was sparking off me as well. We were in the same boat [both had mTBI's in the same car accident] without knowing it. When I got violent and all that, I decided to stop everything, stop teaching...*

Following the "crisis", Barry was able to access psychological services, to address his anger and mood difficulties together with the impairments in his executive functioning and working memory.

The final way that participants in this study acknowledged their persisting occupational performance difficulties was via feedback from others.

### **Feedback from others that all is not well**

All participants sought medical advice most often at an accident and emergency centre as the first strategy to manage the mTBI sequelae. An important precursor for deciding that additional strategies were required to perform everyday occupations was feedback from others. For example, Nigel's wife overheard an angry response and brought this to Nigel's attention, helping him to develop an awareness that a change in his capacity needed to be addressed, initially via his general practitioner.

*I got really angry with someone at Vodafone – they had done something stupid, wrong. I screamed at the guy down the phone – and afterwards when I came back in, my wife said that wasn't a good conversation, ... and it was one of the warning signs, that something was really wrong.*

Caroline commented that the neurologist in her night class recognised her uncharacteristic processing difficulties and organised for her to have an assessment at a local concussion clinic. To highlight the significance of this timely advice, Caroline's experience is compared with

Bronnie, who described similar cognitive processing difficulties, which also came to the attention of others.

*I just kept going, I just went back to work, and each day I couldn't understand why I couldn't do it anymore .... like I had to put in accurate information [into the computer] ... it [data] wasn't going from my head to my hands, and I just didn't know what was wrong with me. And people around me started to notice, they'd say "Bronnie doesn't make mistakes, it's not like her". So in the end I wasn't comfortable even staying there, so I left.*

Neither Bronnie nor Caroline understood how to resolve the persistent cognitive difficulties that were interfering with their occupational performance. In Caroline's case, a friend who was knowledgeable about mTBI recognised the significance of her occupational performance difficulties and navigated access to the experts at the concussion clinic. In contrast, Bronnie relinquished her employment, but with hindsight commented that timely expert advice may have been helpful.

*Things had to be done by deadline and I just couldn't ... I needed someone to say to me to do it in my own time...*

Others also identified that those around them identified uncharacteristic changes in performance but didn't know what to do to help. Barry provides a clear example of how misunderstanding can occur in the early stages of the recovery, and suggests that a strategy of providing early advice to the family may have been helpful.

*Telling my family after the accident that I have changed, they didn't get it – they did after seeing me react and this and that, and they still didn't get it ... because there are going to be hit and miss days, ...and they didn't understand – they didn't get it. And there was confusion, there is anger, there is siding with one another type of thing, a 'me and them' mentality, that happens, ...it was a shame there wasn't information for the family.*

In summary there were delays in developing a strategic approach to manage the sequelae of mTBI. No participants described accessing written information at the time of their first medical assessment. There was often a mismatch between recognising problems and knowing what to do in the acute period after the mTBI. Most participants returned to their general practitioner when they had tangible proof that their capacity had altered, or after engaging in uncharacteristic behaviour that was potentially harmful. Feedback from others assisted participants to recognise the significance of their capacity changes post mTBI.

Standard strategic advice from the experts was to engage in a short period of rest and recuperation, before returning to normal occupational routines as soon as possible. One participant reported an early intervention to treat benign paroxysmal positional vertigo (BPPV),

caused by the detachment of otoconia (crystals in the inner ear), triggering vertigo and nystagmus with certain head movements. All other participants commenced their recovery process by inserting additional rest periods into their routines.

## **Taking Off the Load**

### **Balancing rest and recuperation with occupational performance demands**

Inserting extra rest periods into their daily routines and reducing the cognitive load was standard expert advice for those with persistent symptoms post mTBI. However, this advice did not directly address the capacity impairments influencing occupational performance. Participants reported finding out about these difficulties, when they were unable to perform everyday occupations in the manner they were accustomed to.

Two different patterns emerged when participants were advised to reduce the cognitive load and rest. First, participants acted on the advice and, largely through trial and error, recognised persisting difficulties when trying to carry out occupations in the usual manner. Second, some participants resisted putting advice into practice, and needed to understand for themselves what happened if this advice was resisted. I have utilised these two different responses as headings to describe the strategies that emerged in response to this early advice.

### **Implementing advice from the health professionals**

As explained by Gerald, the crucial reason for accepting advice for rest and recuperation was to restore normal functioning, as quickly as possible.

*I remember one of the Canadian guys saying every single episode of pushing things too far puts you back x number of days in your recovery. And I was terrified of that ...because all I ever wanted to do was get back to normal... And that was when the occupational therapist was quite useful. They taught me to look for symptoms like nausea, headaches and things like that.... I used to have a name for it, but I've forgotten what it was, totally overwhelmed, where I can't breathe and that sort of thing. But I learned to know how to avoid those happening.... My coping was accepting that I couldn't rush around a million miles an hour. So calming down, restricting myself was an important thing... I had to get used to the fact that I needed to go and rest quite often during the day.*

In this extract, Gerald accepted advice that exacerbating his physical symptoms would prolong his recovery, and he was motivated to follow advice. He learned to slow down the tempo of his day, by restricting the number of occupations he was trying to achieve, and by inserting regular rest periods. By implementing this advice, he learned to avoid triggering acute episodes of panic, presumably reducing the intensity of headaches, dizziness and nausea.

Similarly, Leigh was taught to avoid situations which exacerbated the acute symptoms of nausea, dizziness, headaches and fatigue. She adds to the findings by providing details of the triggers which exacerbated acute symptoms in the early stages of her recovery. The following four extracts from Leigh demonstrate the different aspects of implementing advice, and the accumulation of distress when the capacity impairments are not well understood.

*... grocery shopping ... that was tough; I couldn't do that ... you had to strip away all those triggers – for me these were; light, noise, interruptions, stress, decision making, looking after children - keeping them happy making sure they weren't naughty. All of that load needs to be off taken. You need to be given time, to sit in a blanket outside in the garden for three hours at a time, because you can't do anything else. If you watch TV, you feel sick. If you read, I couldn't read for months, it was horrible... so you have to strip all of that off and give yourself permission to be a slob, basically.*

As Leigh describes, bright noisy environments were difficult to tolerate, as were occupations involving reading and watching television, making decisions and caring for her children. To stop exacerbating her symptoms, Leigh relinquished most of her daily occupations and spent time sitting outside in a pleasant environment for several hours at a time.

She went on to describe the difficulties she had working out how to reconfigure her routines, demonstrating the initial difficulties understanding the extent of her capacity impairments.

*... you [husband] need to organise the kids, you need to cook. I don't even know what to cook for dinner – maybe if you could tell me, I'd be able to cook it, but I can't make a decision ... so tell your husband he has to step up and he has to step up fast – take all of the time pressure off you, all of the decision making and appointments.*

Leigh's husband, who worked from 6 am to 6 pm, initially arranged for help from relatives. Leigh, who was unable to manage the role of host, described this as particularly distressing. She went on to describe the type of help that may have been more useful.

*...so, don't have visitors – it doesn't matter how well meaning they might be. For me unless they are there to cook dinner and do the washing and they are going to be quiet and get out of the way and give you space where you feel safe – having people to stay is a really bad idea. Strip that pressure off, kind of accept to keep a low profile for a while and just build up slowly...*

In addition to difficulties planning how to achieve the recommended rest period, rehabilitation expectations in the early stages of recovery contributed to the level of distress.

*I ended up having too many appointments. I had two OTs which was over the top. I had my back to work OT, then I had another OT, which was more the personal side – that's the way they [ACC] stream it ... it was too much intervention and I just wanted to go and lie down... physical activity in a safe controlled environment is really good, but ACC put me into a gym with music*



*blaring and a spin class beside me with all these people ...and because it was all new, and I had to learn everything, it was too much....*

Thus, at the time when participants had been advised to rest, some participants became overwhelmed by trying to sort out new routines and meet other people's expectations. Leigh went on to describe an acute stress reaction, and the development of avoidance strategies required for "self-preservation".

*The OT explained when I felt supersensitive, I wanted to get away from everyone.... She explained that it was your fight or flight, .... I don't want to deal with it, I want to get out of here ... self-preservation comes first. So there is probably a little bit of that still there [one year post injury].*

In addition to advice that rest would restore energy levels and brain functioning, some participants recalled advice that balancing rest with exercise would be good for recovery. In contrast to Leigh and Gerald, Caroline was not given a period of time off work, but was directed to stop driving and reduce her work hours by half. She voluntarily relinquished all of her extracurricular activities, citing disabling fatigue. The following two extracts demonstrate how Caroline structured her time at home, so she could remain living independently.

*I was really lucky there was a dairy at the end of the road, and the supermarket was in walking distance as well. If I hadn't been in that kind of area I would have struggled to stay independent. So I was just able to, get a back pack for her [dog] and a backpack for myself, walk to the supermarket, and kinda find my way in the supermarket with those terribly bright lights. I'd get the bare basics... like just making sure I had like bread, so I could have sandwiches, because cooking was [gesture of non-existent] and my appetite was completely gone as well, I'd lost weight. So I'd load her up and my backpack and I'd walk all the way back home. And I'd need a cup of tea and a lie down, because that was such an effort ...*

*She [dog], was used to running and going mountain biking with me, then to nothing. So I upped her feed, because fat dogs are a lot less active. Basically fattened her up a bit and forgave her for digging out the lighting out of the garden, 'cause she was going mad just about...so if I could, and I'd been told exercise is good for you, I would walk around the block.... I couldn't believe how long it was taking me to do that circuit – it was basically taking me twice as long as what it was before my accident.*

The crux of these extracts is learning to perform at a minimal level, after removing occupations that are triggering acute symptoms and exacerbating fatigue. For example, Caroline stopped eating properly after the mTBI, and found she was unable to sequence steps for cooking when she was exhausted at the end of the day. To remain living independently, Caroline combined tasks that could be completed at the same time, and used her dog to help carry groceries back from the grocery shop, while she was unable to drive her car. Whilst other participants delegated

the grocery shopping to others, Caroline pushed through an exacerbation of her symptoms and bought ingredients for sandwiches which were both nourishing and easy to prepare.

Despite performing at a minimal level at home, and following advice to reduce her work hours by half, the capacity issues preventing sequencing complex work tasks were not addressed. As little guidance was provided by the experts on how to restructure work environments, a trial and error approach, of learning what was and wasn't possible, was adopted. I have continued with Caroline's story as it provides insights into understanding the occupational performance difficulties which were not addressed as part of early interventions. The following two extracts focus on managing the mTBI sequelae in the work place.

*I realised I wasn't going to be able to do any of the supervisory sort of work. I also realised very quickly that I couldn't even answer the phone at work which was a pain in the butt as the phone lines were actually quite busy - with people replying to items that were being held. It was just that I couldn't hold the information long enough to get to the next step.*

As Caroline describes, she relinquished the complex aspects of her work that she couldn't perform. Supervisory work, and tasks requiring intact working memory were quickly recognised as being too difficult to complete. Caroline describes offering to take over an assistant's job, so she could continue participating in the work environment.

*At the same time a guy who had been there not very long, who had been an assistant at the time he left for a new job, which meant there was his job that needed to be done. I kinda realised that's what I kinda needed. .... X-ray operations because they are snap decisions, and you don't have to need to know - what was there, to make a decision, about what is here.*

As Caroline describes, the work on the X-ray machines required immediate decisions about what she was seeing. This was easier to achieve compared to her usual role of accessing her specialist knowledge, formulating a rationale as to why the problem was occurring, and then deciding how the problem needed to be fixed in the future. The continuation of Caroline's story, demonstrates that working on the x-ray machines, for six hours per day, could not be sustained, and she was advised to further reduce the cognitive load. She described replacing operating the x-ray machine with "treatment stuff", which she later outlined as an assistant's grade position requiring one of three pre-determined treatment process to be applied to contaminated goods, which was much easier for her to perform.

*...initially I was doing the X-ray stuff – it took a bit to give that up – but I really needed to give it up, because it was such a cognitive demand. And the moment I actually stopped doing it, I saw an improvement in my energy levels and everything. For some time, I would do this treatment stuff and tidy up, and that some days I would get to a point that there wasn't anything else for*

*me to do, that I was capable of. And I'd make cups of tea and coffee for my colleagues, because that was something I could do.*

Caroline describes that by reduced the complexity of the occupations she was performing, she was able to stabilise her energy levels and reach the end of the day without being exhausted. In this example, Caroline identified that cognitive demands of the X-ray job were harder compared with the treatment procedures. The demands of the treatment job, whereby Caroline could work at her own pace, rather than on a conveyor belt, and had sufficient slack in the routine to take a break and, for example, make coffee for her colleagues, may have been a determining factor, rather than the type of decisions that were being made in the two assistant grade jobs. Comparing participants' experiences in what made one task exhausting and another simply tiring will be continued in chapters six and seven. Regardless of this, Caroline needed to perform at a basic level, at home and at work, before she could establish a baseline, and function without disabling fatigue, confusion and headaches. Thus reducing hours of work was insufficient to achieve the benefits of a prescribed rest period.

Nor was it clear that reduced hours in the work place facilitated a restoration of occupational functioning. To illustrate this, the different experiences of Robin and Leigh, who were both instructed to work part time and take Fridays off work to facilitate their recovery, are reported. Both Robin and Leigh had a background in engineering and were working with similar levels of complexity in their jobs, albeit with different temporal demands.

Robin, who designed the building process and supervised the production of large mechanical items for export, explains the disadvantage of part time work and being directed to have Fridays off work. First, the occupational nature of the building process is explained.

*The job was very dynamic and the problem with that – really, really dynamic job - you plan the things – you plan the builds as best you can, and there is so many things going on, so many things involved – the opportunity for variation is very high – the whole job – there was continuous change all the time. Things happen all the time and when they happen – things can go wrong with a lot of people.*

Robin, who was having difficulties with his working memory and became confused with matching up all the different threads of information and sequencing tasks, found that part time work added to his confusion.

*I found it really confusing – I wasn't on top – I couldn't get on top – I was disjointed being six hours per day and because I only worked four days per week. By the time I got back on Monday at 9 o'clock a lot had happened you know – and that was really hard... I talked about, if I did five hour days, over five days per week – it would give me more continuity...but she [OT] was quite hard and fast that [Friday], had to be my rest day...*

Leigh had more flexibility within her timetable to work at her own pace, producing technical reports. Previously in the interview she reported that overall her cognitive processing speed was slower than it was before her accident. If she pushed herself to work harder, or if there was a lot of new learning involved with a contract, she experienced the return of nausea, dizziness and disabling fatigue. In contrast to Robin, Leigh found that Fridays off work eased her load and permitted her to balance out her home and work responsibilities.

*Fridays I don't work, I'm not 'sposed to work, I try **not** to - but it's always loose end reports that are due - get those done - get my time sheet in. Occasionally I get hauled back to work. I'm supposed to be doing my professional development papers.... but I'm only just getting to the point now, 'cause of everything else I've got on in the week - I actually need the rest on Fridays, so I have kind of put things off a bit. So ... Friday is a catch up day. I might actually tidy the house, do some vacuuming, do whatever errands that need done, and I walk to school on Friday mornings ...*

Whilst it may be tempting to speculate on the advantages and disadvantages of having a Friday off work, the crux of this story is that for neither Robin nor Leigh a three-day weekend facilitated a timely full recovery post mTBI.

The final aspect of implementing expert advice in the early stages of recovery is provided by Doug. Plotting the course in Doug's recovery faltered, when he was placed back at work on reduced hours, ten days after his mTBI. The point of difference with Doug's story is that the safety issues which caused the work related accident had not been addressed. Not only did Doug have to contend with nausea, dizziness, noise intolerance and emotional dysregulation, he needed to sort out his own safety gear.

*When I say I went back straight away, I was off work a week... no 10 days. I did not think it was fair that I went back so quickly to work. I was petrified, I was absolutely petrified, because going back and doing the maintenance; I fell on the slippery surfaces .... so I went out and bought myself a pair of spikes, and I actually wore them to my job at night ... but it was so cold [cleaning with the fire hoses], that I went out and bought myself some boots and screwed the spikes on so my feet would stay warm .... I didn't think that they helped me or supported me, because I had the anxiety all the time.*

In summary, the benefits from expert advice to get extra rest was successful only when the occupational demands of required routines were also met. By the time some participants learned how to recognise their symptoms, and organised their routines to stop exacerbating symptoms, the possible advantages of an acute period of rest after the mTBI, had passed. Most participants were not given expert advice on how to reorganise their work routines, learning through trial and error about changes in capacity. This process was stressful with evidence of

anxiety and despondency and reports from some participants that they reached a threshold for a diagnosis of a mental disorder.

In summary, some participants resisted early advice and did not think additional rest would be helpful. Once participants were able to function at a level where they were not exacerbating early symptom, they began to feel better. Reconfiguring a suitable routine required reducing the cognitive load, and adding extra rest extra rest periods. However, for this to be achieved participants needed to develop an understanding of the capacity impairments impacting on their occupational performance and for contextual implications to be understood.

The remainder of this chapter identifies and discusses the strategies that participants found helpful in the beginning stages of plotting a way forward. The first precursor to accepting the need to deploy new strategies to manage the sequelae of mTBI is depicted as seeing for oneself.

## **Relearning How to Do Things**

### **Seeing for oneself**

Not all participants were willing to take expert advice, even after reaching a crisis point and recognising they were not capable of performing their everyday routines. Nigel, whose work and home roles were competently managed by his wife and employer, initially resisted advice to implement a period of rest and recuperation, despite the emergence of daily migraine headaches and disabling fatigue.

*I wasn't aware at the time how demanding it was on my wife and my kids – I wasn't really aware of much, ... and I must admit I did not welcome her [occupational therapist] input at first **at all** — because she was stranger who was a busybody telling me what to do with my life. Trying to give me lots of information that I had no ability to assimilate ...I was a 37-, no 38-, year-old man; I didn't need to do nana naps, although they called them power naps, they were still nana naps. First it was morning and afternoon. I hated them because they just reminded me how powerless, how injured I had become. But eventually I got my head around them, that they were the way in which to get better...*

The crucial component of this story is the awareness and processing difficulties, which made it difficult for Nigel to assimilate all of the factors, contributing to his occupational performance difficulties. It was also not possible to explore his experience of powerlessness, when he was not capable of processing complex verbal information. Nigel identified that the repetition of simple instructions from as many different people as possible was a good initial strategy to facilitate the recommended rest period.

*My wife and the OT and everyone around me told me I just had to do it and to stop complaining – it was just part of the recovery and not to make a big deal about it – I couldn't change it – and I saw that if I didn't do it, it got worse rather than better.*

Eventually Nigel recognised that ramping up his effort while his capacity was decreasing exacerbated his anger and frustration. In the following extract, he suggests that developing metaphors made it easier to understand the implications of not having sufficient rest.

*I would get angry and frustrated; I wasn't there mentally. And once I was at that point, it was like somebody had pulled the plug in the sink, just all the energy goes... You are running up hill against the headwind with lead boots on, and it just becomes impossible. At first I was trying to fight that, ... well my effort would ramp up and my capacity would decrease, and you would have this huge deficit, and it would take days to recover from.*

Thus, providing opportunities for Nigel to see for himself what happened when he did get a rest period, was an important first step in his recovery. Later in the interview, Nigel discussed developing a deeper understanding of the vulnerability he experienced after the mTBI, after attending a workshop. This intervention eliminated the sense of shame when using long-term strategies, to manage his chronic impairments. In drawing attention to this stepped approach in the delivery of rehabilitation, I am alerting readers to the finding that some of the difficulties, identified in the acute period after the mTBI, continued to be present later in the recovery period. Strategies to support self-regulation will be elaborated on, in chapter six.

Barry adds to the story, by alerting us to the importance in the timing of giving advice.

*I sort of had to rely on my wife and family ... they could see things I couldn't see – they could sense things I couldn't sense at the time. And they would make suggestions and all that – but it would have to be at a time when I had slept – had plenty of rest. If I hadn't rested and had plenty of sleep, I would react quite a lot – react, react, react.*

Learning how to manage post mTBI irritability and anger was not easily achieved by some families. As Barry points out, his family could see that he was struggling, but if they pointed this out when he was at his most vulnerable, he retaliated angrily and rebuffed the help that was being offered. Without early advice on how to manage irritability post mTBI, it took time for Barry and his family to work out how to navigate around the awareness impairments and anger difficulties which prevented both parties from using their usual range of communication skills to resolve conflicts. Similar to Nigel, Barry outlined how he needed to manage his fatigue before he could begin to appreciate how his behaviour was affecting others, and before he could begin to trust the judgement of his family. Barry also commented that specialised help for his wife may have prevented much of the mTBI sequelae.

Another part of the story demonstrating the importance participants placed on seeing for themselves, is provided by Robin. Similar to Nigel, Robin had a supportive partner and employer, and was placed on sick leave for a period of rest and recuperation. A point of difference from other participants was the provision of a list of tasks with a high cognitive load, provided by the occupational therapist, with directions to stop these activities while his brain was healing. As soon as Robin experienced sustained periods of time without exacerbating acute symptoms, he became frustrated that he was being prevented from returning to his employment, which perhaps prevented him from fully relaxing.

*I did feel like I was letting the side down a bit you know .... because I felt I wasn't allowed to go and do the work – although I know now that I couldn't do it anyway, because even more recently I still can't do it – and I got frustrated by not being able to work....*

Robin went on to describe that he went against medical advice and started completing the time sheets while at home. He later reported that he pressured his general practitioner to let him go back to work.

*I was doing the timesheets at home. As long as I had the right job numbers coming through I would do them at home, and that was the only work I was doing for a while to help out – because suddenly – those guys were left in the lurch – a busy place – and suddenly they were left to pick up the pieces...*

Two months post mTBI, when Robin returned to part-time employment, he described similar experiences to other participants, whereby completing complex tasks, rapidly depleted his energy reserves, and triggered headaches. Thus, it was unclear if an early rest period was beneficial. It was the experience of seeing for oneself that allowed Robin to understand the changes in his capacity and to start making some long-term changes to the ways he performed complex occupations.

### **Making a start: Doing things a bit at a time without pressure**

Participants reported early efforts at participating in everyday occupations as confusing or weird. They described it as if they were doing things for the first time. Experimenting without pressure and learning to balance activities with symptom control was viewed as important.

*For me it was about letting me come back on my own terms. You need to sit around - go for a walk when you feel you can do that ... it's a real tough one - to get some activity but not make yourself sick. Because your head is doing this – like on a boat and feeling like you are going to throw up constantly - for months. So it's a real fine line keeping active but not provoking the symptoms.... Accept the fact that you can't go and do a big cardio workout 'cause that just isn't going to happen – leave early so you are not pressured to get there on time....*

Leigh describes two important strategies that emerged with her early learning. These were making small incremental steps and leaving plenty of time between activities.

Another strategy used by participants to redevelop skilled sequences, was engaging in project work. For example Doug reports that engaging in things he was passionate about was a helpful way to start his recovery, and showed me the “small thing” he made., This suggests that having an early opportunity to structure sequences is important for redeveloping skilled occupation.

*...at the beginning that was hard. I did not cope well with it at first. I think it was just the small things that started it [recovery]. They said ‘What do you like doing?’ And I said ‘Gardening – vegetables’. So I made a gardening box – and I’ve still got it. So doing something you are passionate about, I think that is the way to get back into normal life — it was hard work.*

Nigel’s adds to the strategies by describing ways of being helpful in his wider community, which encouraged him to start increasing his participation in everyday occupations.

*And very slowly – church was amazing – I found things to do in a church context, which were small and manageable – helping cook for alpha – going to a one-on-one prayer meeting with one of the members of staff, just helping out in small ways which weren’t hugely demanding...*

The next set of strategies are the changes participants made to support increased participation in everyday occupations.

## **Making Things Easier**

### **Adjusting the environment**

One way to make it easier to participate in everyday occupations was to adjust the environment so that the factors exacerbating acute symptoms were better managed and occupations could be tolerated for longer periods. This included reducing the intensity of light and noise and creating quiet environments with minimal interruptions.

A frequently reported strategy was to reduce the glare from light sources.

*For me florescent lighting was a killer ...and I was really struggling with the light, when I got shifted within the building to a different desk, [in an office reshuffle]. Anyway changing desks coincided with me feeling a whole lot better because I don’t have all that bright light coming at me. I got inside sunglasses- they are very “style” – not — but they did the job.*

Leigh describes the benefits of positioning her desk away from the glare of office lights. This was beneficial even though she was wearing indoor glasses, which she later reported had been prescribed to reduce the glare of florescent lighting. She also describes that she had turned down the brightness of her computer to the dulllest setting.



*...the next day when I turned my computer on [after a spontaneous sudden reduction in light sensitivity] - man that screen is dull – I had to turn it up – I had knocked it right back to as dull as it would go - and that seemed bright – felt like I had a light shining in my eye.*

Another strategy to make computer work easier was to use the page up buttons to prevent triggering episodes of dizziness and nausea.

*....my workmates didn't notice a lot of difference – other than anyone scrolling a screen up and down – wooahh – stop – throw up – that is going to make me hurl. Use the page down and tell me when to look.*

Doug adds to the strategies for managing an increased sensitivity to light in a work environment. He instructed the disk jockeys to announce when they were going to use the strobe lighting, so he and others had time to exit the room. Similar to other participants, Doug looked for ways to benefit others in the environment if there was a need to make changes affecting them, perhaps reflecting an increased awareness on just how detrimental some environmental conditions can be in preventing participation for people with some conditions. His choice of words “protecting himself”, also suggests a sense of vulnerability which was evident in the early stages of recovery. The discussion on vulnerability will be continued in chapter six, when I expand on strategies to regulate emotions.

*... of course the bright lights – strobe lights – I really made sure to hold it together. I also said to the DJ's that if they are going to use the strobe lights – tell me – and announce it of course – because there are people like me, who are affected by it, and it gives them time to take the kids away or whatever. So I was feeling the same – so in that sense I was able to get over it – and protect myself...*

Gerald prevented exposure to unsuitable lighting by informing a receptionist that he was waiting outside of the designated waiting room, so he could tolerate attending appointments.

*...like last night was a trial for me at the doctors – the waiting room is an old villa ... and I don't like that space ...there are lights on, and it's too hot. And so I always stand outside ... the doctor knows I won't be in the waiting room.*

Doug adds to the story of deploying strategies to limit exposure to environmental environments which are exacerbating symptoms of mTBI. He rearranged his work duties so he could alternate tasks between the noisy environments and those that could be performed in a quiet environment. As Doug points out, being the manager made it easier to reorganise routines, and insert the breaks that are required.

*At certain times of the day it was very noisy, and at certain times of the night – it was a public arena and people did like loud music ... I was fortunate to be manager at that stage ...and as I said – security was an issue there – there*

*was quite a lot of breaking into cars – so it was a good opportunity to say to the staff – carry on I’m just going out to check the cars – so for me that was one of the biggest strategies that I used – to get away from that noise... and that helped me. Even if I went down to the change rooms to check on them – it was very quiet down there.*

Others reviewed their daily work schedule and eliminated exposure to the environments that were taxing but not essential to the completion of priority tasks. For example, Robin avoided the lunch room, which was busy and noisy, on the days he was struggling to maintain his concentration.

*It was confusing. Normally if you were sitting around the lunch table – there would be eight or 10 people sitting around that particular table...just relating, keeping up with the conversation. Sometimes it was better not to go there – the noise level was bad at that time with the laughing and things.*

Although Robin found the noise level in the lunchroom difficult to filter, he also acknowledges a precipitating factor for triggering confusion was struggling to keep up with conversation. Others working in open plan offices moved themselves to a quiet room or used headphones, to block out background noise so they could concentrate.

*I found the office chatter was really, really tough to deal with for a long time. See normally it doesn’t bother me – I couldn’t care less what anyone’s talking about – what your phone call is about ... you get some people who are very much the noise police, but it never bothered me until I had that concussion. But unlike all the other busy bodies who go around and tell everyone to be quiet, I move myself to a quiet room or put some headphones on.*

The following extract from Leigh explains both the increased sensitivity to office noise after the mTBI, and the effort she puts into developing strategies to manage things that would not have irritated her, prior to her mTBI. As with other participants, successful strategies were often ones that solved the problem, and did not alienate the person with the disability from the social milieu.

Participants also sought out environments with minimal interruptions, when they first participated in complex tasks.

*I actually want when I am reporting – to want to go into my wee bubble and - also the headphones tell everyone else to bugger off as well and not interrupt – because with my job I get interrupted a lot – a big thing is that I have had to restrict interruptions. If I work at home on a report, I can just get into it, whereas at work you get interrupted all the time – and you lose your train of thought, or you get side tracked. It’s good if I’m working at home...*

As Leigh explains, interruptions were hard to tolerate in the early stages of her recovery, and it was often easier to take work to the home environment where she could guarantee to work

uninterrupted, during the day. By using the headphones to minimise distractions from background noise, Leigh also discovered she was interrupted less often. This suggests that visual reminders may be helpful in training others not to interrupt a person in the early stages of recovery after an mTBI.

In summary, participants limited exposure to residual symptoms that were triggering acute symptoms by adjusting their environments to reduce exposure to the unwanted sensory information and/or alternating between high stimulation and low stimulation environments. Strategies that prevented being singled out as incapacitated or needing special attention, were preferred. Another set of strategies to make things easier was the use of schedules and planners.

### **Using a schedule**

Processing and sorting information was described by many as confusing. Without the filters working properly, participants described feeling overloaded and not knowing what they should be doing, requiring cues to guide them on what to do next. Persisting with challenging occupations while capacity was decreasing resulted in disabling fatigue and irritability expressed in explosive angry outbursts. In addition, everyday occupations were no longer routine. Tasks took longer to perform as participants navigated around changes in their working memory and decision-making capabilities.

In developing a daily schedule, participants described making an overall plan reflecting their altered capabilities, and priorities to keeping things running.

The first advantage participants gave for developing an itemised daily schedule was to reduce pressure and take the stress out of not knowing what to do. Even if the plan did not always work, Barry suggested that having a reference point was useful, and it gave him clues as to why things did not work out.

*...two magical words ... routine and a plan, the same lessons I can give to the students. A routine and a plan eliminate pressure – eliminate stress, that is the heart of a lesson – the routine and the plan, sometimes it might not work out – because I have a family, things happen and I have to adjust – readjust.*

Leigh adds to the story by demonstrating that knowledge about repeated breakdowns in her occupational schedules were used to develop new occupational patterns. In this instance, Leigh changed the organisational routines of her family and planned several days in advance, so she could target the transitions between occupations to deploy new strategies and then embed these to form a new occupational pattern.

*I'm always pushed for time. I normally have to plan three or four days ahead to make sure everything flows smoothly- it's the little things that will trip me up - like my daughter has to make sure she's got her sports gear ready for Monday and Tuesday. She doesn't have much time when she gets home from school. As long as she has organised herself on Sunday – makes sure she knows where her uniforms are – made sure they have gone through the wash – and I have remembered to make sure she has actually done it .... If I don't remember to check that they have done it, it can all fall over very quickly when we can't find the soccer sock or the soccer boot or the basketball uniform or my own gear. So Sundays is the night that we have to make sure everything is sorted...*

Nigel adds another variation to the theme of developing new routines to accommodate post mTBI changes in capacity. He anticipates which occupations may be stressful, and adds a buffer zone. Therefore, if something unexpected happens, he has time to recuperate and plan his next occupation without a breakdown in his planned schedule and a prolonged recovery period.

*...so it is planning – having a sense of knowing what I was doing each day and allowing for unpredictable stuff – deliberately planning the day allowing for buffer zones in the day...I tried not to have appointments back to back especially if they are going to be stressful in any way, so when I found myself over loaded or frustrated I could just take a bit of time out. Even if it's not a nap – even if it is 5 minutes of quiet – I'll close my eyes kind of trying not to think – just stopping, stopping.*

In this instance, Nigel recognised that issues come up in meeting that cannot always be predicted. By scheduling time between meetings, he can use strategies to relax, clear his mind and transition to his next occupation without triggering frustration or a fatigue backlash.

Others schedule set times for breaks, reminding themselves that if they push through a break it would become problematic.

*...but I have to make sure I actually stop and take a morning tea break and that I stop and take 10 mins or so - making sure that I actually have lunch break at work sometime between 12.00 and 1.00, making sure I actually get up and go and get a drink of water – real basic stuff. Whilst pre concussion it wouldn't be such a big deal, I'd suddenly realise I've got a bit of a headache – have some water and I'm fine ... [now] I get rundown faster.*

Typically, participants outlined stressful occupations as those requiring sustained concentration or these requiring continuous effort to meet a deadline. Robin adds to the story by providing additional detail on cues to recognise the potential for overload and to take a break.

*I would have to stop ...if there was any concentration. I could feel a dullness coming on – I could feel the headache coming on [points to a narrow frontal band across his forehead], this part of my head and so I would just stop what I was doing. So if I doing a spread sheet, or computer work or something like*

*that I'd just stop doing it and go do some different work like critiquing things on the [factory] floor.*

In recognising a need to change occupations, Robin also has to prepare for how this occurs, and keep up with where he is in his schedule, thus navigating around impairments with working memory.

*...just using my diary – writing in my diary all the time – things that I'm going to be doing for the day – things to achieve -then tick them off...before I could remember everything but now there would be things you missed out on – could be just small things that happened, and you had to make sure you took notes. Writing it down is really important, mark it off as you go – keep track of where you are going ....*

Robin describes forming a master plan for the day and then listing the steps he needs to accomplish. He then ticks off things as they are completed, and writes down details he needs to remember for later in the day. Thus he can keep track of where he is going, and what he needs to complete if the master plan needs to be adjusted in response to the unplanned parts of his work, such as a mechanical failure, or the onset of a headache which necessitates swapping to a less challenging occupation for a period of time.

In addition, a schedule was a useful way of pinpointing where the breakdowns were occurring. For example, Caroline quickly learned to supplement her schedule with auditory reminders on her phone half an hour or so before appointments, so she could remember to transition to a new occupation at the correct time.

*Appointments and the like I put in my phone with a [auditory] reminder maybe half hour or longer before depending on travel distance.*

To supplement the daily schedule, participants learned to prepare backups to remember important transitions or to deploy crisis management strategies to cope with the unexpected. These strategies, along with the other refinements made to daily schedules, are examined further in chapter seven.

With communication being the result of thinking, and the vehicle with which to share ideas with others (Cornis-Pop et al., 2012), any capacity changes or changes in thoughts of one's own competence post mTBI will impact on communication. The following section describes the communication difficulties participants experienced in relation to the early mTBI sequelae.

## **Communicating Differently**

The fundamental processes of communication are necessary for shaping one's own behaviour and influencing the behaviour of others. Strategies designed to both manage the early sequelae

of mTBI, and maintain the integrity of relationships were deployed in the early stages of the recovery.

Robin displayed good executive control, but similar to some other participants he experienced word finding difficulties which interfered with the flow of conversations. Robin learned how to talk around word finding difficulties and persevered with keeping conversations flowing. He credits this early advice, for never giving up on engaging in conversations with others.

*I'm probably not as bad as I was even a month ago, but I still lose my way a bit – I can't find words – can't think what to call it. You just had to talk around it – come back another way – she [OT] said to forget about what I was going to say there, to talk my way around it otherwise I'd get stuck on thinking for the word. No, [I never gave up on conversations] after Sally taught me that at the beginning.*

In contrast Nigel, who had difficulties with both working memory and executive control, captures a range of early strategies which he used to manage conversation when he was having difficulty processing complexity.

*... I'm 5%, 90% of the time, or I'm fine right now – or just saying it is a rubbish day – I can't really spend long – text me don't call me – I stopped answering the phone.*

First, Nigel stopped answering the phone and instructed people to text rather than phone him. This allowed sufficient time to process the message and prepare a reply. Next he learned to give short answers, which he could formulate without too much effort, but still remain polite and give an answer, thus maintaining social niceties and preventing rebuffs to people who were kindly asking after his health.

Nigel also provides an eloquent example of how participants built up capacity a bit at a time. Participating in social events occurred in stages similar to any other occupation that was initially challenging.

*I went to some social things as the recovery progressed – like someone's 40<sup>th</sup> birthday party, and I think it was the first big social thing I'd done. And after about 15 mins I told my wife I'm going to sit in the car – no pressure on you – I'll come back when I'm ready but I need to nap. I'll just get angry – and nobody needs angry me at a 40<sup>th</sup> birthday party – so I disappeared off - took some time.*

Nigel describes how he was able to participate in social events, a bit at a time. The effort of keeping up with communication and making timely replies was hard work and initially required regular rest periods. Thus, Nigel needed to recognise the cues for becoming overloaded and

initiate a break, before he became irritated. In adopting this strategy, he also demonstrated to his wife he could regulate his emotions, an important skill for effective communication.

Another strategy Nigel deployed was to partner up with his wife and let her do most of the talking while he made non-verbal contact and the odd comment to fulfil social roles when he did not have the capacity for complex conversations.

*... and I stuck close to my wife, and she did all the 'Hi how's it going, yes he's fine, he is getting there' - and it's that kind of partnering alongside her in short bursts...*

This partnering up with others to begin navigating a way around communication obstacles was an important step in the recovery process. All participants emphasised how difficult it was finding ways to communicate with others while they were having occupational performance difficulties. It was also difficult for some to pick up on others' expressions so they could effectively shape behaviour. The following four extracts demonstrate the different ways that collaborative relationships were utilised in the early stages of the recovery process, to address communication concerns.

*...the biggest turning point was when I went back through my doctor and said I needed some help and I got an occupational therapist ...and she and I met with my boss, and she told him basically, you have to leave her alone, to back off; she's not working. That made the work back off – my boss was actually really good after that. Leigh*

This extract was selected as it demonstrates the benefits of working with an expert, so they can articulate the sequelae of mTBI with a third party. This is particularly effective when the person with the mTBI is having difficulties expressing their needs.

To continue the discussion, Leigh reported that her boss recalled her to work, to help with the bidding for their new contract. With his new understanding into the sequelae of mTBI, he was able to recognise that Leigh was struggling and communicated with others to take over Leigh's role in negotiating the new contract.

*We were bidding our current contract, and it was a big deal. He did call me in, and I did manage to go in and do that, in a room that was really, really bright. But he could see I was really struggling, and from that he realised I was not up to it at all. He just backed off, basically he knew I would come back on my own terms, and do what I could ... that was a few weeks after it (accident) happened, so that was the single biggest help work wise.*

*Others also expressed their gratitude of working with colleagues who knew them well, and knew that they were not attempting to use the mTBI as an excuse to dodge work. This understanding made it easier to communicate needs in the workplace and set the scene to discuss new strategies to address*

*persisting occupational performance difficulties. I was really lucky because I had been in the same job for six years with a very stable team. So all the people around me knew me from before the accident, ... knew me so well and knew I wasn't skiving off at all...Caroline*

These collegial relationships were important in negotiating suitable conditions for a return to work and for generating ideas, and supporting new ways to work around the symptoms.

*My colleagues were amazing... I was invited to give the two-minute talk at the end of the walk through thing that everyone does. And I said that I think I could manage it, if I was paired up with someone else. And I did every other talk through an evening, and as soon as I got tired the other guy said, 'Look you head home whenever you are ready'. So I had huge support...and I was very grateful because I know that not everybody gets that.*

In this instance, when Nigel was struggling with fatigue and the aftermath of depression, his colleagues were forthcoming in creating opportunities for him to redevelop his confidence with public speaking.

Through reflection and discussion, in a collaborative relationship, Barry was able to start developing strategies for developing executive control and reduce the frequency of angry outbursts that were interfering with important relationships.

*...and the in-between bit was quite crucial ... because I was aware of the things I did, but how do I get around it, prevent myself from getting to that dangerous spot I shouldn't be in? Is there a way around? Could I avoid it or could I conquer it? So through the counselling, we got to talk about all of that. And the answers really lay within me, but it was a matter of sorting through it. What is the best for me? What can I do? And what works for me now, because it may not have worked for me before. So that was the most important thing, that's what the councillor did, redirected me to 'what do you think?' She did a great job...*

Crucial for Barry was the support he received to sort through previous coping strategies, and deciding which strategies he could incorporate into his repertoire and what new strategies he needed to develop to address the presenting difficulties. As with all participants, Barry developed an initial plan and built and refined this over time.

## **Summary**

In summary, participants did not immediately recognise that their recovery pattern would be prolonged, and were all expecting symptoms to fully resolve within the first few weeks after injury. Pushing themselves to establish normal occupational routines as quickly as possible, appeared to further exacerbate acute symptoms, including fatigue, headaches and stress responses. Furthermore, recommendations from health professionals for extra rest and a



graduated return to work programme did not address the capacity difficulties interfering with completing everyday routines.

Participants stopped exacerbating acute symptoms when they simplified routines at home and at work, relinquished occupations with a high cognitive load, and inserted additional rest periods during the day. Occupational sequences were re-established a bit at a time, introducing new challenges following a rest period. Compensation strategies were introduced to make things easier. Strategies were deployed to manage the environment and reduce the intensity of symptoms which were exacerbated by light, noise, visual complexity, movement and interruptions. Schedules were developed to compensate for altered memory and to reinforce newly configured routines. Further strategies were introduced to maintain essential communication and preserve the integrity of relationships.

In chapter six the strategies deployed by participants in the subacute stage of their recovery to manage persisting capacity changes in energy levels and regulating emotions.

## **Chapter 6 - Managing Changes in Energy Levels and Learning to Regulate Emotions**

Post mTBI, participants consistently described altered tolerances for sustaining energy levels, managing emotions and processing information. In the previous chapter, the early strategies used to accommodate changes in occupational performance were discussed. In chapter six the ongoing implications of these altered tolerances for managing energy levels and emotional regulation are explored and the strategies for increasing participation in everyday occupations and reconfiguring sustainable everyday routines are identified.

The information in chapter six is presented in two sections. Section one outlines the strategies deployed to match the occupational demands with available energy, and is further divided into four parts. These are; coping with night time sleep disturbances, recognising and acting on cues for taking a break, understanding and managing the different characteristics of fatigue, and finally engaging in challenging occupations to boost energy levels and satisfaction.

Section two explores occupational functioning in relation to the persisting changes post mTBI in regulating emotions. Strategies utilised to understand and accommodate these changes are divided into six parts. These are; understanding the changes in temperament, developing awareness through collaborative relationships, managing emotions and tolerating frustration, changing perspective coping with others responses and lastly maintaining hope.

### **Matching Occupational Demands with Available Energy**

In the early stages of recovery, participants learned that pushing through early signs of fatigue comes with a cost of headaches, more fatigue, and irritability. Continuing to ramp up the effort while capacity was decreasing could trigger further episodes of nausea and dizziness, and/or lead to an energy deficit taking several days to recover. Fatigue affected all aspects of occupational performance and contributed to feelings of dysphoria and hopelessness, fuelling concerns that things may never get better.

In the later stages of recovery, participants recognised that fatigue had different qualities, and they learned that rest and recuperation was not always restorative. Furthermore, extended rest periods could interfere with getting on with life. The first set of strategies were used to manage chronic alterations in night-time sleep patterns.

## Achieving adequate sleep

Achieving adequate sleep was viewed as an essential part of managing fatigue. For some an additional two hours of sleep at night was sufficient, to prevent excessive tiredness during the day.

*I go to sleep between 9 and half past and get up at 7 in the morning – if I had shorter sleeps, I notice I'd be tired during the day. Robin*

Some participants described being tired all the time despite additional sleep at night, and day time naps. Barry describes how he slept as often as he could and gradually over a period of two years, progressively stayed up later in the evenings.

*...for the first two years after the accident I was wasn't myself straight away – I couldn't stay up; I was always falling asleep – different periods of the day – I couldn't stay up late at night. I'm normally a night owl, I normally could stay up during the night – but this was different – I might have been present in front of my children and awake during the day, but I wasn't there with them.... Sleep was the number one thing, but as the years and months rolled on I noticed a change where I could stay up a little bit longer than normal – and that is how I progressed – staying up after 6 pm increased, then from 7 then to 8 then I realised there was a change...*

Caroline describes how facilitating good sleep routines at night, combined with a lunch time nap, allowed her to build up her energy levels over time.

*I'd try and get a good night's sleep ...and have a snooze every afternoon – I could feel my energy levels were building again...*

Others describe learning to live with disrupted night time sleep patterns. For example, Doug tried to get to sleep earlier at night, but when he finally managed to sleep earlier at night, he woke in the early hours in the morning, and was unable to get back to sleep.

*I get to bed at 12 o'clock at night. I have tried to go to bed at 10 o'clock and try and try and try to get to sleep, and at 5 o'clock I will wake up and I can't get back to sleep. It is one of the things I haven't really been successful with... I'm really bad at having a nap...*

Doug went on to describe how he gave up trying to get extra sleep and now just sleeps when he needs to. Nigel demonstrates two further strategies to facilitate being at peace with periods of insomnia. First is to get up out of bed, and doing something until he feels sleepy again.

*Disrupted sleep, at the beginning, was a huge issue. I have always had little bouts of insomnia and always get them - it's being at peace with disturbed sleep in the middle of the night so it wasn't something to worry about – I'm awake, I'll do something useful, try and read, and if I couldn't read I'll make myself a cup of tea- doing something and then trying to go back to sleep...*

Second is to address the underlying anxiety, with strategies that are designed to minimise catastrophizing.

*...taking the anxiety out of all of these things – how am I going to cope tomorrow – I'll cope by having an extra nap or I'll cope with not doing what I had planned – if I've been awake for three hours in the night or four or five hours then my capacity will be reduced – so big deal – this is a process of recovery. Nigel*

Establishing a regular sleep pattern, and minimising anxiety associated with periods of insomnia, did not eliminate day time fatigue. Participants described learning to recognise cues for taking short breaks during the day.

### **Recognising and acting on cues to take a break**

Participants recognised tension in a band across their forehead, and dulled thinking as a precursor for further fatigue, headaches and increased irritability. This typically occurred after a period of sustained concentration, engaging in complex occupations such as computing and conversing in groups of three or more people. As demonstrated by Robin, recognising early cues and switching occupations until the tension and dullness dissipated, was sufficient to prevent an exacerbation of symptoms.

*...if there was any concentration – I could feel a dullness coming on – I could feel the headache coming on in this part of my head (points to a narrow frontal band across his forehead), so I would just stop what I was doing. So if I was doing a spread sheet, or computer work or something like that I'd just stop doing it and go do some different work like critiquing things on the floor... in 30 to 40 minutes the dullness would pass.*

For this strategy to be effective, participants identified that sufficient flexibility in planning their work routines was required so they could switch occupations. In addition, an ability to gauge the fatigue loading of different occupations was required. In this instant, Robin alternated computer work with a task that offered multiple short breaks while completing an inspection circuit on the shop floor.

Typical of participants in this study, Robin recognised the fatigue associated with complex tasks, but did not identify specific impairments contributing to this fatigue. For example, differentiating between ocular motor difficulties and working memory impairments may provide additional data for resolving problematic fatigue. This is important given the large number of participants, including Robin who were unable to sustain employment following their mTBI. Management of processing impairments will be explored in section 6.4.

Participants described a fatigue backlash, when they continued to ramp up their effort while capacity was decreasing. If left unchecked, the resulting exhaustion was associated with a three-day recovery period, whereby participants increased their rest periods and refrained from participating in complex occupations. Participants learned to anticipate which occupations were associated with high levels of fatigue, and then balance these with less taxing occupations and rest.

*There has been a couple of times in that my work schedule has been heavy – like speaking at a conference – and at that point, it's like I will need to take a nap to recover, and so it's either [missing] a seminar slot in the afternoon, that I'm not speaking in, or not disappearing off late at night, with everyone else, as they go and do social things...or I'll swap it about – If I'm doing social stuff later, I'll take time by myself now – it's like looking for a balance throughout the day...*

In this extract Nigel describes achieving a balance during the day. Not only was he able to plan a balance between occupations with a high and low fatigue load, he was able to balance his time between work, and play occupations.

In contrast to Nigel, who looked for a balance during the day, others describe that scheduling an opportunity for an extended rest period sometime throughout the week was sufficient to avoid a fatigue backlash, should this be necessary.

*...getting that sleep in – because we can be busy as a family, I can be busy – so I have to insert these sleep periods in – and sometimes I can't – so I know that – so I'll have to wait for the weekend – and that is when I will just fall over and sleep, which is expected...*

Barry provides an example of catching up on sleep in the weekend. This meant he had flexibility during the week, to fulfil his roles as a father, husband and worker. Thus pushing through fatigue for short periods, did not appear detrimental to overall functioning, and supported greater participation in everyday activities.

Another cue, for deploying fatigue management strategies, was the emergence of dizziness and nausea. I have included extracts from both Robin and Leigh, who reported on incidents triggering, dizziness and nausea 8 and 12 months post mTBI. The different interpretations of the seriousness of these symptoms are reflected in the selection of the management strategies deployed.

Previously in the interview, Robin described the emphasis that the vocational occupational therapist placed on fatigue management. Consequently, Robin had set rest periods, and defined work hours, designed presumably to support a full recovery of the brain.

*I recently worked a longer day and it set me, really set me back. I had a very, very busy day as we had sickness at work. So I carried on – I wanted to see for myself – by the time I got home it was only half past 4 – only that much [30 minutes] over – I was quite nauseous when I got home, and that night the vertigo came back. When I got out of the car I had to really concentrate on relaxing – that gave me a fright – that happened only three weeks ago... It was a week or two before that, that I decided to knock off work [permanently] – that reiterated I did the right thing.*

In the above extract, Robin describes working half an hour over the prescribed work hours at work, on a day he had worked much harder than usual. He interpreted the return of the vertigo and nausea, as evidence of a poor recovery post mTBI. This confirmed for Robin, that he had made a good decision to relinquish his employment.

In contrast to Robin, when Leigh triggered vertigo and nausea after a busy week at work, she recognised this as a cue to deploy strategies to reduce the work load, while re-establishing a workable balance.

*I pushed it a bit this week and last night and it was the first time I'd felt dizzy in a long time – I was feeling just a bit seedy and (gesture and sound of throwing up), I haven't been sleeping well... the stress at work has been too high... and has now resulted in feeling a bit shit – but I haven't been this bad for ages, and the stress has come on too high, and I need to dial it back a bit and get everything in balance again... so I stole the graduate first ....*

In this instance Leigh linked the return of the dizziness and nausea as an indication she was pushing herself too hard. She immediately looked for ways for reducing her workload, and in this instance commandeered the graduate to off load some work responsibilities. Beliefs about the seriousness of triggering an exacerbation of symptoms in the later stages of recovery, can shape future participation in challenging occupations. Health professionals need to be mindful of this when prescribing interventions where there is little or no evidence to support their utility, in the later stages of recovery post mTBI.

In the next extract Nigel demonstrates how he stopped cramming things into short times to prevent a fatigue overload at work.

*... and other things I do deliberately which I didn't do before my injury – it's learning to do more with less – creative approaches. So if I only have two hours and three people to meet – I'm not going to meet each of them for 45 mins – I'll try and bring that meeting together if I can. And I acknowledge there are very few meetings that have to happen right now.*

In this extract Nigel describes analysing his work tasks and looking for ways to lighten the load. He discovers that learning to do things differently doesn't necessarily result in an overall decrease in the quantity or quality of what he produces. Learning to perform occupations differently is further discussed in section 6.5.

Over time, participants recognised that fatigue had different qualities and that not all fatigue resolved with rest.

### **Managing the different characteristics of fatigue**

All participants recognised that rest did not resolve difficulties with excessive fatigue. Understanding different qualities of fatigue, together with a desire to get on with living, prompted participants to experiment with different ways of managing fatigue. In the following extract, Bronnie describes a constant presence of fatigue, six years post mTBI. She found that gardening made her feel better and suggested that having a socially acceptable reason for the fatigue made it easier to tolerate.

*Anything like boiling a jug, that's physical — that that would make me tired. I'd get to the end of the day and I'd be tired — if I have done some gardening it makes me feel better — I'm tired because I done the garden, whereas if I've just sat in front of the computer or done something, well sort of simple like watch television you are still the same tiredness and it just feels like I shouldn't be.... Even if I just sit and think about all the things I need to do, I'm still as tired*

In this instance there was no indication that Bronnie's continued interest in gardening either at home or in her previous employment, led to sustained improvements in her experience of fatigue. Participation in gardening improved her mood temporarily.

Nigel joined up with his local gym six months after his mTBI. As readers will note, Nigel enrolled in the gym during a break in his rehabilitation programme, suggesting early control of his symptoms focussed on getting sufficient rest.

*...I guess in the depression that followed the injury — there was the removal of hope, and planning and future possibility and I guess I kind of hit rock bottom six months after the injury — thinking this isn't going to get any better and it didn't look like it was ...there had been a hiatus in OT visits because the ACC case manager at that point hadn't authorised an extension or something ... and at that point I started going to the gym, for something to do each day — because at that time I was still signed off work ...*

When I asked Nigel if he found the physical exercise beneficial, Nigel responded by reinforcing the importance of having a routine and participating in occupations he was still capable of performing.

*... having a routine – not just an empty day – that’s really what drove me to it [signing up at the local gym]. I’m not only bored, I’m not really capable of doing stuff that is social interaction. I didn’t have to drive, I couldn’t drive at that point – all of these things and yeah it meant I wasn’t at home, watching day time television and eating biscuits – none of things helped – day time television should be stopped for anyone with a brain injury – it is all depression; it is all terrible...*

The importance of engaging in everyday life as soon as acute symptoms settled was reiterated by other participants. Whilst it was clear that Nigel benefitted from increasing his activity levels, not all participants benefitted from improving physical fitness, to improve their overall stamina.

*...then luckily I had the opportunity to take on a secondment within my work when someone was going on maternity leave [who didn’t work shift work] ... I was swimming twice a week and working less hours – trying to get my general reserve back up – get back my physical fitness. Then after the six months, the secondment was over and I went back to my original job, but still, I wasn’t able to do it full time, it just wasn’t working...*

Caroline describes a six-month exercise programme which did not result in achieving full time work in a competitive work environment, as she had anticipated. Hard physical exercise did however improve her mood as discussed in the following extract.

Caroline went on to describe how analysing the different characteristics of her fatigue prompted her to experiment with different management strategies. These descriptions were representative of other participant’s experiences, but are most eloquently described using Caroline’s words.

*...like I had a whole rigmarole going on with ACC as well – which was extremely emotionally fatiguing, and I remember that I went for a major hike - like a five to six-hour hike because I was really aware that I had all this emotional fatigue, frustration, and it wasn’t physical. So I went on this quite significant hike, and then I was physically fatigued after that – it made me feel so much better... ...physical activity it gets you out of that depressed state – the physical activity is like an outlet, and also the achieving of the physical activity then boosts you as well – like I **am** able to do **this**.*

In the above extract, Caroline differentiates physical fatigue with emotional fatigue, and she provides a clear example of the benefits of hard physical exercise, on mood regulation. In the next extract the qualities of what Caroline calls cognitive fatigue are presented.

*...with cognitive fatigue, I forget things and basically lose the plot. I’m tired but not so much physically tired ... I can get very frustrated and angry - like I still get that [cognitive fatigue] – but man if I then try and do something like cooking [the gas hob was in the outside shed, with many belongings still in boxes], I get **so** frustrated. Whereas, if I am emotionally fatigued then it is much more like getting anxious about things that are not really a problem,*



*but they become problems, ...it is like then making mountains out of a mole hill sort of thing.*

In this extract Caroline associates cognitive fatigue with a reduction in working memory when she starts forgetting things. Pushing through this cognitive fatigue, triggers the explosive angry outbursts, characteristic of post mTBI irritability, when tasks are not sequenced to get the desired outcome. This explosive anger is different from the distressing anxiety and catastrophizing associated with emotional fatigue.

In the following extract, Caroline summarises the management strategies of the different types of fatigue.

*Cognitive fatigue is easier – rest up a bit ...like last week I had worked three hours in a completely new place – working in a rotary shed and I'd never worked in a rotary shed before, I'm cognitively fatigued – I just need to take it easy - I ended up pottering around putting a bit of washing on, but I noticed I'm not too keen to read for instance – because adding to it.... I remember that in some stage in my recovery I got a lot better at sort of picking the fatigue apart - because you know - combat one with the other – like if you are really physically fatigued - and you can't seem to settle, then a bit of reading – will be really good to get you cognitively fatigued a bit as well, and you can nod off – umm with emotional fatigue, I find then that physical activity is the best thing for me.*

With cognitive fatigue, rest or engaging in occupations with a low fatigue load, restored Caroline her energy levels. Conversely, she noted that if you are physically fatigued but can't seem to settle, then a little bit of reading or occupations with a high cognitive component will help promote a restful sleep. Finally, with emotional fatigue, occupations with a sustained component of physical exercise, can help with regulating one's mood. By differentiating the different qualities of fatigue and matching these with corresponding strategies may help reduce the frustration when “nothing seems to be working”.

In the next section, I explore the finding from participants that some tiring occupations boost energy, while others simply suck energy and are draining.

### **Engaging in challenging occupations to boost energy levels and well-being**

All participants described relinquishing occupations in the early stages of their recovery that were physically and emotionally draining. Resuming occupations perceived as difficult occurred in response to tangible improvements in capacities, peer pressure, and a desire to get back into living. In this section I will present extracts which pinpoint the different components of participating in challenging occupations, which participants perceived boosted their energy levels and feelings of well-being.

Bronnie relinquished many occupations post mTBI, including three different paid jobs, which she attributed to fatigue, exasperated from driving. As Bronnie explains, she became fearful that participating in pleasurable occupations may overtax her energy reserves, and she didn't want to experience further disappointment.

*Something that might make me happy might stimulate my mind too much and make me really, really tired. Like I want to be able to go out and do the things I enjoy without feeling like this [fatigued] ...I'm more scared it will be the same rather than worse – because I used to be able to do all those things and not get tired – and if I do it again now I've got a high expectation that it will be like it was before [enjoyable] and I don't think it will be...*

Despite this underlying fear of stimulating her mind and exacerbating fatigue, Bronnie demonstrates the importance of changing her attitude and making the difficulty into a challenge which can be overcome.

*...and I just love driving ...if you said to me to drive to Hamilton now, I'd be there – and its being on my own too – I think, I don't have to worry about people ...driving has become a bit of a challenge, it's like oh yeah I've found it – good on you – it's a moment when I can say yeah...like the other day I looked at the map on the computer beforehand, but ended up in Mission Bay instead of Remuera, and I thought this is a sign – I am not meant to be at this place at this time, so I didn't panic. Then I thought no, I really want to find this place... so I turned around and went back to main intersection and turned the opposite direction than I had gone and actually found the street I was looking for – but not the house I wanted. I went up and down the street about three or four times looking slowly. In the end I stopped and collected myself, as I had got all hot and bothered, and thinking why is this place not visible to me ...*

Thus, without addressing the post mTBI navigational difficulties, and underlying anxiety that Bronnie experienced when she couldn't find her way, the change in attitude making a difficult tiring occupation into a challenge, seems to be an essential part of participation.

Leigh explained that she decided to try and take her share of the night inspections, after her visual and vestibular problems had settled, approximately six months post mTBI.

*I scheduled it for the school holidays – so there no pressure on me to get up and go anywhere in the morning; the kids weren't enrolled in any activities or anything – it was tough but I managed it, I got through that, and I managed it OK - I was tired by the end of it – but no - it was OK - I could handle it ok – this feels relatively normal.* Leigh

Typical of participants resuming occupations which had previously been relinquished, Leigh eliminated other high energy occupations, on the day the new occupation was introduced. A “fatigue backlash” was anticipated and in addition to scheduling the challenging occupation on

a day where Leigh could schedule a rest period, she also described taking annual leave so she was well rested before starting the night inspection.

Following successful participation, Leigh reported being tired but not overwhelmed, and participation in further night inspections did not require extensive rest periods, reiterating a common theme that fatigue becomes less bothersome after the occupation has been successfully performed. Furthermore, the successful participation in one challenging occupation prompted decisions to engage in other occupations which had previously been relinquished, which is concisely captured by Leigh.

*I got through that [night inspection] and thought - I could probably handle the referring now...there was slight peer pressure. I'm on the officials' association – you have to kind of pull your weight a little bit, ... so I decided to give it a go and see what happened and if it is too much I'd just have to pull the pin. I was a bit nervous about going back this year, and now it doesn't seem stressful at all, whereas last year oh my gosh - it was a scary place to be – but now I've done a couple of games – they haven't been heated or anything - it's a walk in the park. I wasn't able to do that for a long time.*

Caroline adds to the picture, by participating in a new occupation which replaced some of the losses she experienced post mTBI. Caroline credits her attendance at an AUT research group focusing on goal setting, for helping her learn the difference between participating in occupations that were exacerbating fatigue and despondency, and those which promoted wellbeing. In contrast to Leigh, Caroline had been unsuccessful building up her work hours, and at the same time she engaged in orienteering, she was facing a medical redundancy from her employer.

*I was lucky I wasn't in the control group, ...and what came out of that, was that my mountain biking prior to the accident, I did just for fun – pure fun, exercise and fresh air – it ticked all the boxes for me – I just really enjoyed it. I remember I had read something about mountain bike orienteering and so I wrote up this goal about further investigating orienteering. ...*

Caroline went on to explain that she bypassed the remaining goal setting part of the exercise, and started orienteering the next week, at the start of the season. Similar to Leigh, Caroline anticipated a “fatigue backlash” and organised for extended rest periods, even though this occupation was new to her.

*Initially I would only go to the summer nav [navigation events], on an evening of a day that I wasn't working the next day, so I didn't have to worry that if I was quite tired from it, I'd have to get up early the next morning ...and from there to the point when quickly then – ended up being able to go to an event when I did have to work the next day. And I also remember that I went to an event – where I had gotten home from work, and was feeling really, really shattered, so I had a lie down and a sleep and everything, and woke up*

*feeling a bit better ... I felt good enough to drive to where ever it was, because by then I also knew that the actual activity was in a way invigorating as well - rather than draining – because that is what I was already realising earlier on - that certain activities are going to boost your energy levels even though they are tiring, but they still boost you — and there are other activities that are just draining.*

Similar to Leigh, after participating in a challenging but manageable occupation, the need for additional rest periods quickly diminished.

Barry adds another important consideration for participating in challenging but tiring occupations. In the early stages of recovery, when Barry was pushing through his fatigue and becoming angry and irritable, he used the onset of a frontal headache as a sign that he hasn't rested enough.

*When I start getting a headache that is a sign, it get really tight up here (points to forehead), and it gets really heavy, and those are the indicators for me, that I haven't rested enough, but I'll know why – I've been busy and I've overdone it ... like at camp, but we had put a lot of planning into it – small planning big planning, ... but it was worth it – worth it – now that we have had had the first big camp, now we know, had time to reflect on it – it was great.*

However, in the later stages of recovery, when Barry understood his post mTBI responses better, perhaps it was not so important that he needed to so tightly control his fatigue levels. Regardless of the reason, Barry described being able to push through the *early* signs of fatigue, in order to increase his participation in challenging occupations.

Similar to Barry, Gerald also starts pushing through his fatigue, when it became clear that regular rest periods were not supporting a full recovery post mTBI. Gerald stated he first proposed a trip away by himself to experiment with fatigue management and get back on track with his recovery, when he didn't make the expected full recovery about a year after his injury.

*... since I was 18 years old, backpacking has been a thing of mine ... it is a hunger for understanding and knowing. ...I honestly felt that if I went away backpacking I'd be so much better off for it. I can't really analyse that one – I think it is just the fact that I've got 7kg of possessions on your back – no one telling you what to do or what to do it – if you need to lie down you lie down do if you need to sleep in – if you need to go to bed at 6 o'clock that is fine... Inevitably in your everyday life you can't do those things – there is all sorts of things that go against it – so I said to ACC —this is it – let me go for six months; I would be happy to pay my own way because it wouldn't have cost much money – but I really think that would be really, really useful to me ...*

This proposal was declined by ACC, and Gerald continued with the recommended rehabilitation pathway, which did not facilitate the expected recovery. Several years later when another opportunity presented to combine travel and send art work back for an indoor décor shop,

Gerald explains how the hard work was tiring, but exciting, and provided him with the opportunity to develop an understanding of his post mTBI capabilities.

*... At the end of last year I went for a month, and I did my research - and came back, and then I went and I bought my first container back, and umm it looks as if it is really successful.... but it's bloody hard work – I mean I was literally working manual labour in a corrugated iron shed in 45 degree temperatures trying to get things ready and packaged – showing people what to do – and it became more and more stressful as the time went on. I didn't know how much longer I could have carried on – I'm still learning in fact... but it is clear I am passionate about it – I'm excited about those things. It all seems like a hell of a steep learning curve to me – but if I'm not pressurised by other things – I can meet those.*

Similar to other participants, Gerald described needing time to concentrate on the challenging occupation with intrinsic interest, without the pressure of having to participate in other cognitively demanding occupations at the same time. He also reinforces the need for opportunities to experiment with managing fatigue, and learn what is or is not possible. The point of difference from other participants, and the reason for including these two extracts from Gerald, is to demonstrate that participants who created opportunities to experiment with different recovery processes, were able to facilitate change many years after the initial injury.

### **Prioritising the important occupations**

Finally, chronic fatigue required participants eventually to make choices about occupational routines.

*I think I've really come to terms with the fact a few years ago – that if I get fatigued enough – work hard enough whatever you want to call it – I'm always going to end up with symptoms of the head injury.... so what do I want to be spending my energy on? I've only got x, I'm not like I used to be, when I can do that and that and that – now I have to make a choice. In the end it is as simple as that...*

In this extract, Caroline describes making substantial lifestyle changes, after identifying her priorities for a satisfying life. As with other participants this occurred after repeated attempts at restoring her occupational performance to a pre mTBI pattern, and exhausting one's repertoire of strategies to improve participation.

### **Summary**

In summary, managing fatigue is complex. Participants recognised that there were different qualities to their fatigue and that rest did not always resolve their difficulties with sustaining energy. Successfully participating in occupations that were perceived as a challenge to be overcome, were described as invigorating if a “fatigue backlash” was avoided. Participants prepared for engaging in challenging occupations by being well rested, eliminating other

cognitively challenging occupations from their timetable, and had time to schedule extended rest periods. Management of chronic fatigue improved, following opportunities for experimenting with pushing through early warning symptoms and working out how far one can push without triggering exhaustion. To accommodate persistent changes in energy levels, occupational routines were reconfigured. These lifestyle changes appeared more satisfying if core values were reflected in new occupational configurations. In the following section, strategies for achieving emotional control, are outlined and discussed.

## **Achieving Emotional Control**

Section three explores the changes in emotional functioning and how this impacts on occupational performance. Not only were everyday occupations more difficult to execute, but also the emotional responses to difficulties were altered. Without previous experience to draw on, participants described not knowing *how* to manage these changes.

Typically, participants described explosive angry outbursts, increased sensitivity for tearfulness, acute stress responses, and periods of despondency and depression. More subtle difficulties such as alterations in empathy, and chronic anxiety, also impacted on everyday occupations. Maintaining hope after repeated failure was important, as was finding constructive ways of dealing with people who did not understand how an mTBI was impacting in their functioning.

## **Understanding changes in temperament**

Understanding the effects altered tolerances are having on everyday routines is an essential part of anticipating what strategy needs to be deployed. The following extracts demonstrate the range of difficulties participants experienced in knowing what to do to regulate emotions after a mTBI. In the first extract, Bronnie neatly describes the complex relationship between anger and distress.

*I used to get upset. It used to bring anger out in me, aggressive, more aggressive than I've ever been before. I couldn't handle being upset, that's just not me, I never used to get upset and cry over things. And that made me feel angry, because I shouldn't be getting upset...*

In the following example, Leigh demonstrates how this complexity can play out in real life.

*[Pre accident] if they [the children] didn't have their stuff ready, it didn't piss me off so quickly. If they could not be ready, ... it was their problem. If you haven't got your shoes on you go to school with no shoes, [or]... if you are not ready, I'm just going to sit here and wait on you, but **now** I just get angry, get stressed... I have to make that extra effort ahead of time to make sure they have done what they need to do. Not so much for their benefit, but for mine.*

*... a lot of time if you are late for places, people get all bitchy because you are late. Whereas before I would have ignored them, and gone whatever. Whereas now I feel I have done something wrong; they are attacking me, which is retarded.... yep its stress, stress that I don't need. Apart from work, if I cry, I cry; I don't really care. It's more - that stress level, that cortisol level which isn't good for me and that's what I want to avoid – it makes my skin itchy, gives me a headache, umm I just don't need that - it's the whole physiological stress response that I don't want.*

Without sophisticated knowledge of how anger and anxiety interrelate, it is difficult to integrate strategies which simultaneously address the anger and anxiety components. Leigh demonstrates this lack of integration by putting considerable effort into developing new occupational routines to eliminate running late and triggering an anger response. Thus the frequency of her angry outbursts decreases, but the intensity of the underlying anxiety, which is contributing to the angry response, persists.

Others describe having no previous experience to guide them on what to do to control uncharacteristic rage.

*At first it was scary, because I was doing all those things, I'd never done in my life, ...like when I assaulted my son and all that...and when my wife was standing in front of the car, and I was so angry about the situation we were in, that in my mind, I wanted to run her over, .... The person before the accident had lived life. I had taught myself strategies to cope under pressure and stress, and to naturally love it, embrace it. This was different, when I elevated, those strategies I normally would have, were gone. I couldn't use them; they weren't even there.*

In this instance Barry knew that acting on his impulses was inappropriate but in the heat of the moment, he didn't know what to do to control the uncharacteristic rage. In contrast, others knew what they wanted to do, to resolve interpersonal conflict, but were prevented from using their usual strategies due to their altered emotional response.

*...but because I spring to this teary response, I've just got to walk away, because I can't just turn around and actually be smart about it, or condescending back, or aggressive back, because I'm just wanting to cry... and there is nothing I can do about it, except get out of the way...it actually rattles me and makes me very angry, very quickly whereas before I wouldn't like it, and I might be a little bit - man you're a dick, but that's where it would stop....*

In this example, Leigh still sprang to a teary response during conflict situations, one year post mTBI. Unless strategies such as sarcasm are skilfully deployed at precisely the right moment, they cease to be effective. In this instance, Leigh didn't know what else to do to resolve the relatively trivial interpersonal conflict, with a co-worker she had known for many years. She temporally left the office tearful and very angry.

Typically, participants recognised that their anger response was out of proportion to the incident triggering their anger and began questioning their judgement. Leigh captures one such moment.

*I think, when I'm feeling like I'm not going to burst into tears, when I talk to him, I want to gauge, if he thinks he is trying to be helpful. I think his heart is in the right place, I think it is just him, ... condescending... which is fine I can accept that and I can deal with that, but I think it's because, I don't know if he is trying to needle me ....*

Selecting an appropriate strategy, and deploying this in a timely manner, becomes difficult, if you cannot accurately and quickly interpret the intent of your communication partner.

More subtle changes in emotional responses, also interfered with deploying one's usual range of strategies.

*...one of the biggest things, from the accident till now is that I'm not as empathetic; I can't connect with the person who is crying in front of me. That was really weird, when someone was crying and being emotional in front of me, I'd be sitting there and in my mind saying ok, get over it. But I'm not like that, I couldn't feel what they were feeling and all that.*

In this instance, Barry describes how weird it felt not being his usual empathetic self. Implicit in this example is the need to learn how to communicate differently. Others sprung to a teary response and were hypersensitive to the emotional distress of others.

*... even watching something on the television I felt emotional about the thing, whereas it was just a story. You seem to be much more fragile than you used to be; in the past I could cope with anything, but suddenly I couldn't... Robin*

Post-traumatic stress responses, when engaging in occupations associated with the mTBI injury, were described by some. For example, Doug describes the chronic anxiety which persisted five years after his mTBI, until he left his workplace.

*I was petrified at work, I was absolutely petrified of doing the maintenance, because I fell at work, .... I did not feel comfortable at work for a long time. Actually I was quite pleased when I left, 'cause I never felt comfortable working at the place. I carried on working for another four-five years, more than that, but I am happy that I left and that I made a career change.*

Similar to others, Doug reported that the acute post-traumatic stress response's reduced in intensity over time, but didn't fully resolve. Barry, whose mTBI resulted from a car crash, stated his persistent anxiety had been interpreted, as being needy.

*I can appear to be very needy – my wife knows that, I can be very needy, and it's the same with my son; like when I go somewhere it has been a pattern for me - I like someone with me for comfort, when I drive up to corners and get [demonstrated startle reaction], it's still in there, and it comes out of nowhere, meaning it is automatically there. I won't say anything to the kids*



*but then I'll go [deep sudden sigh]. Being anxious over the years has been a common pattern ...*

Repeated failure contributed to feelings congruent with clinical anxiety and depression. Pushing through the anxiety, and trying harder, was not a successful strategy for any of the participants in this study. In the following extract Caroline provides an insightful example that trying harder and harder to fulfil expectations of both oneself and others can set up a vicious circle that self-reinforces.

*...at that time as well I was still trying to get more hours – and it wasn't working – it wasn't working – it wasn't working - I wasn't getting the sleep that I required and then of course I am fretting that I wasn't getting enough sleep – and fretting that I couldn't work the hours, ...because I actually knew having a job and working is really important as well. I basically burnt myself out because I was pushing myself too hard, and ... I was made to feel really bad, because I wasn't filling my job full time...*

In the final extract, Nigel gives a good example of temporarily giving up hope. Previously he described not knowing what else to do, when the recommended strategies did not resolve his severe post mTBI migraine headaches.

*...kind of seeing the way forward, was one of the things I had to learn again because within the injury – I guess in the depression that followed the injury – there was the removal of hope, and planning and future possibility and I guess I kind of hit rock bottom six months after the injury – thinking this isn't going to get any better....*

The above extracts pinpoint the times that participants didn't know what else to do, when their best efforts to continue their everyday lives were not enough. In the remainder of this section the strategies deployed to manage the alterations in emotional expression are described. First, the value of collaborative relationships to improve awareness on how emotion dysfunction was impacting on occupational performance is discussed.

### **Developing awareness through collaborative relationships.**

The participants suggested that feedback from multiple sources, helped to develop an awareness of underlying mood difficulties.

*...just through talking to other people [work colleagues] and the likes of my partner, I realised, I wasn't getting it altogether. I always thought I was doing really well, I didn't even know I wasn't doing as well as I thought.... Once this came to realisation, I talked with my doctor. Robin*

Reflection was important strategy utilised in collaborative relationships to enhance understanding, which is described in section five. In the following extract Barry described the

strategies that were helpful for him in learning how he could make interventions to stop him acting on his rage.

*Because [now] I know my brain, know that it doesn't work absolutely cool, and around the same time [as impulses become intense] I need to be thinking about intervention, how can I prevent it going to that other place, and all of that. In the heat of the moment [in a family argument] when we set out feet in concrete, that is when I need to be flexible, and the more I practise it, the more I'll get it, others will get it. Sometimes it is hard to practise, when you are tired and those skill sets that you had before come around...*

Barry describes how reflection with a health professional assisted him to integrate knowledge and education about his brain injury, with his previous experiences in controlling his emotions. Reflection helped him identify, where in the sequence of antecedents, a strategy needed to be deployed. Through reflection, Barry learned that the crucial factor for regulating his behaviour was deploying strategies, in the mood state, where the dysregulated behaviour was occurring. Arguably this is the hardest part for the client to implement, and it is the hardest part for the health professional to facilitate.

Reflection worked well for Barry, who demonstrated good awareness of his behaviour. In contrast other participants became frustrated and angry when they experienced occupational performance difficulties, but couldn't work out what the specific difficulties were. Getting feedback from others and trusting their perceptions required a collaborative approach, as demonstrated by Nigel.

*I consult people who I trust as to how I am doing. So rather than think "this is going very badly", I'll ask "what do you think"; "is this going ...", "how did I do"; "what do you think?" So it is kind of a collaborative approach, but it is also learning to trust other people as well, which I never did before...So it was acknowledging that my perception is not the be all and end all. Acknowledging that someone else's perception is not the be all and end all, and planning toward a goal together.*

Probing questions, enable targeting information to be gathered, however further interpretation was required to make sense of this feedback. Nigel draws attention to the complexity of differentiating between his perceptions and those of others. Others also described the importance of listening to others point of view and being given the opportunity to agree or disagree.

Similarly, Barry describes the importance of having an understanding partner, to lessen the burden on him when he needed to put effort into regulating his emotions and managing irritability. In this extract, Barry describes an incident when he misinterpreted a comment from his employer and thought his employment was in jeopardy.

*So sometimes when things do play on my mind, I know I need to do something about it, because it is not healthy for me, mentally not healthy for me, or for the kids, and family – so I came home that day... so I went and saw my wife and went down into the garage because it was quiet down there, [and after a rest], I explained to her what was making me sad today....*

As described by Barry, this incident had the potential to trigger a negative chain of events, so he removed himself to a quiet place where he could safely regulate his emotions. The later part of the process was made easier by talking through the event with his wife who presumably acted as a sounding board, helping Barry to put the incident into perspective, so he could problem solve effectively.

Not all participants developed collaborative relationships with the important people in their social circles. For example, Gerald's family was not actively involved in the early stages of his rehabilitation. Six years post injury, Gerald was investigating a business opportunity with support from his adult sons. Several times throughout the research interview, Gerald described how difficult it was, not having contact with health professionals, while he experimented with developing his occupational roles, in the later stages of his recovery.

*I need someone to focus me a bit more and to analyse where I am at the moment and what I'm doing wrong – I've been feeling quite deserted – I been saying don't feel sorry for yourself this is just part of the course – [but] other people can't understand – can't, get into your head....*

Gerald went on to describe being unsure, if he was making good choices. Without Gerald family's having a good understanding of his post mTBI difficulties, a ready source of support for Gerald did not appear to have been developed to its potential.

In addition, participants described miscommunications and strained relationships, while learning how to manage their emotions. Working through the complexities, often occurred in steps which built upon previous learning. Progressing through these steps, took time.

For example, Barry describes refining his coping strategies over a period of two years before stopping an overreliance of using his family to help him regulate his emotions. Barry now consults with his family before involving them in his problem solving strategies.

*Just through my mistakes – just through what I've learned in life, the way I operate is like this - there is my family, time and energy and sacrifice and all that, ... so making a decision will involve their involvement, in some tiny way or some big way ...so I asked my sons ... and the first thing my wife said was, 'and I'm not coming'. I can be needy, and she is helpful, and all of those things ... but sometimes my wife has things to do.*

Earlier in the interview, Barry described that before he could effectively consult with his family, he had to address his own impulsive behaviour, and better manage the behavioural changes of

his other two children, who also sustained mTBIs in the same accident. In addition, he repaired a strained relationship with his wife, and demonstrated that it was safe for others to voice their opinions, without the fear of violence. In order to achieve the above, Barry relinquished his paid employment, working through the financial implications and changes this had on the way his family operated. Thus deploying effective strategies which, on the surface, can look easy and straight forward, may be the result of many refinements over many months.

Participants described the importance of collaborative partnership with others who knew how to step in and help when needed.

*I've accepted it [emotional incontinence] and the nice thing about it is that the people around me have accepted it. About four years after my accident, my son got married in Dunedin, and I was vulnerable at the reception. Everyone wanted to know what was wrong. But then my son got up and said this is what happens, 'My Dad had an injury – it's not because something is wrong'. You see, because I just couldn't talk. Eventually I could, but this is just the way I am - and if people don't like it, I don't care. I've got that attitude now.*

In this instant, Doug's family pitched in, and directed others what to do, while Doug waited for his tears to settle, so he could carry on with his speech, thus minimising the disruption in the flow of occupational sequences. Participating in collaborative relationships where difficulties could be explored, and strategies developed without fear of sanction were valued by all participants.

In the next section the strategies for staying calm and tolerating frustration are explored.

### **Staying calm and tolerating frustration**

A stress response often accompanied performing difficult occupations. Managing both stress and anger was often required for successfully completing complex occupations.

*...and when I am getting frustrated that's when I'm putting the brakes on, because if I'm working from calm it is much better, especially with the work I am in, dealing with people.... so breathing was really helpful, just kind of deliberate breathing exercises that the physio, the OT and the speech and language therapist all gave me, breathing exercises as did the neurologist. Everyone said breathe... During the intensive recovery period I was doing half an hour of deliberate breathing exercises every day, no twice a day...Nigel*

Learning to work from calm was frequently described as the first step in learning to manage dysregulated emotional reaction. It is not known, in this example if the breathing exercises differed between the different health professionals. Certainly the repeated advice reinforced to Nigel the importance of controlling his anxiety by breathing.

Bonnie also describes the importance of remaining calm, providing an example of how participants demonstrate to others their preferred way of operating.

*If I want something done and they say they will be there tomorrow at 9 o'clock or whatever - I'll say, 'No hurry – just when it is convenient for you'. So instead of expecting people to come, I move around with them – I feel as if I have become – umm, if I don't put pressure on them, they won't put pressure on me.*

By reinforcing a new tempo, Bronnie demonstrates how she became a person who learned to take things easy.

In the early stages of recovery Leigh was provided with information on the fight-flight mechanism thought to underpin the stress response, recognising that she used the flight response for “self preservation”. Utilising protective strategies such as avoiding stressful situations may be necessary in the early stages of recovery but can become counterproductive in the medium to long term. A year post mTBI, Leigh remained frustrated at having to use the default strategy, of exiting the conversation when she was unable to maintain her composure. She described observing conflict situations to try and understand conflict resolution processes better.

*...I won't engage in an argument, I won't flare up and tell them that I think they are idiots even when I feel like it. Whereas most of the others I have noticed in my other office - they would do that, they would stand their ground....*

Unless there is support to explore the interactions from different perspectives, and to identify if or how the stress response is interfering with assertive responses, it may be difficult to develop alternative strategies using observation. As identified by all participants it is the hidden parts of not being able to do what you could easily achieve before the mTBI that are the most difficult to understand.

In the early stages of recovery, participants learned to recognise the early signs of being tired and frustrated and took a break, as described in chapter five. In the later stage of recovery, deploying additional strategies to remind themselves to tolerate the frustration, and priming oneself not to set off a chain of events which would lead to an angry response were further developed.

*Those breaks that I'll take when feeling stressed and tired – it's closed eyes, deep breathing, it's finding calm, reminding myself that I am not God ... I can't make everything work exactly as I want it to.... [so when the] stupid stuff happens, ... it's [demonstrate a big breath], this is not your universe, you are not the maker of it, I'm not in charge of you – so that kind of talk and deep breathing, changing perspective.*

Nigel trained himself to link the possibility of inappropriate angry outbursts, referred to as “stupid stuff”, when he was feeling tired and stressed. Thus when Nigel first recognised the build-up of stress, he initiated a break. During the break, Nigel added breathing exercises and self-talk, reminding himself to tolerate irritability. Hence he was able to capture frustration early enough to interrupt the sequence of events, preventing an explosive angry outburst.

Similarly, Caroline was able to prevent an angry outburst if she noticed the build-up of agitation soon enough.

*....as I long as I actually **noticed it** and was not that far agitated – sometimes it was then as simple as taking a deep breath and going outside or go for a little walk or even go to the front of the house to the letter box or something like that in the garden ...*

Caroline also learned to recognise changes in her dog’s behaviour to cue her into early signs of being frustrated, and to remember to interrupt the chain of events leading to an angry outburst.

*I could always tell as well with her [dog] when I was getting umm frustrated, — she would slink away and I would notice I’m getting into a state of being agitated, frustrated, and if I could then stop myself and do something else....*

Learning to consider the needs of others, seemed to help participants tolerate their own discomfort, and reduce their demands on others to meet their needs.

*...down time after work, scheduling down time ... sometimes it is hard, my wife has things to do – so I have to suck it in take a big breath and push on knowing the time for a break will happen. Barry*

However, negotiating a suitable balance was often fraught with difficulty. As explained in chapter four, families were often left with the burden of care when the person with the mTBI needed to take off the load.

*Telling my family after the accident that I have changed, they didn’t get it – they did after seeing me react, and this and that, and they still didn’t get it – but when I am with the psychologist it is different, — we are talking psychological understanding – they just get it, ... but for my family – nah it is not the same – it was a shame there wasn’t information for the family....but family has to be part of it – because there are going to be hit and miss days, and weeks when you wake up on the wrong page, and they didn’t understand – they didn’t get it and there was confusion, there is anger, there is siding with one another type of thing, a me and them mentality, that happens. Barry*

Understanding how significant others influenced mood states and coping strategies post mTBI, would be a useful price of research. As Barry suggests, the emphasis is on the individual with the mTBI and not the others in the family that are also affected by the mTBI symptoms.

Chronic anxiety associated with stressful occupations, can persist over time. Utilising others in one's environment as a motivator to persist with the unpleasant occupations was employed as a coping strategy.

*... as I go there [supermarket], I sit in the car and I don't want to go out. I say [to my mother] will you will be able to go, but her eyesight isn't good and her hearing isn't good, so I don't like doing that to her. But sometimes she'll say to me, I'll go and start it and you just sit here and come when you are ready....*

In this instance, Bonnie knew if she took her mother supermarket shopping, this would be a sufficient motivator, to attend to the "hated" occupation. In turn, Bronnie's mum provided the incentive for Bronnie to push through the anticipatory anxiety. In common with other participants, pushing through the anxiety failed to eliminate the anxiety response over time.

Another set of strategies which encouraged flexible thinking and alternative to angry stressful responses was learning how to change one's perspective.

### **Changing perspective**

Altering one's perspective, enabled a more flexible thinking style, which all participants found helpful for changing their mood state.

Self-talk was utilised by participants who experienced uncharacteristic stressful and angry responses to everyday problems. Typically, self-talk was combined with anxiety management strategies and deployed as a reminder to keep the precipitating incident in perspective and to tolerate the inconvenience, while planning what to do.

*It's very tricky, and in all aspects of the whole bloody thing is that I just have to stay calm about it, stay logical. Just beating yourself up about it is pointless – there is no point to it. I have to say, "Oh well that's it, – it's no point farting against thunder".*

Gerald found that giving himself a pep talk, combining logic and proverbs from his youth, helped prevent him from panicking. Others thought about the example they were setting for their families, if they were to continue explosive angry outbursts.

*I have to find some gusto – find a reason to change the attitude. I think of the bigger vision, the example I am setting my family. For example, they need a dad and I'm not being a dad — like they could imitate me and do what I do, copy exactly what I do and that is not going to be healthy, for them for the house and all of that. Barry*

Nigel attended a research group at AUT, and used a structured process to facilitate self-regulation. He described matching what he wanted to achieve, with a plan on how this could

occur. He developed a set of statements to cue him into remembering what needed to happen so he could achieve his plan.

*...and the last bit of research I took part in with AUT, it was around goal setting and goal planning and how to do that, and you know, a set of things to remind myself – like my perspective is not the final perspective, and an immediate response is not always the best response.*

Differentiating between shame and vulnerability, helped participants accept altered sensitivities of their post mTBI emotional responses.

*I think I just accepted it myself like that - that's me and I can never change it – I'm 62 and there is nothing I can do about it – and if they say a man doesn't cry – well I'm not crying because I am a woose, I'm just crying, crying because I can't choke it off – because of something that happened in my past – I can never restore it again ... – so it doesn't bother me at this stage – the teardrops are always just hanging around – my wife, my kids, my friends accept it.*

In the above extract, Doug differentiated between the vulnerability imposed on him by the mTBI and the social stereotypes that are often made about men who cry. Education about the physiological process that underpins changes in emotional responses, post mTBI as well as an exploration about the individual meanings, the altered sensitivity to tears, seems important. Ensuring family and friends have access to this information may be helpful. As participants point out, much of the education is directed at the person with the mTBI, with few written resources made available for families.

Similarly, Nigel describes the benefits of attending a workshop in the post-acute phase of his recovery, which allowed him to differentiate between shame and vulnerability.

*Accepting vulnerability as part of life and actually as part of recovery and growth – admitting vulnerability is not admitting weakness – that was a major shift for me – ummm – here I am a community development worker – I know that that is true –, I help other people to see it, but for me at that point in the recovery it was a tough thing to hold on to umm but absolutely crucial....like if I have a full day of meetings – I just acknowledge that I have got to plan in recovery renewal, battery charge time afterwards. I am no longer as frustrated by that... and I don't apologise, and I'm not ashamed of it.*

After making this shift in his thinking, Nigel reported he no longer felt ashamed and did not need to apologise for changing routines. Without the shame, developing new occupational routines was no longer resisted.

Another effective strategy deployed to change one's perspective was prayer.

*...prayer is one of the best places for me to go as it opens me up, opens my brain up, opens my head up and allows somehow – not to rely just on your*



*feelings.... it's not that it works straight away or anything like that - it gives me a release and lets me develop a different attitude, a different perspective... I can [after prayer] slow down reassess, and now come up with a plan, regardless if was a tiny little thing – or something quite bigger. Barry*

Others took account of the wider picture, to put the limitations imposed on them by the mTBI, into a different perspective. Nigel provides an eloquent example which stopped him using the mTBI as an excuse for limiting participation in everyday occupations.

*I acknowledge ongoing realities post concussive injury, but I don't allow it to kind of define me – quite early on in the return to work and when I returned to work full time – it was, I need to acknowledge this [changes in the way of doing things] but I'm not going to lean on it as an excuse – I'm not going to allow it to be something where I think — no that's a limitation. So if there is stuff required of me then I have to approach things differently, if I have still got this vulnerability – I'll use that as a way into communicating better and choosing to be positive, and then becoming a positive reality.*

Participants also recognised the positive side of learning to work through the difficulties of sustaining a mTBI. In the following example Barry reflects on his increased sensitivity to become angry. This helped him accept the changes to his personality, *after* he had learned to control his rage.

*But it has made me a bit of a diverse person, believe it or not, and I can mix it with that and mix it with this – and I'll tell you something really funny – people who have known me before, when they heard about my accident that I can get angry and all that, they have clapped and gone - about time, (laughter), and the kids with teaching — I am less patient, I am a very patient person — but with the kids I can do the old hurry up, clap my hands come on hurry up, the instructional military person comes out – no nonsense...*

In this instance, linking the mood state with a role such as the instructional military person, assists Barry to make sense of his changing mood states and perhaps helps him anticipate the behavioural responses that are associated with each mood state.

Other ways of using post mTBI learning as a positive experience, is demonstrated in the following three extracts.

*I changed from being a leader of the team [after the mTBI], to then being a team member, and actually I got quite a lot of satisfaction – being in a supporting role for other people to achieve. So at the moment for me, making sure we have nice healthy dinners and looking after the animals and stuff like that gives me quite a lot of satisfaction... Caroline*

*I love connecting with people and always have, just I got these interruptions along the way, things are a little bit different – yet some things are the same, in a funny way it has made me more experienced – because I know anger – I've tasted it, anger, I know crazy thoughts, I can be more, I won't say the word compassionate, but I'll say understanding about issues. Barry*

*...there is a young lass of 18, in my community - she had a brain injury three years ago, and I haven't met her yet [but] what I am hearing is that she is hitting failure after failure after failure... the brain injury hasn't been treated ....and she hasn't been given equipment [coping strategies] ...so as soon as I'm back in position and she is in the country we will have a conversation around it's not too late to do something – you can recover it is just going to take some time – because I think she wants to start university. Nigel*

The final strategy that participants used to change their perception was the use of humour.

*...and to use humour as well – that's another good one that works for me – just to use humour, just smile about things – because I can't do anything about it, and when things get out of whatever, just have a little laugh, and that's helped a lot, if I'm not getting serious, then I'm not getting anxious, I'm not getting worked up. Barry*

With a change in perception, participants acknowledged that they were able to “see” things differently, and with a different outlook, new ways to address occupational performance difficulties began to emerge.

*... so I might have gone on instinct and experience and training before but now I'm a more deliberate...So the planning for conversations that are going to be tough and difficult – I can more deliberately go in thinking what is the outcome here – what is the good outcome – what is the worst outcome, and if it's not going to go as well as it can, how can I get it going as well as I can actually manage in this meeting – so we can end in a way that we can all at least all positive about the way forward. Kind of seeing the way forward was one of the things I had to learn again. Nigel*

All participants discussed difficulties in learning how to respond to others' responses after the mTBI. For some this was the most difficult part in the recovery process.

### **Managing others responses**

Most participants stressed several times in the interview how difficult it was learning to manage others people's responses. Not only did participants have to learn to manage their own dysregulated behaviour, they also needed to learn to manage the other people around them. Barry described how he anticipated flippant responses and enlisted the support of others around him to alert him to inappropriate responses.

*...because when I am tired I can be flippant, with my words and very direct and all of that, and if it wasn't my child or someone else they would probably get frightened by the way I am talking, I don't mess around... I have to let them know they are part of my rehab, believe it or not – so I will let them know that I have weaknesses, I've got this and that because of this and that, so keep an eye on me. Let me know if I overdo it, because I really don't mean it – and they are OK with that – and that is the children the other teacher aides, and those are the teachers as well.*

Such support enabled prompt remedial action and in some instances prevented a cascade of responses escalating the fallout from an impulsive unplanned response. Teaching others to give cues about overstepping the mark, also reduced the risk of others becoming frightened or offended.

In contrast, Doug chose not to explain to others his history of an mTBI. He diffuses concern about his tearful responses by deflecting comments onto the event triggering the response. The following two extracts demonstrate the use of deflection, the first with adults and the other with children.

*I just can't stop it [the tears]. I just get stuck, and then I carry on again. It's like when my grandson was born last year – he was born with a disability – and it was just a very emotional time for me .... You tell other people at school about your grandson – and they want to know why I am all emotional about it. Because I'm at a new school you see – well, it is my grandson, and he does have problems – and then it's 'Oh I'm so, so sorry' – and it's, don't be sorry for me, I'm worried about my grandson....*

*I haven't cried [in the class room], but I have had tears in my eyes, when some of my kids really achieve. And I can actually tell them that. They will say – you have got a teardrop in your eye, and I tell them that it is not because I'm sad, I'm really, really happy. And I think it makes quite a big impact on them, that there is a man that can have a teardrop in his eye, and he is teaching, and he is happy, that I've achieved something. They are only eight, seven- and eight-year-olds, and I think they actually see it in a different light as well.*

Not all environments are supportive of those with chronic health issues. Participants all described how difficult it was interacting with people who did not understand the impact on the unseen things associated with a brain injury. Getting what you need, while simultaneously learning how to manage changes in occupational performance, in a competitive work environment, was particularly stressful.

*I did try and tell my team leader that I needed more resources but he just went off on a tangent and pissed me off - so we didn't get that far.... So I have got to be a little bit competitive... [for example] I stole the graduate first [to assist with workload], ...I'm not wired like that – I don't normally do that but that's what I have to do in order to make sure I'm not that stressed...a little bit cunning a little sneakier which doesn't come naturally to me...*

A combination of word finding difficulties and slowed processing times, contributed to difficulties implementing verbal negotiations. Leigh provides an example of deploying non-verbal strategies to meet their needs. Leigh perceived herself as being cunning and sneaky, and expressed distress at needing to do this. Presumably this contrasted to pre mTBI functioning, when she felt confident with her skills and utilised verbal negotiating skills to get her needs met.

Participants described flow on effects, which weren't always accurate, when they changed their communication style.

*...and they don't want me to ring IT [information technology] – I'm not quite sure why, but I decided – it's more efficient for me to go – "no I can't fix this in two seconds so you deal with it" – which is the delegation, and basically take it on the chin that everyone thinks I'm numbee [incompetent] when it comes to IT [information technology]*

In this instance Leigh expressed confidence with her decision to immediately delegate IT faults and appeared to easily shrug off, the odd bit of teasing about her incompetence. Checking that reactions to changes in occupational performance, are tolerated rather than perpetuating feelings of guilt and shame seems important, in the recovery process post mTBI.

Repeated failure and managing the setbacks while plotting a course to recovery, was associated with dysphoria and periods of depression. The last section discusses the strategies which participants and significant others deployed, which supported hope.

### **Maintaining hope**

Preventing a sense of failure, when designing programmes to increase activity tolerance and practise new combinations of occupational routines, was viewed as important.

*It was a planned increase, so when I did overstep my capability there were others that stepped in and made it as though there wasn't an overstep at all – these were the things that really helped. Nigel*

In this instance, accessing supportive community members to take over public speaking or counselling assignments, should this be necessary, permitted Nigel to engage in training sessions.

Participants described, a great deal of satisfaction when they noted they could perform aspects of everyday occupations without effort. Often these improvements were first noted months after the mTBI, as demonstrated in the following two extracts.

*...reading a proper book and I was able to retain the information, I can remember being quite elated almost that that ability had come back – I think it was about 6 months after the accident and so through that you know that things are coming back. Caroline*

*...but I was actually able to move my eyes around in a square and not feel I was about to throw up – or that my head was about to spin and feel horrendous - whereas before then I couldn't even follow a finger without feeling awful – so that was one turning point [several months post mTBI]. Leigh*

This suggests that expecting people with an mTBI to perform as usual, in the weeks post mTBI, is perhaps setting people up to experience failure. Understanding the occupational limitations associated with persisting symptoms may better prepare people for the challenges facing them in everyday life, and support a more realistic recovery, for those people who do not experience a rapid return to pre-injury functioning.

Successfully participating in occupations that are compatible with interests and values, had a positive effect on mood. For some this was resuming previously enjoyable occupations. For others it was participating in new challenges.

*I've got like 4 or 5 songs, not complete but I'm chipping away at them, I never used to do this before, but she [counsellor] asked me what would you like to do – one of them is art and one is writing songs, ...its stuff that sits well for me, I've never written songs before – it's awesome. Barry*

Participants who learned a problem solving process, were also able to prevent stress from dominating stress their responses, and develop confidence in their ability to keep going, knowing things will get easier.

*...so on the days I wasn't thinking well, well umm – and I'd get it wrong, ...sometimes those things were getting the better of me, ...and then I'm going I'm doubting myself, but the other thing was to push on, plan prepare. Barry*

*I keep on having to remind myself that nothing is abnormal about what is happening [difficult and stressful] – it is all learning curve stuff – it is the first time – I don't know how many times I said I can't wait for this first time to be over with – just because when you've been through it all – things become easier – I don't get as stressed about it. Gerald*

However, it was the generating of new ideas, that determined the success or otherwise of the problem solving process. Once participants learn the new strategies for problems solving there were numerous examples of independently deploying these new strategies into novel situations. As described by Doug his wife was a good resource, for generating ideas for problem solving.

*At first I did not believe in myself. My wife [a teacher] is guiding me a lot – giving me a lot of support – she will say – try this – try that – and that has made it easier for me.... Doug*

Changes in occupational performance had a profound effect on self-esteem and sense of efficacy. For some seeing the way forward involved relinquishing occupations or parts of occupations that proved too stressful to continue.

*...and I got frustrated by not being able to work and do my work properly. I really thought I was letting the side down you know.... nobody wanted me to leave. Robin*

Delegating difficult parts of occupations, so the enjoyable and /or manageable parts of occupations could be continued was a commonly utilised strategy.

*... which if push comes to shove, that is what we'll have to do – someone else can do the leg work [transporting the art works to the buyers].... Gerald*

Others considered the emotional impact of persisting with difficult occupations, and reached a compromise between maintaining relationships, earning a living and enjoying their life.

*...if you end up with adversity or anything it is really emotional draining on yourself – but also it then stuffs up your working relationship with other people – in the end it is as simple as that - and I'd rather be a relief worker on a farm down the road three days a week than the assistant manager down south... Caroline*

## **Summary**

In summary participants gained additional knowledge about their altered emotional responses through education, reflection and in collaboration with others. Feedback from multiple sources helped participants develop an understanding of their altered capacity after mTBI, providing clues as to where strategies needed to be deployed to improve satisfaction with occupational performance. Strategies which facilitated a more flexible thinking style facilitated new ways of problem solving, as did suggestions from others including health professionals and family to try different strategies when problem solving. Trying harder, without making changes to the way the occupation was performed, was not an effective strategy. Occupational performance difficulties remained, after stress responses were controlled. In addition to persisting changes in energy levels and emotional functioning, participants described persisting processing difficulties which impacted on occupational performance.

Chapter seven focuses on the strategies deployed to manage these cognitive impairments.

## Chapter 7 - Managing persistent changes in cognition.

Chapter seven describes the strategies deployed to mitigate the difficulties performing challenging occupations. All participants described limitations in their processing capacity, after their mTBI. As discussed in chapter four, the majority of participants were unable to sustain full time employment in the early stages post mTBI, citing difficulties completing complex occupations. Difficulties were more pronounced when fatigued, whilst under pressure to perform at speed, and during periods of new learning.

The strategies deployed by participants to manage cognitive changes are presented in four subsections. The first, describes strategies participants utilised to sustain attention and adjust to slower processing speeds. The second set of strategies describes managing the alterations in cognitive skills which are impacting on non-verbal occupations. Next, the strategies to manage alterations in verbal communication skills are discussed. The fourth group describe the strategies that are deployed to support new learning and the last set of strategies were used to differentiate between “normal” difficulties with everyday routines and those requiring additional effort due to the mTBI.

### Managing the Non-Verbal Processes

#### **Sustaining attention and adjusting to slower processing speed.**

Immediately after the mTBI, participants described needing a quiet environment with no interruptions to sustain attention and complete routine occupations, (see chapter five). Seeking out quiet environments to work in, persisted months after an mTBI, with this example from Leigh occurring one year post injury.

*I'm just getting a bit slower and taking a little bit longer to figure stuff out, and it's easier when there are no distractions to sit down and do it here. [home]*

Participants also described using background music, to help sustain attention on priority occupations, and to block out distractions in their work environment.

*...for a while after the concussion I needed it to be relatively quiet for me to concentrate on something, but now I'm back to my old self I want some music on .... I know this sounds dumb but you have this music going on in your head that you almost ignore but it actually blocks everything else out.... [initially]*

*it had to be familiar music though, as soon as it was something new it was really distracting. Leigh*

For background music to be helpful, both the occupation and the background music needed to be familiar. In contrast to other participants, Gerald found music overwhelming, post mTBI, but utilised background television and radio stations to assist sustained attention.

*I can't really read anymore, I can do paragraphs, short things. I can't read a novel ...I often put the radio on or the television on, which you would think would drive me nuts – but umm in the background while I'm reading a magazine, it helps... like I can't analyse why more than one thing happening calms me down .... Whereas music – I was crazy about music – all types of music ... music overwhelms me as well somehow.*

In both Leigh's and Gerald's account, the "noise" they used to block out other distractors seems to be have chosen because it did not, in itself, demand any attention. However, background sounds, became a hindrance when attention needed to be alternated between different occupations and participants took action to reduce background noise.

*...now I do have radio on but almost exclusively Concert FM as I had low tolerance for chat in the past and almost no tolerance after the accident. Also, it is the kind of music I've always studied with in the background, so there is a direct association with concentration, and staying on task. Still at times have to turn the radio off, as I cannot listen to someone talking in the car, and on the radio at the same time. Caroline*

It was not clear if background music would be beneficial if switching attention between two or more tasks that were both familiar and predictable.

Instructing others to eliminate unnecessary levels of background noise also occurred. Similar to other participants, Doug focused on the benefits for the group, when requesting specific changes to support his functioning post mTBI.

*When I got my own class I sat them all down and said this is how we are going to work – if you guys what to hear me ... because I don't shout ... and if I don't shout you don't shout ... I did shout once when something severe happened and they all were like 'Wow he can shout', but I have just started my whole year like that.... I haven't told them that I am brain injured and I don't like noise – I think it is just that I create a good environment and the kids cope and it's a good learning environment...Doug*

Additional development of attention skills occurred when responding to environmental changes.

*They [administrators] blocked Spotify [music streaming system], on us this week – probably sucking too much data. And I did find it a little bit tougher in the office this week. I noticed the chatter more – I'd notice it and then I'd ignore it. Leigh*



By persisting with her work, Leigh began adjusting to the environmental changes, and started ignoring background noise in the busy office, without the help of background music. It is not known, if the extra effort required to ignore people talking around her, would reduce over time if Leigh continued to practise blocking out background sound without music.

In addition to blocking out distractions, participants described reducing the demands of a task, to make it easier to sustain attention. Breaking complex occupations into smaller, manageable components was a commonly deployed strategy, as described in the following extract by Nigel.

*I couldn't do it [preparing a lecture] in a single sit down. Like before, I would tend to work – think and think and think – background – mull it over and would then sit down and would all in a creative two, three hours write it - done and dusted – ready. And it took me probably three years before I could do that again, because I didn't have the brain space to be having lots of things running at the same time.... Now I've got to sit down and think about this, that's all I'm doing, is think about it, and write stuff down at the end of it. So it was breaking the task down into smaller chunks...*

Nigel estimated it took three years before he developed sufficient capacity to prepare a lecture in one sitting. Breaking tasks down into smaller chunks was not always possible, however, as not all occupations could be timetabled to be stopped and started. One strategy to manage that scenario was partnering up with others, which permitted occupations to be completed a bit at a time. Capacity was then gradually developed over time.

*By the end of July, I could drive again – that took a while. I did some short driving – a bit of longer driving on the way to work, then my wife could take over. Robin*

Sharing the responsibilities of complex projects also had the advantage of allowing the person with the mTBI to target the components of high priority, without becoming overwhelmed with the complexity of the whole project. In describing how he was now thinking about being a buyer for a retail store, Gerald explained:

*The people who wanted me to brand for them – they said 'You have got three things going. You have excellent taste, you have got huge amount of knowledge as far as this stuff goes' – 'cause everything has a story attached and I like writing little things to dangle from it, 'and you are hugely passionate about it - and people are seeing that' ... how about you send us pictures back if you see anything – and then we will pay for the item and the shipping things out...*

Partnering up with others also permitted selected parts of complex sequences to be targeted for development.

*I would arrive late to the community development meetings, so I wouldn't have to deal with the social stuff and I would leave early again to avoid*

*conversations. And I started off with 10 mins of the programme and then 15 and slowly over three to four months built up to being there for the whole meeting. But if it got too much, everyone knew that I'd just leave. Nigel*

Despite deploying multiple strategies, sustaining productivity expectations in a competitive environment, was a challenge for most participants. Leigh who experienced a slower processing speed, compensated for this by working longer hours without financial compensation.

*I still find I get a bit tired when the things are a bit complex, I do some stuff at home and aren't charging it as actually the old me would have done it the first time.*

Leigh also demonstrates how eliminating unnecessary steps reduced the cognitive demands of the task which made it easier to achieve required performance expectations.

*I have to be really clear what our actual performance measures are make sure I hit those and just not care about anything else.*

Not only did participants describe a slower cognitive processing speed and impaired attention, they found it more difficult to read and write and manipulate complex information. The next subgroup of strategies describes managing the non-verbal changes in occupational performance.

Participants described a range of non-verbal components which interfered with occupational performance post mTBI. Although I did not have access to assessment data, describing the occupational performance difficulties and the context in which it occurs, readers can gain useful knowledge on why strategies were deployed, and how these strategies facilitated improved participation. I begin this section discussing the strategies deployed to mitigate changes in reading and writing skills, then move managing complex visual information and finally discuss manipulating complex data and planning difficulties.

Many participants described reading as requiring more effort post mTBI, including those who were avid readers. For most, sufficient content was retained to persist with reading, if the book was interesting.

*I love reading but it's hard for me, the concentration. Because it is quite hard for me I leave it for a few days before I go back to it, and then I won't remember what I'm up to.... I'll go back one page and it doesn't ring a bell so I'll have to go back further.... then I'll read it all again the second time and its quite exciting – I can remember this I can remember this – but then sometimes when you are back to where you were before you are tired again so you don't get far – but I try, I try to at least get a few pages on each time. Bronnie*

Challenging oneself to read at least a few pages more at each setting, was a useful strategy for Bonnie to remain engaged with reading as a leisure activity. However, reading a few pages every few days did not improve her capacity and reading remained difficult, five years post mTBI.

An occupational therapist provided Robin with a list of occupations to avoid, so he could conserve energy and focus on building up his work hours. After resigning from his employment, nine months post injury, Robin recommenced reading, one of the occupations that he had previously been advised to stop.

*...so I started reading again, just a novel – it was hard reading I don't know why it took so long. One book, was an engineering book building aircraft. Maybe it was just too detailed. I still haven't read it. .... At first it was keeping the line in order – that's right now – and I just seem to be reading slowly – maybe comprehending... I could remember [the content], I know because the book was interesting. In that particular book, I can remember on page 23 ... it could be handy for what they did for work. Robin*

In contrast to Bronnie, Robin puzzled over what was making the reading difficult. The more obvious ocular motor control difficulties, such as visual tracking, appeared to resolve soon after the mTBI, with no obvious memory deficits impairing reading ability. Without a visual assessment it was not possible, to identify specific reading difficulties, making it difficult for participants to target the difficult components of reading, to improve function. Both Robin and Bronnie resigned from their pre-mTBI, employment, unable to process complex computer data at speed. If reading basic text was problematic, it is difficult to understand how people with reading difficulties were expected to perform complex visual processing tasks in the work place under pressure.

In contrast to other participants, Barry was required to participate in core reading and writing skills, multiple times per day, when he resumed employment as a teacher aide, three years post injury.

*...they told me my writing was messy – before I was really efficient. I was a note taker and all of that ... and when I draw now, I draw really slow. But I have been practising these things ... with the kids. I'm also a kid with them and it helps them settle as well.... it is very therapeutic as well, like in the graphics class at school, I love it, seeing my ideas come out...*

Barry benefitted by deploying the same strategies as his pupils to redevelop his writing and drawing skills. In an education setting he had multiple opportunities for targeting specific skills and practising these at a speed he could cope with, interspersed with scheduled breaks. In Barry's case being able to practise these skills during work time, meant he didn't have to try and do this at home, in-between responsibilities associated with being a husband and father of five children.

In addition to rebuilding capacity, participants deployed strategies which compensated for alterations in processing skills, making it easier to continue participating in priority occupations.

### **Compensation strategies**

Others such as Gerald compensated for persistent difficulties with reading and writing, by utilising images and pictures, which were easier for him to process. He therefore flicked through designer magazines, looking at the pictures, to keep up to date with the vogues. He also emailed pictures of proposed items to potential buyers, with the price attached and waited for a conformation before purchasing the item, reducing the amount of written information he needed to process.

*... I've read thousands of magazines and designer books – Well read? – I looked at the pictures, so I had a pretty good idea of what would work and what the vogues are, that go with furniture ...and I would email these people [potential buyers], back with photos...*

Visual reminders also assisted people to effectively retrieve information that escaped conscious memory, when a task was interrupted.

*...like I got some glue out yesterday to mend something and mum bought it over to me, and I had forgotten all about it. I remembered when she gave it to me – but not in a million years I would have remembered about it. I would have gone past [the glue] tomorrow or the next day and gone – oh that's right - but for that day it had gone.*

In this instance, Bronnie's mother utilised a visual cue to remind Bronnie of her intentions, demonstrating that family members, also adopt effective strategies to support functioning.

Bronnie explained the futility of writing a grocery shopping list, and a preference for using visual images to prompt her memory.

*Lists are a waste of time. It would take me so long to write it and I'd probably forget to take it, and then I'd probably change my mind by the time I got there and not get what I had written down – it's sort of like a visual – I'll see something and, oh yeah, I'll see what I come up with .... but always there's something I forget, and I'll end up coming home and get so frustrated that I can't remember the last thing ... you aren't near the aisle so it just doesn't come to you.*

Bronnie's strategy of committing to memory the essential items and using visual cues to help her decide what else she needs, was partially successful. Further consideration of the difficulties associated with writing lists and reading these in a busy noisy environment, along with search strategies in visually complex environments, may have allowed Bronnie to improve her

strategies for grocery shopping. However, with her focus on escaping an unpleasant environment as quickly as possible, precluded the development of additional strategies.

*....it is, 'What are we going to have for tea tonight?' I have to decide – it's usually just something that comes into my head – not especially that you want it – just that it is easy and it is the first thing you think of and you know where it is in the supermarket. If I go past an aisle which is really busy with lots of people, I just go past it. I'll do that when it is a bit quieter ... but it takes you out of your way and makes it a bit longer. You just think its wasting time and you could be out of there quicker.*

Participants all described moments when their mind went blank and they needed to stop what they were doing, which has safety implications for some occupations. It was not always possible to predict the exact moment, where the demands of the task overwhelm processing capacity, as Barry explains in the following extract.

*One time I came up to a T intersection, and my mind was tired. I was busy and my mind went like this (gestured blankness), and I decided to stop – that was the safest thing, and when I stopped all the cars had to stop too. Then we just had to sort ourselves out and then I had to apologise to the kids, but I was happy I did that, but at the time it was (inward gasp demonstrating panic). Like, I was a van driver, so I know driving, but just because I'm used to it doesn't mean I'm OK, I still have to be safe...*

In this instance, Barry, who had passed a driving assessment post mTBI, regained his composure and then continued driving to his destination, without further incident. In selecting an example with a safety concern, the difficulties in determining what is or isn't safe practise, post mTBI, are highlighted. Doug, the only participant in this study who had a work related accident, expressed concerns that he was cleared for work, without his safety concerns being addressed, as discussed in chapter five. His anxiety persisted, but without completing his psychology interventions, or undertaking vestibular or balance testing, it was not possible to comment further on his safety concerns, that remained problematic years after his injury.

*.... I felt that they didn't give me enough time, because I was still being treated by the psychologists, I still had quite a lot of appointments, and ACC just bought me in and said right stop. The psychologist was very shocked about it, said they can't stop it – there was quite a big story going on about it, but you know you can't fight ACC, so I lost out ....*

Participants in this study who resumed competitive sporting activities did so in a stepped approach, and refrained from re-engaging in situations where they felt at risk for another injury.

*I think it is a confidence thing – I haven't been back to netball– I was playing in a social league ...and there is a lot of physicality .... so I have just decided not to do that again. I've only just started referring basketball again. I tried*

*last year but the stress was too high - it was all the noise and the light and you've got coaches yelling at you...*

As demonstrated by Leigh, when participants had the choice of when they returned to physically challenging occupations, they did so in their own time when they felt comfortable. In the early stages of her rehabilitation, Leigh described participating in an exercise programme supervised by a physiotherapist, which included visual motor and tracking exercises. It was not known if subtle motor control difficulties were also contributing to a lack of confidence, in the chronic stages of recovery.

Other persistent perceptual difficulties, including differentiating right from left, inverting verbal or written answers to questions, and initiating movement when a choice has to be made about which hand to move first, were described by some participants. Management strategies included, putting up with the inconvenience, apologising for incorrect answers or directions, using gestures instead of words, and relinquishing parts of the occupation which were difficult. Combinations of these strategies are demonstrated in the following four extracts.

*...and I think I was in K-mart when I thought oops something isn't right [laughter] – how stupid is that, yeah I put my shoes on the wrong feet and I just carried on - but I find left and right very hard... and when I am in the car people say to me which way do we go, I'll point rather than say left or right*  
Bronnie

*I can flip things in my mind. When somebody gives me a question, or wants an answer, I'll give them the opposite, it inverts – even when I'm taking notes, I'll give the opposite of what was intended. It looks silly when I've done it, and I'll apologise that I've given you the opposite answer, - those things sort of happen.* Barry

*And here is another little quirky thing – when I have an object in one hand and an object in the other hand, my brain slows right down and freezes, so if I have to manipulate them or do something with them, it's hard — it's really hard. You see I had these \$10 notes in my hand and the keys in another and I didn't know what to do ... and my wife knows about it and if I'm tired she will come up to me and take it out of my hand, and you will hear me go (sigh)...* Barry

*I find it hard to look on the computer now – especially if I want to buy something. I can't relate that picture to an actual thing. I think how do people buy off this little picture? I have got no idea what it is going to look like or the size of it. I do buy on line occasionally – but it's something really simple that you have seen out in the shop and you know what it looks like.* Bronnie

In providing these examples, the subtle changes in cognitive capabilities which impact on everyday life and require adjustments to the usual way that occupational routines are carried out are highlighted.

Participants, became proficient at selecting essential components of their occupations so the tasks could be completed with the minimal amount of processing. This happened both spontaneously and with conscious application. Caroline provides a good example of how her attention is focused on the essential components associated with driving, with peripheral features no longer consciously registering in her mind.

*...people seem to be surprised how I don't see or notice things along the way [when driving], as in animals in paddocks and buildings along the way. My explanation is that if it is not on the road or about to get on the road and thus be a hazard, it is not important. Just the road, driving, and traffic is what needs my attention. Buildings are unlikely to jump out into the road, I say.*

Whilst Caroline describes becoming aware of changes in her capacity which initially occurred without her realising it, Nigel describes the benefits of reviewing pre injury patterns of work and being open to changing ineffective work habits that occurred prior to injury. In this instance, he stopped cramming things too closely together, redefining his interpretation of what is urgent.

*... and I acknowledge there are very few meetings that have to happen right now... but it's that kind of stuff that I'm doing rather than feel a need to cram everything in which I did do before my injury – which wasn't necessarily a healthy way of working anyway.*

Planning ahead remained difficult for most participants post mTBI. The frequency of mistakes and 'being caught out' was unsettling for many participants.

*... and my car broke down a few weeks ago – so I went down to the mechanic, and he said, did you know your warrant is five months overdue .... and I could have been stopped so many times – and I probably would have argued the point – because I don't normally do that sort of stuff. Bronnie*

Participants described using schedules and reminder lists to help keep them on track during the day [see chapter five]. Over time, these schedules were tailored to specific needs, as participants became proficient at planning and anticipating likely difficulties.

*...like I have reminders from one to ten things for the things I have to do for the day, underneath is for the week – it is all broken down, there is one for bills only .... and it's the planning – like if I'm not working next year I'll have to do the bills differently – I don't like being caught off guard, it's really unsettling, and there's a section for concepts and one of these is for writing songs, and for art, I want to do some art....*

In this extract Barry describes planning for the day and week ahead. He also anticipates changes to be made in the future, and keeps notes on pursuing new interests and managing changes. An ongoing commitment to organising the day into a logical sequence and to build in reminders for

what needs to be attended to in the future, enables participants to keep an eye on the big picture and structure the steps, so plans can be implemented both in the short and longer term.

Participants describe simplifying schedules over time, of which Barry gives a clear example.

*...and on the phone list I, I think I've got like 7 different things, ... because I had 12 there at one time, and then I realised it wasn't working, it's too many ... so I simplified things and it works best for me...*

As described earlier in this chapter participants learned to anticipate when occupational difficulties were likely to occur and adjusted their routines accordingly. This ability to keep an eye on the big picture, as well as planning the steps for current and future occupations, required consistent planning.

*I am getting up early –because of the job I'm getting up quite early about 6:30 which isn't a good thing — I need that energy- I need the sleep but [by] getting up early I can prepare...*

This extract from Barry, describes the importance of planning. Barry was careful to dedicate sufficient time so he could continue his planning processes, after he increased his employment hours, three years post mTBI. He went on to describe that there was no other “down” time in his routine, when he had sufficient energy for the complex task of planning hence he rose early, sacrificing some precious rest time. Perhaps by reframing this “sacrifice” of rest time, as part of the process for increasing work hours, the hidden aspects of increasing hours of employment, may be more fully appreciated.

Capacity difficulties were also apparent, when processing complex verbal communication.

## **Managing Persistent Communication Difficulties, Post mTBI.**

Participants described having persisting word finding difficulties and stumbling over words, which interfered with the communication flow.

*...but I still lose my way a bit. I can't find words – can't think what to call it. You just had to talk around it – come back another way, forget about what I was going to say there, otherwise I'd get stuck on thinking for the word.*

Earlier in the interview Robin stated he was taught by an occupational therapist, in the early stages of his recovery, to stop trying to search for words he couldn't retrieve in a timely manner. He credits this advice with never giving up on continuing conversations and expressing his ideas with others.

Some participants found that a slower cognitive processing speed, interfered with joining in conversations with three or more people.



*I am usually a listener when there are three people. I kind of feel left out – I like to put my opinion forward – I think about saying something but by the time that you do they are onto a different subject, so it's not relevant any more ....*

In this extract Bonnie demonstrates the social implications of feeling left out, when unable to join in casual conversations.

Many social occasions occur in conjunction with food. Contributing to both cooking and conversation, remained difficult for participants over time.

*I'm the cook in the family. I have always been. Like when we entertain, it's usually me. I just can't do it anymore – even when the family is here. If the family comes for dinner, and I've stuck a roast in the oven, it's pretty easy to do – and they are all here and I'm trying to make a gravy, and they are all talking, I'm done for three days [with fatigue] .... but because I haven't been giving myself the luxury of those recoveries – now I'll just go outside, with just the children maybe. The expectations with adults is different – conversation, paying attention, listening, probably going oh god, do you have to go over that, why can't you just get on with it ... kids are great – but it's a bit of a lonely place to stave it [fatigue] off –*

In this instance, Gerald eliminated the role of cook, and scheduled regular breaks from the adult conversations, tolerating feelings of being left out, to eliminate a fatigue backlash, requiring a recovery period of several days. Gerald found that taking breaks outside with the children was less taxing than sustaining complex adult conversations, where he suspected he had to put more effort into the interpretation.

Some participants learned over time that they missed hearing and processing vital pieces of information. This interfered with effective communication, and triggered an unwanted chain of events.

*...I have basically completely given up on the idea of ever being in a more in a kind of management position. I struggle with staff management and I feel it would not be fair on the people I am trying to manage. I miss cues and things thing and me being very aware that I then get frustrated and have a temper - and I don't want to - if you end up with adversity or anything, it then stuffs up your working relationship with other people....*

Caroline, after her second attempt at managing staff post mTBI, decided that she no longer had the capacity to communicate effectively, when she was under pressure, and relinquished occupations with managerial responsibilities. This extract demonstrates the career and presumably financial implications, that persisting communication difficulties can have post mTBI.

In contrast to other participants, Nigel received rehabilitation over 18 months for his communication difficulties preventing him from chairing meetings, delivering public lectures and conducting counselling sessions. The strategies he deployed, are described in the following three extracts.

Part of the process involved the development of planning skills.

*I can more deliberately go in thinking, what is the outcome here. What is the good outcome, what is the worst outcome? And if it's not going to go as well as it can, how can I get it going as well as I can actually manage in this meeting, so we can end in a way that we can all at least be positive about the way forward.*

Another part was practicing each component that was necessary for effective communication.

*... we spoke about verbal cues to help other people to give me more time to frame the question ... and practising, practising speaking, lots of tongue twisters. A bit of a verbal tic developed, it wasn't a stammer, it was a stumbling over words that I had not really had before. So, I would get about 20 tongue twisters a week that I would have to practise, and she [speech language therapist] would come and we'd laugh at how awful they were, and we would talk about how I was communicating, and practise strategies for hearing what people were saying, processing that and then responding, ... the stuff I had done pre injury without a thought, at that point became an actual exercise that I had to practise and now I'm back, to where I don't really think about it....*

Finally developing strategies to get the conversation back on track, were developed. This included controlling anxiety, interjecting with clarifying comments, and reducing the amount of data that needed to be processed at one time.

*....and if there is frustration- acknowledge it, then it is deep breathes, didn't mean for it to come out like that – sorry – lets go back and actually see what I wanted to say – and its often when I'm trying to do two things at once, like trying to do something on the computer and talk to him at the same time – much better to close the computer down and concentrate on the communication ...*

The other point of difference in Nigel's rehabilitation experience, compared with the other participants, was the ability to co-ordinate his return to work, in a stepped approach to compliment the skill development. Previously in the interview, Nigel explained that he had one occupational therapist coordinating all aspects of the rehabilitation, without a division between home and work roles. This collaborative approach required a willing employer, and good co-operation between health professionals, ACC case manager, family and colleagues. Nigel was one of two participants who were able to sustain full time employment, in the same job they had prior to the mTBI.

*... my employer was amazing – there was no pressure on me to return to work – they worked fully with ACC, and then it was two hours a week and then slowly, slowly build up and sometimes I had to pull hours back. Working for two hours a week was incredibly frustrating – it didn't feel useful – and I wasn't useful – except in my recovery – there again it was a small step, towards getting back....*

Nigel's initial period in the workplace was not productive, however this allowed him to identify the skills he needed to redevelop over time, which is demonstrated in the next extract.

*...and meetings with people I'd keep them really focused. Looking back on it – in terms of useful conversation - too focused – I couldn't deal with - and didn't have the capacity to deal with lots of side issues so it was, "right we are here to talk about this specific set of issues – we have to think about just this set of issues – and if people started wandering off I said it's..." - because normal conversation you deal with anything and everything and still steer a pathway through – my capacity for that was really limited at first.*

In contrast to Nigel, Caroline was not able to identify the specific difficulties she was facing in the work place, five years post mTBI, when she made a further attempt to sustain employment with managerial responsibilities.

*...because it was so demanding I'd lose the flexibility – the flexibility of thought – and I'd forget stuff – that's one thing they said as well – because I was working 12 days on and two days off, and we have noticed that we have to manage you a bit differently depending if it is the first week or the second week – you tend to forget things and it's yes I believe you - but I don't actually know I am forgetting them - that is the nature of having brain injury – it like there are just some things you cannot see because it is not your toe that is damaged – the hurt is inside your computer that you are using to see what you know...*

Unlike Nigel, Caroline did not have an opportunity to pinpoint where the occupational breakdown occurred, or to experiment with strategies that may have enabled her to work around the fatigue, memory and cognitive flexibility issues she was facing. Thus the redevelopment of complex communication skills, and her post mTBI ability to manage staff remained elusive, when she was working long hours in a pressured environment.

Participants described that new learning and managing unexpected difficulties remained effortful post mTBI.

## **Managing New Learning After a mTBI**

Participants described scheduling a bit of down time following periods of new learning, months and years after their mTBI, as described in chapter six. Occupational changes involving large

amounts of new learning, such as changing work environments or adjusting to new contracts, necessitated careful planning, and falling back on previous strategies to manage fatigue and anxiety. An example how a range of strategies were deployed is provided by Barry, who both changed to a new school environment and increased his hours of paid employment, four years post mTBI.

Prior to the following extract, Barry explained negotiating with his family to support him increasing his hours at work. Next he prepared his employers and made prior arrangements to cut back hours of work if he needed to.

*I told them from the word go what had happened to me, how it has affected me and also if they were prepared to take someone on like myself, ... let me give this a go and all of that, and if I find it is too much I'll let you know, and I'll pull back, .... so they were understanding.*

Next he scheduled additional rest times, and put effort into learning the new systems, controlling his frustration, when the schedules he had been given unexpectedly changed.

*For the long hours, it was all about sleep ... and the second bit was learning the system, and I had to write that down, because sometimes they would chop and change. But in my mind, I didn't like it when they chopped and changed, ... so then learning to be flexible was one, and having a good laugh, a good smile about that...*

Finally, ongoing effort was needed to commit a basic plan to memory. Sequencing the steps in the right order required consistent practise, as did putting mistakes into perspective, and moving on to planning for the next day, rather than dwelling on the mistakes that were made.

*...remembering things as well, trying not to rely off the writing – so that was another stage – trying to memorise stuff and all that. But at the same time I still needed a back-up – so on the days I wasn't thinking well, well umm – and I'd get it wrong, I'd go to the wrong classroom, not once or twice – at different times and ...sometimes those things were getting the better of me, and those were the early stages, and then I'm going, 'I'm doubting myself'. But the other thing was to push on, plan, prepare.*

In contrast to Barry, Gerald's planning skills were less developed. To compensate for these difficulties, Gerald simplified processes so he could make a start on a new project. In the following extract, he describes putting some money aside for his project rather than trying to work out a budget.

*...its crazy, I was trying to work out what the percent what the repayments were going to be ... I just couldn't do it .... [So], we had a bit of money in our account – and I thought to myself, if I spent it all I wouldn't be any better or worse off.*

Congruent to Gerald's planning difficulties, he failed to consider the storage implications of his purchases, when they reached New Zealand. His probable executive functioning difficulties were conveyed in the chaotic description of his planning processes, a small portion which is replicated here.

*...so I had to hire a garage thing — and a storage thing — which this whole week I have known, - I've moved out enough stuff - it's like a double garage — and it costs \$800 a week, no, a month, and I can now make do. But I just haven't been able to make those decisions — it's really, really hard - see the woman actually phoned me and said 'Do you want to move as someone else wants that?', — and I said 'OK let's just do it' — but how do I move with a hernia — carrying all this stuff. — But ummm, she came back to me, and said the guy has decided he doesn't want it now so, and so those decisions are really hard — but it is all learning and it's exciting for me — but it does take a lot of my energy.*

Eventually, however Gerald developed two plausible ideas, for solving his storage difficulties. Furthermore, persevering with making a decision, prompted him to consider more sophisticated strategies to assist with problem solving, which prior to engaging in the project were too difficult for him to consider.

*...the old jamming of ideas and thoughts — like this whole thing of should I give up the garage or not— I've felt the need to sit down and write something down...*

In contrast to the above examples of deploying coping strategies to support new learning, Caroline shares an experience of exceeding her capabilities, when taking on a new job five years post mTBI.

*I was living in an area that I wasn't very familiar with — I was living on my own as well and — I ended up burning myself out ... and when I came over here [to new accommodation] I said I am defiantly going to have a month off - just to recover. I had to go back to some of the coping mechanisms from way back — have a snooze every afternoon...and to make sure I do eat — fuel your brain, it almost seems like my brain needs more fuel now than it used to need. I get real major migraine problems when I get [exhausted], so make sure I get a good nights' sleep and I'm getting those without medication —But overall I'm taking it a lot easier — I'm a lot easier on myself ...*

By drawing on previous learning, Caroline organised a month's leave to recuperate and re-establish good routines to look after herself. She successfully reduced the recovery time, when she had a repertoire of effective coping skills to draw on, compared with her first experience of burnout, post mTBI. However, in contrast to Barry, whose extended period of counselling, taught him to anticipate the likely difficulties he would face, and what he could do to solve these capacity difficulties, this level of understanding was not apparent in Caroline analysis, of her post mTBI difficulties.

In the following extract, Nigel described how he had to make deliberate changes in his planning style so he could mitigate the difficulties he had sequencing complex steps, as a conversation was evolving.

*I actually think the process of recovery has helped me to be more deliberate in all of these things [planning]. My boss who has known me for 20 years said I was a destination person, rather than a convoy person. I'm very clear about where I want to go, and if a couple of people fall off the convoy as we go ... it might not be something you are happy about, but it happens. The process of recovery from the injury has helped me to see the good and the bad about that, so if you do not get to where you want to in a conversation – it is not the end of the world, there is stuff to learn in the process as well. ... I have to do it differently – or acknowledge that I have to think about how to do it, rather than do it instinctively.*

Nigel describes needing to adopt a new style, so he could continue facilitating meetings effectively. He needed to spend more time reflecting on the process so he could work out a way to channel the discussions towards an outcome. He learned to take advantage of knowledge gained by consciously analysing the meeting dynamics, to improve the quality of his facilitation skills. Maintaining the changes in his communication style, required overriding his “instinct” to engage his pre-injury style, which was presumably perfected in the twenty years prior to his mTBI. This was achieved by thinking about what he needed to do differently and planning how this would be done.

Eight years post mTBI, Nigel provides an example of taking cues from his wife that he needed to deploy his well-rehearsed strategies, in this instance to organise speech so it can be understood.

*Still now when I am tired, when I am fatigued, I do have to think around what I am saying. Particularly at home, my wife notices it more than anyone.... I noticed this week with the house sale, and a number of other complex things, and I've communicated with her on a couple occasions, and she has said, 'I'm not entirely sure what you have been saying' – and I say 'neither am I; let's start again' – so it's a deep breath...*

The cue from his wife also acted as a prompt for Nigel to consider environmental factors and overall fatigue levels, contributing to the breakdown in communication. By adding a “big picture” understanding as to why he was having specific communication difficulties, it becomes possible to anticipate further difficulties and to evaluate if additional strategies need to be deployed, for example to manage fatigue utilising strategies outlined in section one, chapter six.

Participants also came to recognise that not all capacity difficulties are mTBI related. How this occurred and why this was deemed important will be discussed in the last section of this chapter.

## Differentiating Between mTBI and “Normal” Challenges of Everyday Life

Another strategy in making the transition between accepting persistent changes and pushing oneself to improve capacity, was differentiating between challenges pertaining to the mTBI, and difficulties occurring as part of everyday life.

*... this week I have a new contract, and all of the calculations, that we are required to do, aren't defined ....so little old me, struggling with everything else has to figure out what the hell these guys in national office actually meant. I've actually found that quite difficult, and it has taken me a bit longer as I get a bit tired and I try it this way – no this way, and it takes me a little bit longer to problem solve. But then everything is new — this is all new ground and it's like I have to stop and go ... if I gave this to Sam could he do it? The answer is of course he couldn't - if I gave this to Martin could he do it? He might be able to write a good report that looks right, but would be completely wrong because he doesn't understand what this is actually about. I have to remember to cut myself a bit of slack sometimes too — part of it is taking a breath and going actually, we are the first people in the country doing this – cut yourself a break.*

In this extract, Leigh provides an example on how she compared her own performance with those of her colleagues, when reporting processes in her office changed. Following this appraisal, Leigh describes taking the pressure off herself, after recognising that working with the new contracts was hard work for everybody in the office. This appeared to be an important part of learning to accept post mTBI limitations without striving all the time to work that bit harder, which presumably makes it difficult to relax.

In contrast to Leigh, who compared her skill levels with others, Nigel compared his social circumstances with his peers, also reaching the conclusion that some occupations are intrinsically difficult, regardless of an mTBI.

*I was 38 at injury – looking at friends now who are in their mid 30's - late 30's they are facing similar issues without an injury – I can't have loads of late nights like when I was 20 – like do you want to (laughter). No one can because what you are carrying as a 38-year-old is kids, a house, more responsibility and less resources to throw at a stupid schedule so acknowledging that not everything that was difficult was about the injury – taking a wider broader perspective is really helpful.*

Following a comparison with his peers, Nigel concluded that not all fatigue and processing difficulties are associated with the mTBI. Together the extracts from Nigel and Leigh suggest that reaching this understanding, provided an impetus to appraise their participation in every day occupations differently and paradoxically make it easier to problem solve. To use this comparison strategy, participants required a reasonably sophisticated ability to analyse occupational performance difficulties and determine why specific tasks remain difficult.

## **Summary**

In summary, living well with persistent difficulties post mTBI, required a focus on overcoming complex occupational performance difficulties. Some participants were able to improve reading, writing and verbal processing skills, with consistent practise over several months. Others persevered with finding new ways to perform complex sequences, adjusting for a slower processing speed and for processing less information at one time. This included learning to slow down occupational sequences, breaking complex occupations into pieces, and using pictures and photographs to reduce the amount of written information that needed processing. Learning to anticipate when errors were likely to occur and deploying strategies to mitigate the difficulties, improved the quality of the participation, which resulted in less occupations being relinquished from their usual repertoire. Recognising that not all new learning was difficult due to the mTBI, resulted in some participants relaxing and allowing themselves more time to problem solve.

Chapter eight situates the research findings within the literature and discuss the implications of the finding for practise and future research. The strengths and weaknesses of the research are also outlined.



## **Chapter 8 - Discussion**

This small-scale qualitative descriptive study was designed to answer the question “What strategies do people with persistent symptoms post mTBI use to manage everyday occupations?” This study had three purposes. First, to fill a gap in the literature and document specific strategies that people who do not make a full recovery from a mTBI use to manage their participation in everyday occupations. Second, to examine any patterns in the strategies adopted, which might indicate that the strategies used by this small sample of participants may benefit other clients to participate more fully in their everyday routines. Third, to determine if an occupational perspective could offer new insights and fruitful suggestions for further research. What emerged was a nuanced account of developing strategies in direct response to unresolved mTBI symptomology experienced as the participants endeavoured to resume participation in previously familiar domestic, community, and work related occupations.

Chapter eight is presented in eight sections. First the research findings are considered in relation to the literature pertaining to the early sequelae post mTBI. Next a synopsis of the strategies deployed to mitigate the early symptoms that persist for more than a week after mTBI are presented. Third a synopsis of the strategies emerging in the later stages of the recovery are presented. Fourth the research findings are considered in relation to the literature pertaining to symptoms persisting more than three months post mTBI. In section five, the implications for practice are presented, followed by the implications for further research. The seventh section outlines the strengths and weakness of the research and lastly a conclusion of the thesis is presented.

### **Situating Findings Within the Literature on the Early Sequelae Post mTBI**

While the early mTBI sequelae experienced by participants were not the intended focus of this study, the interplay of symptoms and occupational performance emerged as an important aspect of the findings, providing the context to the strategies they deployed and the relative success of those strategies. The sequelae participants reported were consistent with the literature pertaining to mTBI, as discussed by (Bigler, 2008), suggesting that, at least in terms of their medical status, the participants were representative of people who experience ongoing effects of a mTBI. Specifically, alterations in cognitive and emotional processing capacities, together with physical symptoms of headaches, dizziness, vertigo and increased fatigability, disrupted the participants’ occupational patterns and interfered with planning and problem solving. Each person had a unique mix of strategies which they applied to improve occupational performance post mTBI. This aligns with Alla et al., (2012), individualised approach to recovery,

whereby the different mechanisms and severity of injuries underpinning a mTBI, and the wide range of pre, peri and post injury biopsychosocial factors impacting on recovery, need to be considered.

The participants had all expected to make a full recovery within a few of weeks of injury, following a medical assessment at the time of their injury and advice from the treating doctor. Despite that reassurance, changed tolerances to various types of movements and occupations were reported. In addition, all participants described early experiences of disabling fatigue and an exacerbation of acute symptoms with strong stress responses, with dizziness and nausea for some, when attempting to resume their everyday routines. Despite this, participants placed a high value on maintaining paid employment and related how considerable effort was channelled into returning to their everyday occupations as quickly as possible.

A period of despondency and/or depression, was experienced *after* repeated failure to achieve usual routines in a timely manner. This behavioural pattern contrasts with Silverberg and Iverson, (2013), who suggested that rest, physical inactivity, and avoidance behaviours, may limit mastery opportunities, and contribute to the cognitive distortions and misattributions that prolong recovery. Thus, in my study, the limited opportunity for mastery was reported as occurring as the result of disabling fatigue after pushing oneself to “get back to normal” as quickly as possible. As described in chapter four, no participants were functioning in their pre-injury employment with the same hours at the same level of productivity and satisfaction, within the first year of their injury.

Congruent with longitudinal studies (Andersson et al., 2011; King & Kirwilliam, 2013), the symptom profile remaining at two to three weeks post mTBI persisted months and years after the mTBI. Although depression and anxiety complicated the recovery process, persistent mTBI symptoms remained, after these mood disorders resolved.

Participants reported both cognitive and motor impairments impacting on occupational performance, separately from anxiety and despondency/depression. The many acute difficulties with occupational functioning participants described were congruent with impairments in information processing speed, attention, working memory and executive functioning, which commonly occur post brain injury, and are explained in the various cognitive coping models (Ponsford et al., 2014). Participants recalled difficulties in managing time pressures, prospectively sequencing occupations in a logical order, simultaneously processing multiple pieces of information and engaging in complex communication. These difficulties were more pronounced in work environments and when executing complex hobbies. Furthermore, the need for constant mental effort to perform to pre-injury standards, was exacerbated by

cognitive fatigue and distress. Deploying effective coping skills in the early stages of recovery was further complicated by cognitive deficits, with participants relating how confusing it was trying to work out what to do when they could not work out what the problem was that needed to be solved.

In addition, sequencing was experienced as weird, as if the routine occupation was being completed for the first time. Descriptions of having to “recalibrate” each skilled pattern of movements, so the motor requirements matched the executive plan, were reported by many of the participants. There is growing evidence of difficulties post mTBI with integrating motor, cognitive and sensory data. For example, Sosnoff et al., (2008) demonstrated correlations between postural control deficits and deficits in neuropsychological functioning 24 hours post mTBI, which were not present in the athletes in their sample before the sport injury. Speculations were made that a shared neural process such as visuospatial attention is damaged, resulting in deficits in concurrent cognitive and motor functioning. Furthermore, Heitger et al., (2009) demonstrated errors in multiple motor systems which remained impaired 12 months post mTBI, differentiating the cohort who did not make a timely recovery post injury from those who recovered quickly. These oculomotor and upper limb tracking errors remained when motivation and depression were accounted for, and correlated with self-reported difficulties performing everyday occupations. The authors were not able to say if this correlation was causal, given the subtle nature of the motor impairments.

Finally Bottari, Gosselin, Chen and Ptito, (2015) compared 3 participants with persistent symptoms 3-4 months post injury with 12 healthy controls. Results from a variety of tests were compared which included; a battery of neuropsychological tests sensitive to mTBI, functional magnetic resonance imaging (fMRI), a visual externally ordered working memory task combined to event-related potentials (ERP), the Instrumental Activities of Daily Living Assessment (IADL), post concussion questionnaires and participant profiles. Results suggested that reduced independence in complex everyday activities (budgeting), may be explained, at least partially, by decreased brain activation in the prefrontal cortex, abnormal ERP, or slower reaction times on working memory tasks.

The type of errors identified by participants in my study, which prevented them from successfully completing complex occupational sequences, suggest that factors other than cognitive distortions and misattributions about the seriousness of the mTBI may be operating. However, systematic investigations into the nature of persisting symptoms with adequate numbers of participants have not been completed. The neuroanatomical model for persistent symptoms remains controversial, as discussed in chapter two.

## **Strategies Deployed in the Early Stages of Recovery**

Strategies utilised in the early stages in recovery are presented in three categories. The first are the strategies deployed to take off the load and reverse the pattern of exacerbating acute symptoms. Second is relearning how to do things, which depicts the difficulties participants experienced when they first attempted to perform occupational sequences that had been routine performances prior to their mTBI. Third are the compensation strategies which made it easier to function while acute symptoms were resolving.

### **Taking off the load**

The sequencing of strategies deployed by participants in the early stages of recovery overlapped with advice from health professionals. This suggests the uptake and utility of sequencing strategies to reduce cognitive and sensory overload, and resolve acute vestibular impairments before moving onto strategies to compensate for cognitive and executive functioning difficulties.

In a nutshell, reversing the pattern of exacerbating acute symptoms was achieved by inserting rest periods and slowing down the tempo of daily patterns. Non-essential occupations were removed and others were performed as simply as possible, such as having sandwiches for dinner rather than cooking a hot dinner. Environments which were loud, bright and visually “busy” were generally avoided. Essential conversations were reduced to simple sentences, and, as much as possible communication was limited to one person at a time. Work expectations were reduced, most often by halving the number of hours that were usually worked, and when that was not sustainable, sick leave or voluntary resignation followed.

Taking off the load and reconfiguring sustainable routines was seldom achieved within the first few weeks, after the mTBI. First, participants were not able to recognise that they weren’t making the expected progress and initially thought they just needed to keep up with normal activity while things righted themselves. Secondly, impaired capabilities prevented “sensible” decision making. For example, participants whose spouses took over the running of the household, cared for the children, arranged medical appointments and reorganised diaries, commented that they did not realise the extent of their impaired functioning. Similarly, participants living alone, those with dependent children, and those without support to sort out employment issues, stated that initially they couldn’t think of even simple solutions to make things easier. Deciding what to make for dinner was too hard. Thirdly, those without a supportive partner needed to continue a larger number of household management and

childcare responsibilities, and it took longer to make arrangements for these tasks to be allocated, and to achieve a suitable work/home balance.

The fourth delay occurred with those who were determined to keep working and resisted early advice to slow down and rest, despite impaired functioning. Hearing repeated advice from multiple sources (family, friends, health professionals and employers), helped break down the resistance. Presenting advice in short simple sentences, or in the form of a metaphor, *after* a rest period, was easier to absorb, demonstrating both the extent of cognitive impairments in addition to the strongly held work ethics and/or beliefs about not giving in to an illness. Lastly, referral for ACC funded rehabilitation set in action a flurry of assessments (concussion clinic, driving, return to work, fitness training, assessment of vestibular/ocular motor functioning, workers' compensation), which for some triggered an exacerbation of acute symptoms and further delayed achieving a work/rest balance. It was also impossible to commit to the recommended home programmes, generated from each different assessor.

Avoiding triggering an explosive resurgence of symptoms and stress responses was a powerful motivator for participants to continue using strategies to balance rest with activity. With clearer thinking, fewer disabling fatigue headaches, and descriptions of "feeling more like their own self," participants set about redeveloping occupational routines.

### **Relearning how to do things**

As mentioned earlier, participants explained that the first time they attempted routine occupational sequences post mTBI, it was difficult to match the executive plan with the required motor responses, and extremely tiring. With practice, these routines quickly became easier to perform. Strategies to enhance this relearning process included finding small projects to complete at home or in supportive work environments. Recalling the steps that were used when complex skills were first learned, helped rebuild mastery. Paying attention to where the task was breaking supported learning on how to accommodate acute changes in capacity. Stress management strategies, especially breathing exercises, helped reduce frustration at not being able to do things that used to be so easy. A guided exercise programme to facilitate accommodation within the ocular/motor and vestibular systems was reported as helpful, especially for those with dizziness and nausea. Experimenting with small incremental steps, in non-pressured environments was more successful than pushing through difficulties, and perpetuating a 'vicious cycle' of disabling fatigue, explosive angry outbursts and self-recriminations.

Most participants appreciated suggestions from health professionals to ‘try this and that’, perhaps suggesting that generating ideas on *how* to do things differently was more important than formally learning problem solving processes. Occupational therapy support to negotiate work place changes was reported as beneficial for three reasons. First, it was difficult for participants to explain mTBI complications. Second, executing complex discussions fluently in the early stages of recovery was stressful, and third there were fears of being judged as trying to get out of work.

### **Making it easier**

To make it easier to focus attention, participants made changes to their environments to reduce the intensity of bothersome sensory stimulation. Indoor prescription sunglasses and outdoor sunglasses were worn to filter out bright light. Furniture was rearranged to avoid bright sunlight and banks of florescent lights. Computer settings were adjusted to reduce screen brightness/glare and page up and down buttons replaced scroll features to avoid provoking dizziness and nausea.

Working in quiet environments *without* interruptions, supported sustained attention. Wearing headphones to reduce distraction from background noise and as a visual signal not to be interrupted was effective, as was taking work to an empty home to complete. Those unable to escape noisy environments organised frequent short breaks into a quiet environment, and sought opportunities to take on new work tasks away from the noise. Flexibility to change environments as required was preferred, with managers finding this easier to organise than employees.

Instructing others in the work environment to change their behaviours was the least preferred strategy, but sometimes needed so the synchronisation of shared tasks could accommodate post mTBI changes in processing capabilities. Reinforcing agreed changes sometimes required assertive follow-up, which was stressful to deploy if there was a propensity of becoming tearful or explode angrily and/or difficulties in attending to and generating complex speech. In contrast, colleagues who recognised the post mTBI changes in functioning (i.e., pallor, slurred speech and planning difficulties, which escalated with fatigue), were often a rich resource for adjusting work environments and supporting recovery.

Keeping pace with time pressures, sequencing complex tasks in the right order, and simultaneously juggling several tasks or pieces of information, were problematic post mTBI. Schedules were reported as a useful way of locking into place a logical set of steps to achieve the goals for the day. More detailed plans were made for sequencing steps for complex

occupations. Paper diaries, notebooks and/or smartphones were carried to keep track of sequences and for remembering problems that needed to be addressed later on during the day. Tasks were crossed off after they were completed, providing a simple way to keep track of what had been achieved and what still needed attention. Additional auditory reminders such as an alarm on the smart phone assisted with transitioning to new occupations at the correct time, as did asking others to make a timely reminder.

New routines were developed to take off the cognitive load and reduce the frequency of explosive angry outbursts. For example, house work was spread through the week; family were trained not to interrupt while completing office work and children were instructed to complete chores/homework immediately, rather than putting tasks off, therefore preventing the need for a further reminder. More time was allocated for preparing and executing routine tasks, and transitions such as setting off to sports practises were carefully planned. Visual cues were used as efficient reminders to compensate for difficulties in working memory. For example, placing all the family's sports clothes on a chair in full view was a salient reminder for sports practises and preparation routines, as was leaving the glue on the table as a reminder to finish a repair after an interruption.

Not all changes to routines were to compensate for reduced working memory and a need to work at a slower tempo. Putting effort into avoiding potential conflict situations, such as arriving late for an appointment, sometimes became a priority. Some participants were not fully aware of how elaborate their planning had become to avoid situations where they could be negatively judged. Unpicking these responses (with participants who were willing to do so), identified avoidance of a stress response, fear of being judged negatively *and* a lack of ability to deploy the complex communication skills needed for conflict resolution.

The final set of strategies deployed in the acute phase of recovery were designed to compensate for the post mTBI communication difficulties. In the early stages of recovery participants stopped answering the telephone, instructed others to text not phone, and prepared short statements which were not cognitively demanding but made a gesture to be sociable. Others participated in conversations for short periods of time, interspersed with taking time out in a quiet room, going for a short walk or sitting in the car, if they were away from home. Some partnered up with others so their communication partner could do most of the talking and help to navigate around any obstacles. Learning to talk around the subject rather than becoming stuck trying to find the "right" word, supported persisting with conversation. Others explained becoming a listener in group situations, as they could not generate a timely contribution to the conversation before the next topic was introduced.

Managing everyday conflict situations was problematic. Participants described being ashamed and angry with themselves for not controlling their emotions. For some it was as if the filters had been turned off, and they couldn't modify their "primitive" impulsive response. Others explained changes in emotional sensitivities, such as a heightened sense of justice, a lack of empathy for others, increased sensitivity to others' opinions, and/or a lowered threshold for becoming tearful. Without a repertoire of well-rehearsed strategies designed for managing these difficulties, participants reported not knowing what to do. Recognising early warning signs of becoming angry and exiting the situation was the default coping strategy in the early recovery period, as was apologising for socially inappropriate behaviour. Relinquishing occupations with the potential for conflict, or delegating the conflict resolution components of leadership roles, frequently occurred. For delegation to be successful, clear expectations needed to be formulated, which were not always well thought out. Keeping mistakes and failures in perspective was a skill some participants had to relearn. Adding humour was described as a good way to change the intensity of the emotion.

Despite taking off the load and deploying strategies to compensate for altered capacities, restoration of usual occupational routines was not established. This is compatible with the study by Andersson et al., (2007), who demonstrated that the intervention group receiving early education, advice on compensation strategies and support to return to usual activities including work, did not benefit from this support. A small percentage from both the control group and the active intervention group continued to have persisting problems.

The next group of strategies were deployed in the later stages of recovery, when participants were struggling to resume their usual routines.

## **Strategies Deployed in the Later Stages of the Recovery Process**

Unlike the early phase of recovery, there was no consistency in rehabilitation input or uptake of strategies in the later stages of recovery. Targeted input to address the difficult components of occupations, together with a collaborative approach to decrease the impact of persistent symptoms on life roles, occurred for some. Others developed new coping strategies when they exited formal rehabilitation services, and were functioning with less pressure, with opportunities for experimentation. Family, friends and colleagues provided vital support for reconstructing life roles. A united team working together collaboratively was valued by participants.



Most return-to-work programmes did not support mastering the complex components of paid employment. Participants reported an emphasis on fatigue management and ‘getting enough rest’ to support the healing of the brain, and ‘restoring’ energy levels. No participants involved in ACC funded dedicated return-to-work programmes achieved their return to work goals, citing difficulties managing fatigue and simultaneously performing complex sequences to the expected standard.

Broadly consistent with the literature, participants reported difficulties managing altered energy levels, changes in emotional regulation and capacity changes for processing information. This trifecta has therefore been utilised for categorising the strategies deployed in the later stages of the recovery process.

### **Managing alterations in energy levels**

Participants who experienced high levels of fatigue post mTBI, continued to experience an alteration in their energy levels months and years post mTBI. Most continued to experience changes in their sleep patterns. Over time most participants recognised that persisting fatigue had different qualities, and that rest was not always restorative. Furthermore, extended rest periods could interfere with getting on with life.

#### *Managing alterations in sleep routines*

All participants experienced altered sleep patterns after their mTBI. Some added a couple of extra hours to their night time sleep, while others found that a lunch time nap or rest was restorative. Some had their car windows tinted and found a suitable shady carpark, to enable rest periods during lunch breaks while at work. Sleep hygiene strategies assisted in re-establishing sleep patterns for others, as did learning to tolerate periods of insomnia without catastrophizing. Scheduling specific times during the week to catch up on sleep, if needed, worked well for some.

#### *Recognising and acting on cues to take a break*

Recognising and acting on cues for taking a break was often effective to prevent disabling fatigue and headaches. Dulled thinking, and tightness in a band across the forehead, often preceded a headache. Prevention included taking a short break, having a snack and something to drink and/or switching to less cognitively demanding occupations. Forcing oneself to complete an occupational routine while capacity was decreasing could trigger a “fatigue backlash,” described as several days of dulled thinking, headaches, and persistent fatigue.

### *Managing the different characteristics of fatigue*

Most participants explained learning to differentiate between different types of fatigue, and exploring different management strategies, with one participant labelling this process as learning to counteract one type of fatigue with another. Fatigue associated with emotional distress, characterised by distorted thinking including 'making mountains out of molehills' and ruminating over events without using active problem solving strategies, were the hardest to alleviate. Hard physical exercise, such as a hike of several hours, was successful for some to shift the emotional fatigue, leaving them feeling physically tired but better able to problem solve. In contrast, cognitive fatigue, characterised by dulled thinking and short lived explosive angry outbursts in response to relatively minor irritations, required a rest or a period of 'pottering around' to prevent an escalation of unwanted outcomes. Physical exhaustion or being 'over tired' was associated with being unable to switch off and relax, and could be remedied with a cognitive activity such as reading. Finally, participating in occupations with a physical load made the constant fatigue that some participants experienced easier to accept, knowing they had a reason to be tired. Thus, participants learned additional strategies to manage fatigue which did not require extended rest periods.

### *Boosting energy levels with tiring but stimulating occupations*

Successful participation in previously relinquished occupations, or achieving mastery in new challenging but not overwhelming occupations, had a positive effect on well-being, including the boosting of energy levels. A reoccurring pattern was reported, consisting of planning the difficult parts, organising assistance should the tasks prove too difficult, and scheduling an extended rest period before and after participation. Subsequent performances were accomplished with less preparation, with participants expressing surprise at how quickly they could eliminate the rest periods. Achieving one challenging task often became the catalyst for experimenting with achieving another task of similar complexity.

A comparison of one participant's descriptions of participating in an overwhelming hobby (photography), compared with a later successful leisure event (orienteering), suggested that the second activity was successful as it had far less finicky sequences that needed precise timing. In addition, tiring occupations associated with preparing for orientating were carefully managed and the "last minute" load reduced where possible. For example, new driving routes were rehearsed, the care of a pet dog had been pre-planned, and there was no pressure to attend work the next day. When the same participant discussed another attempt with photography, she had reduced her expectations and selected one aspect which she thought might be fun to start with, rather than committing to a complex group project. Others described scheduling

challenging occupations in the school holidays when there was no rush to keep schedules, and taking annual leave, or soliciting help from family and colleagues to temporarily take over some routine tasks to free up the time for new learning.

### *Changing occupational routines*

Associated with managing fatigue, a different configuration of occupational patterns was developed and became the new “ordinary”. Participants related how they began to ‘automatically’ alternate occupations with a high and low cognitive load, slow down the tempo of complex tasks (doing things in my own time), insert a rest period before cognitively challenging occupations, and select strategic times to relinquish lower priority occupations, so higher priority tasks could be successfully achieved. Thus, a new baseline for functioning was established, permitting reasonably accurate estimations to be made on how to maintain energy levels for effective functioning. This included choosing to persist with a high cognitive load, knowing a fatigue backlash would be triggered, with prior scheduling of a recuperation period, such as extra rest times and less activity for a few days.

Fatigue affected both work and home life, and it took time and energy to learn new skills. Triggering a fatigue backlash and continuing a boom bust cycle of coping, was ultimately unsustainable, with one participant requesting a copy of her sick leave record from the previous year, to try and determine better ways of coping. Her strategy of taking a lower skilled job for six months and building up her physical strength and endurance, improved her mood and well-being, but did not restore cognitive processes. Achieving a balance between self-care, productivity and leisure occupations contributed to a consistent level of productivity. Thus, return-to-work programmes with flexibility to both increase and decrease hours were valued by participants, as they learned to match the changes in energy levels with occupational demands, in the different environments they lived, worked and played in.

### **Achieving emotional regulation**

Emotional changes interfering with occupational performance occurred in different ways. First, anxiety was associated with capacity changes and subsequent inability to perform routine occupations skilfully and manage interpersonal relationships. Second, repeated failure contributed to periods of despondency and depression. Third, participants consistently related how they forgot to have fun. Furthermore, all participants reported that regulating energy levels had a positive effect on mood. Additional strategies deployed to manage changes in emotional regulation are described below.

### *Changes in capacity*

Changes in emotional functioning interrupted participation in normal occupational routines. Being tearful in situations which normally would not trigger tears, having less empathy for others, and demonstrating an uncharacteristic bluntness in communication style were experienced by some.

Responses to changes in capacity included expressions of anger and frustration, together with a sense that the once competent person 'had gone'. These changes became problematic when the participant was ashamed of these changes, didn't know what to do to solve occupational performance difficulties, and/or the changes interfered negatively with interpersonal relationships. Thus stumbling over words was less problematic for the grandfather talking to his grandchildren, compared with the community development worker who depended on excellent communication skills for counselling, chairing meetings and delivering public lectures. Failing in occupational roles in a work environment was deeply distressing to both participants, families and in some instances colleagues and employers.

Learning to view capacity changes as vulnerabilities (imposed by the mTBI), rather than as personal incompetence, enabled some participants to regard problem solving as a strength of character and thus deploy strategies without feeling guilty or ashamed. Broadening perspectives on learning to live well post mTBI, seemed to occur when participants could identify with others with impairments who shared the same environment. For example, the teacher aide showed his pupils how he needed to redevelop his writing skills, describing how they became 'kids together' to support each other improve their written skills, and another participant requested that a DJ announce the use of strobe lighting for the benefit of all people who were light sensitive. Other strategies were deployed to maintain social inclusion post mTBI. Such as, following requests to fellow students to stop chattering during lectures (to accommodate noise insensitivity), one participant started passing notes and funny pictures, demonstrating a quiet way to continue the usual social banter.

The benefits of diaphragmatic breathing and stopping catastrophic thought patterns were consistently outlined. Some used prayer, images of desirable role models, and utilised self-talk and metaphors with a moral message, to both interrupt sequences before the dysregulated response, and to improve tolerance of distress.

Recognising the antecedents to distressing experiences permitted participants to draw on 'internal wisdom' and past experiences to decide where in the sequence a coping strategy could be deployed. Taking the time to view things from others' perspective and learning to receive feedback without getting defensive, were important first steps in working collaboratively with

others to solve problems. Observing interpersonal interactions in an open plan office was useful for forming insights on how, and how not to, effectively solve problems.

When it wasn't possible to pinpoint breakdowns in occupational performance, participants requested feedback from people they trusted. This often required learning how to use probing questions to get the required level of detail. Knowing what feedback to trust was not straightforward, with some participants taking weeks and months to learn where an occupation was breaking down. Repeated practice deploying strategies in different environmental conditions, and when the participants were tired and irritable, was essential for reliable occupational performance. This was described by some as the hardest part of regaining skilled behaviour.

Managing the responses of others was an essential part of coping with changes in emotional regulation. Alerting key people of post mTBI difficulties, and organising assistance to manage the aftermath of dysregulated behaviours, was often helpful. For example, a teacher aide solicited the help of both classroom teachers and pupils to alert him when his uncharacteristic "blunt" responses were frightening his pupils. Another organised for a colleague to take over chairing meetings *before* he lost his way and became distressed. Others relinquished occupations requiring complex conflict resolution skills, such as staff management or investigating complaints, prioritising the maintenance of good relationships with others.

Emotional incontinence or the propensity for a tearful reaction, in situations that normally wouldn't provoke tears, remained persistent for some. Ignoring others' reactions to the tears was a useful strategy, as was deflecting attention away from the tearful response by redirecting the conversation back to the topic of interest, as if nothing had happened. The later strategy enabled participants to compose themselves as well as demonstrating to others, not to worry about the tears. At other times age-appropriate explanations were given. For example, one teacher explained to his young pupils, when they mentioned his tears, that he wasn't crying because he was sad, he was just really happy they had achieved good work. Finally, enlisting the support of others to provide a timely explanation or take over a planned occupation such as a speech at a family wedding, supported fuller participation in life roles.

### *Despondency, depression and seeing the way forward*

Repeated failure in achieving life roles had a powerful effect on mood, with some participants explaining how they lost the ability to see the way forward. Behavioural activation programmes were described as a powerful tool for regulating mood, providing persisting symptoms (fatigue and processing difficulties), and associated limitations such as driving restrictions were taken into consideration. For some, getting out of the house and resuming an exercise programme

was an excellent first step, while others found the gym environment overwhelming and unhelpful. Utilising resources within social networks to identify suitable occupations was often successful, as was selecting an occupation of high intrinsic interest and identifying one part to start with. Developing routines, which included getting out of the house, mixing with others, and engaging in meaningful occupations, was described as an essential part of plotting a way towards recovery.

All participants outlined the importance of attaining a balance between too much and too little, having time to do things at a comfortable pace, and simultaneously managing anxiety and fatigue. No participant described achieving mastery by pushing themselves harder to meet their own or outside agencies' expectations to increase productivity. Most participants, described making more progress when they stopped trying so hard and had time and/or support to experiment with different ways of achieving complex occupations. The one participant who sustained a work place accident continued to experience post traumatic anxiety, which resolved when he shifted to a different line of employment.

The later part of the recovery process was characterised by giving up the struggle to get back to "normal". The successful strategies developed to manage fatigue, changes in emotional expression, and processing complex sequences continued. When the new routines and ways of performing everyday occupations were consolidated, they became the new 'normal'. Novel ways to reconfigure and continue a meaningful lifestyle then emerged. For some, accepting part time employment, or work roles at lesser skill level, took off the pressure and supported a sense of well-being. Pinpointing the losses associated with the brain injury, and identifying why these had been important, provided a structure to discuss reconfiguring a more satisfying lifestyle. Others cited the practical help from family and friends, as vital for generating new ideas, and supporting new ventures.

Observing the types of problems affecting peers and colleague enabled several participants to re-establish a sense of 'normal' functioning. A recognition that not all problems are mTBI related, permitted some participants to 'cut themselves some slack' and give themselves time to grapple with problems without the additional strain of striving to remain productive.

Finally, recognising the benefits of progressing through a life changing process helped participants accept their current situation. A greater understanding and tolerance of the emotional and physical issues people face after a brain injury was identified. Participants enjoyed discussing how they used their new understandings to help out others post mTBI, when the opportunity arose.

### *Having fun*

At all stages of recovery, participants described the benefits of having fun and using humour to lighten the mood and put mistakes into a less devastating perspective. Fun occupations improved relationships, and made it easier for parents to supervise children when either party was tired and irritable. By engaging in stimulating interesting projects, some participants reported 'getting the old urge back' to deploy strategies, such as drawing diagrams to assist with planning complex projects, which in the months following the mTBI, were too hard to conceptualise how to use.

Preplanning spontaneity, was the description one mother gave to the process of remembering to schedule fun activities with her children. Small things, such as dropping one child at a sports practice, and taking the other down to the beach a few hundred metres away, was less stressful than sitting in a parked car with a young child waiting for a sport practice to finish. So was preparing a list of simple occupations ready to deploy in the weekend when the children were bored and fighting over the Lego. Participants often reflected on how slow they were recognising the importance of adding the fun element, and how much effort had to go into preplanning fun occupations. Some participants prioritised set times during the week to take time out for oneself, while others chose an aspect of an occupation such as meeting up with mates for the coffee after the swimming practice, to commence inserting pleasurable occupations into their routines.

In the later stages of recovery, several participants enthusiastically reported the benefits of reflecting on their talents and interests, and developing a talent or interest, such as music, art or sport, in a *new* way. This appeared important for two reasons. Firstly, the new interest could be configured *without* requiring to relearning how to do a familiar occupation differently, thus reinforcing the 'new' capable self. Secondly, by doing something new participants stopped comparing their occupational performance against how they did things in the past, thus shifting the emphasis away from 'getting better'.

### **Managing cognitive changes**

Processing written material was more difficult post mTBI and handwriting was reported as being messy and difficult to execute. Discreet perceptual difficulties such as being unable to estimate size when working on the computer, or getting stuck when trying to initiate an occupational sequence when they were holding something in each hand, persisted. However, it was occupations requiring complex visual attention and complex communication demands, and those occupations requiring speed and accuracy that prevented participants from resuming all

aspects of pre mTBI occupational functioning. For example, driving was a complex occupation which all participants resumed within a few months of the mTBI. However, difficulties remained, such as muddling right and left, an inability drive and talk to passengers with the radio on, and failing to recognise objects in the outer range of their peripheral vision. Furthermore, most participants reported incidents where they had to pull over to the side of the road or stop at intersections, to prevent driving unsafely. One participant relinquished paid work she enjoyed, citing safety concerns driving home after work, and others stopped driving to new places at night.

Two sets of strategies were deployed in the later stages of recovery to improve occupational performance. The first are the strategies deployed to increase the complexity of sequences that could be executed. The second group of strategies were used to compensate for the changes in capacity, making it easier to participate in complex occupations.

### *Improving processing capacity*

A stepped approach was consistently used to increase processing capacities to improve attention skills and complete complex sequences. Initially, quiet environments without interruptions were preferred when performing occupations for the first time post mTBI. Next, several participants described how they spontaneously started using music or background radio/television programmes to assist sustained attention on the occupation they were performing. This is in contrast to attention training exercises (Dundon et al., 2015; Sohlberg & Mateer, 1987), whereby clients are trained to remain focused on the task at hand, and at the same time ignore the background distractions.

In my study, each participant was specific with the type of background noise that was helpful and most thought applying this strategy was weird, curious as to why it might be helpful. For some it needed to be music they knew and enjoyed. For others, their appreciation of music was altered post mTBI and they preferred background chatter from the radio or TV, which prior to their injury was irritating. Although participants actively sought out their preferred background noise, over time they noticed they could, with effort, sustain concentration in challenging environments for short periods of time if required to do so. A novel study (n=10) detailed global changes in music listening, including modification of time consciousness which correlated with MRI anomalies post mTBI. Whilst I was not able to locate studies using background music post mTBI to address attention deficits, a small study (n=49) demonstrated improved attention scores ( $p<0.048$ ) with persons with schizophrenia when popular music was played in the background (Yi-Nuo, Chi-Sheng, Hsin-Yu, & Chien-Hsiou, 2015).



Encoding information in more than one way enhanced participants' ability to recall the necessary information at the correct time. For example, writing an appointment on a to do list for the day, and then thinking back and recalling when the appointment was first made, was sufficient for relevant data to be recalled prospectively. This eliminated the need for an additional auditory reminder to transition to the new occupation on time.

Relearning complex sequences was often completed in steps. For example, preparing a lecture, was initially broken into steps, with scheduled breaks between each step. Over time participants' described being able to complete more of the steps at one sitting. Tolerance for driving also increased in stages. Participants reported taking another driver on longer trips, so they could swap drivers when it became too difficult to concentrate, and building an understanding of their post mTBI capabilities. Writing and drawing skills, which remained laboured and messy two years post mTBI, improved significantly when a teacher aide practised these skills with his special needs pupils, *several times a day* during the school term.

Similarly, another participant credited the combined efforts of an occupational therapist, speech language therapist, and his colleagues, for supporting his goal of returning to full time employment. This participant recalled using tongue twisters to overcome hesitations in speech, and exercises to improve his listening skills. He learned to use clarifying questions to slow down the speed of the communication, and made use of regular summaries to check important facts were retained in counselling sessions. Colleagues assisted with supervision, providing feedback and helping out as necessary while skills were being generalised into real world situations. In contrast, most participants did not have access to this level of retraining and relinquished occupations, when attempts to engage in complex tasks or conversations were not successful.

### *Compensation strategies for altered processing capacities*

To compensate for slowed cognitive processing speed and maintain productivity at work, performances measures were scrutinised and unnecessary steps eliminated. Less effort was put into written presentations. Non-essential meetings were eliminated and individual appointments were merged into small group meetings when possible. Some participants took work home to complete and didn't change the company for this time, citing a need to remain competitive. Participants reported being quicker to ring for assistance from technology support services and became competitive in securing support that was on offer, such as assistance from trainees.

Basic reading and writing skills remained effortful for many. Written lists were hard to read in busy noisy environments such as the supermarket, as was searching for specific items on crowded shelves. One participant described that it was easier to walk the aisles and wait until

something ‘popped out’ that was easy to cook, rather than searching for preferred ingredients. Pictures and photographs were easier to process, and sometimes used instead of written lists and plans to convey information. Occupations requiring complex visual attention, such as data entry or drawing complex computer assisted engineering designs, were relinquished. Prospective memory continued to be impaired, with participants perfecting planning schedules and learning to ‘keep an eye on the future’ so important occupations such as crop rotations and planning for the next term’s employment contracts, were not missed.

Some participants learned how to interject and slow a conversation down so they had time to make a response, which improved their participation in social events. Others relinquished occupations requiring complex communication skills such as chairing meetings, managing staff, and socialising with large groups of people. One participant reported being unable to read other people’s emotional expressions and continue conversations in emotionally charged situations, thus preventing effective conflict resolution.

The accounts from participants relating how they adapted their occupational functioning suggests persistent changes in cognition and regulating emotions are influencing the post mTBI sequelae. There was evidence to suggest that targeting the complex sequences that remained difficult to perform, could improve occupational performance years after the index injury.

## **Summary**

In summary, the occupational focus on post mTBI sequelae, provides a clear description from participants on the strategies that are required to manage persistent symptoms. There was a relationship between capacity changes, fatigue, and the triggering of a stress response when routine occupations were unable to be executed, or were perceived as dangerous. Three phases to the recovery process were identified.

Phase one was characterised by taking off the cognitive load and reconfiguring simplified routines to meet essential self-care and productivity demands. The second phase required “recalibrating” the motor and cognitive components of problematic occupations, together with compensation strategies, so occupational routines could be reliably performed. The deployment of anxiety and fatigue management strategies supported increasing participation in occupational routines. The final phase of the successful development of occupational functioning was accepting the changes in the way occupations were performed and stopping the struggle to get better. Strategies which supported living well with a chronic health condition, together with observations of others struggling with everyday difficulties, assisted in reconfiguring satisfying everyday routines.

In the last part of this section, I will briefly situate the thesis findings into the models underpinning the rehabilitation interventions offered post mTBI.

## **Situating Findings Within the Literature on the Later Sequelae of mTBI**

### **Resuming usual occupations post mTBI**

All participants were medically assessed shortly after the mTBI, and most were advised to return to their usual activities within a few days of the mTBI. None reported receiving written information on early management of mTBI symptoms or details on when to seek further medical advice, which are mandated in practice guidelines, in New Zealand and other Western Countries (NZGG, 2007; Levin & Diaz-Arrastia, 2015).

Participants reported a period of confusion when they did not make the expected full recovery within a few weeks of their injury. Whilst Whittaker, Kemp, and House (2007) demonstrated that individuals who anticipated serious negative consequences one to three weeks post mTBI, were more likely to have persistent symptoms three months post mTBI, no research was found exploring outcomes of individuals who were expecting to make a timely recovery, but failed to do so. This distinction is important, as it was the pushing to return to normal routines as quickly as possible that was associated with participants' first experiences of powerful stress responses and, for some, a resurgence of acute symptoms.

In addition, it has been established that too little or too much exercise may be counter-productive to recovery post mTBI (Kreber & Griesbach, 2016), and that early intensive cognitive activity is associated with a longer recovery period (Brown et al., 2014). Participants demonstrated difficulties operating in the middle ground between too much and too little occupation. Pushing oneself to keep performing occupations when capacity was decreasing triggered stress, irritability and disabling fatigue.

Finally many aspects of strategy training protocols contained in the traditional models of cognitive rehabilitation (Cicerone et al., 2005; Cicerone et al., 2011; Park, Maitra, & Martinez, 2015; Sohlberg & Mateer, 1987) originally designed for moderate to serious brain injuries were deployed by participants. A closer look at the reviews of these models, suggest that specific interventions to develop attention, memory, executive functions and social communication skills, target 1) re-establishing previously learned behaviours, 2) establishing new patterns of behaviour, and 3) facilitating adaptation to persisting impairments to improve overall functioning and quality of life (Cornis-Pop et al., 2012). Although none of the participants participated in formal cognitive retraining programme, participants were able to recall how they first learned complex sequences and utilised these processes to redevelop skilled sequences.

Some participants engaged in intensive repetitive practise in skills designed to improve writing, drawing and produce fluent speech, compatible with training exercises designed to enhance neuroplasticity. Attention skills were developed in incremental stages, and compensation strategies adapted to compensate for difficulties with sequencing process over time, and residual working and prospective memory impairments. This finding suggests that cognitive rehabilitation models which target real life difficulties may have value as part of post mTBI rehabilitation, especially if they included strategies to manage social communication difficulties.

It was also apparent that participants generated their own cognitive strategies to facilitate successful participation in both novel and routine occupations. In an exploratory study Bottari, Shun, Le Dorze, Gosselin and Dawson (2014), demonstrated that people who used the largest number and a broad repertoire of strategies, were more successful in independently achieving complex goals, following a severe brain injury. In addition the participants in Bottari et als' study who scanned their environments and made use of physical and social resources achieved more complexity than originally planned, while attaining goal directed occuaptions. This finding is compatible with my research, which also suggested that participants who made use of their social and physical environments and generated multiple strategies, were able to increase the complexity and resume skilful occupations over time.

### **Resuming paid employment**

Not only were participants confronted with capacity changes they were not expecting, the advice from health professionals for a graduated return to work, did not facilitate the expected recovery. Whilst studies suggest that the vast majority of people with a mTBI return to work within two months of their injury (Cancelliere et al., 2014; Wäljas et al., 2014), no studies were located which measured work retention or retaining work with reduced hours of work and altered duties and responsibilities. It was completing complex occupations in the work place, together with an inability to sustain concentration that participants associated with decreased work performances. For example, one participant gave up staff management responsibilities as she couldn't retain sufficient information when she was fatigued and became irritable. She sustained a conventional 40 hour working week, albeit with less mental responsibilities, compared with pre mTBI employment. A year later a more challenging job was undertaken, in line with pre-injury qualifications. Once again this participant experienced disabling fatigue and inability to process complex information and manage staff responsibilities, over time. Thus the quality of employment post mTBI, needs to be considered, when using a return to work as a measure of recovery post mTBI.

The vocational model offered by Dodson (2010), provides a comprehensive set of guidelines for assessing work skills and preparing work environments for participants post mTBI, with congruence to the types of difficulties identified by participants in my study. Whether or not this preparation has any impact on vocational outcomes is not known. However, an understanding of likely problems may be beneficial, given the repeated concerns from participants that they initially lacked an understanding on why the problems were occurring and how they could be resolved.

### **Working in collaboration with others**

All participants expressed how useful it was working collaboratively with family, health professionals, colleagues and employers. In contrast, as discussed by (Kendrick et al., 2012), traditional rehabilitation relies on the expertise of the therapist to remediate client deficits. This fails to make sufficient use of the unique resources individual clients can access, resulting in them being unequipped to handle novel problems after the therapy has terminated. This was apparent when ACC funded services were withdrawn and participants described not knowing what to do to complete their recovery or how to manage the persistent symptoms. An alternative is self-management programmes, which share a common feature of empowering clients to learn to manage their chronic health conditions, utilising strategies to facilitate self-efficacy (Grady & Gough, 2014; Holman & Lorig, 2004). Kendrick et al., (2012), adapted this philosophy in a novel study providing support to address chronic difficulties post mTBI, thus demonstrating that self-management training may improve occupational performance for this cohort of people.

Although my research was not designed to capture sufficient details to critique different models of practice, participants all valued the support they received for drawing on their own expertise to assist with problem solving and finding solutions to their problems. Thus self-managed programmes, as portrayed by Kendrick et al., (2012), may be useful for facilitating solutions to some problems but not others. I offer an example from my research to demonstrate this point.

Bronnie started to form new ideas about some of her occupational performance difficulties during the course of the research interview. Had this been a therapy session, we could have explored her underlying fears that engaging in occupations that she found enjoyable might overstimulate her mind and cause further fatigue. I could have drawn Bonnie's attention to the sense of accomplishment she experienced when she switched her thinking and challenged herself to solve navigation difficulties when driving. This could have led into a discussion on the influence of beliefs and anxiety on emotions and how emotional states can be changed. We might have also selected an interest to develop. Thus strategy training over 6-8 sessions, could

produce statistically significant results on the various rating scales designed to capture occupational performance and quality of life.

However, if a goal of returning to work as a data entry operator was selected, an assessment to determine why transposing numbers at speed was difficult and what made reading difficult would be required. Remedial exercises targeting visual attention and other perceptual skills, would need to be trialled. If effective, locating suitable work and generalising these skills into a competitive work environment could follow. This would likely require many more than eight therapy sessions and a willingness to practise remedial exercise several times each day, between sessions. Over half of the participants, who received both early intervention and support to return to work, described persisting complex processing difficulties, which were not addressed as part of their rehabilitation, as reasons for relinquishing employment.

Furthermore, participants described the benefits of addressing anxiety and depression, and learning strategies to address dysfunctional thinking styles, and preventing panic attacks. However, these strategies, on their own, did not address the capacity difficulties impacting on occupational performance. The possibility of this finding was discussed by Potter and Brown (2012), who suggested that CBT could be beneficial for addressing mood difficulties post mTBI, but may not address broader outcomes such as quality of life and return to work. However, their proposal for a 12 week CBT course draws on the literature suggesting that there is lack of symptom specificity in the post-acute recovery period post mTBI, with a high co-morbidity with psychiatric disorders, and an ambiguous presence of objective cognitive dysfunction. Thus, CBT training targeting dysfunctional thought process, may fail to improve occupational functioning.

In summary client centred, collaborative practice may be beneficial at all stages of intervention. CBT strategies may be useful to address emotional dysregulation and self- management programmes may have additional value in the later stages of the recovery when participants are learning to live with chronic difficulties. However, unless the capacity difficulties are also addressed, occupational performance is likely to remain compromised for those people wanting to engage in complex work and leisure activities.

## **Implications for Practice**

To address the occupational performance difficulties occurring post mTBI, and decrease experiences of repeated failure, the following nine recommendations are derived from the findings of this study.

1. Provide written guidelines for post mTBI management: All participants reported confusion about what was, and what was not, normal functioning post mTBI, and

pushed themselves to persist with usual occupations, until they were unable to cope. Written guidelines at the time of the mTBI, should also differentiate between workers' compensation and ACC funded rehabilitation. Thus clients who are declined workers' compensation, can understand that they are still eligible for ACC funded rehabilitation.

2. Identify clients with a high symptom burden post mTBI: An early emphasis is required to reduce the cognitive load, and prevent repeated failure and escalations in stress responses.
  - Assessment processes need to be streamlined and repetitions in the assessment process eliminated.
  - Rehabilitation processes should be introduced, at a pace that does not exacerbate acute symptoms.
  - Resources should be allocated to manage complex sequelae post mTBI appropriately.
3. Practise problematic occupations: A combination of reduced work hours and increased rest was not sufficient to restore occupational functioning, in the early stages of recovery. Opportunities to practise occupational sequences and "recalibrate" performance seems to be helpful. Practices should be scheduled after rest periods, and at a rate which isn't overloading processing capabilities, or triggering stress responses and disabling fatigue.
4. Implement specific strategies to build mastery:
  - Reduce dizziness and nausea.
  - Understand changed capacities, by engaging in project work or similar.
  - Deploy basic stress management strategies such as breathing, and self- talk.
  - Deploy fatigue management strategies.
  - Reinforce that fatigue has different qualities and rest in the post-acute phase of recovery, does not resolve all fatigue.
  - Use communication strategies.
  - Develop a daily schedule and learn to plan ahead.
  - Remember to schedule pleasant occupations and use a sense of humour as able.
  - Negotiate with family and friends to assist with household management and childcare responsibilities, while experiencing a high burden of symptoms.

5. Complete a task analysis before returning to work: Management strategies of persistent symptoms should be considered *before* occupational dysfunction is experienced in the workplace.
  - For those with capacity changes performing new occupations initially required large amounts of energy, requiring a rest period before and after participation.
  - Complex sequences need to be broken into steps and practised over time before they can be reliably deployed.
  - Environmental changes are needed to support the redevelopment of concentration and manage light and noise sensitivities.
  - Recalling how complex skills were first developed and using these techniques as part of the retraining processes may be helpful.
  - Communication/executive functioning strategies need to be developed before resuming complex tasks such as chairing meetings and managing staff.
6. Implementing Rest Periods: There was no evidence to suggest that stipulating specific times for rest periods away from the work environment enhanced occupational performance, or supported a quicker return to work. Learning how to pace oneself, alternating occupations with a high and low cognitive load, and setting aside time when rested to practise complex sequences is recommended.
7. Anxiety and stress responses accompanying occupational dysfunction: An analysis of occupations that are triggering a stress response, or are being avoided, provides valuable information on occupational performance difficulties, which can be targeted in rehabilitation.
8. Utilise expertise within a client's social networks: Supportive employers, colleagues, family and friends often provided a wealth of expertise which support rehabilitation efforts. Support to tap into these resources throughout the rehabilitation process may be helpful.
9. Support self-efficacy: Utilise a client centred collaborative approach throughout the rehabilitation process.
  - Encourage experimentation.
  - For clients with chronic symptoms, teach self-regulating strategies and assist to reconfigure meaningful occupational routines.



- Consider using a self-managing programme as a constructive way of transitioning out of ACC funded rehabilitation services, when a full recovery has not been attained.

## **Implications for Further Research**

The functional implications of persistent capacity changes post mTBI are not well understood. Understanding how capacity changes impact on occupational functioning both in the short term and long term needs to be addressed. Four areas of research are suggested.

First, the capacity changes following mTBI impacted on complex occupations in ways that were consistent between participants. This suggests that describing the reasons for relinquishing occupations and the contexts in which breakdowns in occupational performance difficulties are experienced, at one month, three, six and 12 months post injury, may provide useful data for rehabilitation planning.

Second, the experiences of participants relearning occupational sequences post mTBI needs further investigation. What are the neural implications of performing complex sequences, and how best are these sequences restored? Are remedial exercises, designed to assist homeostasis within the different processing systems, useful to improve overall occupational performance? Driving may be a useful occupation to consider if comparing outcomes with different training initiatives. Driving is complex, encapsulates the visual processing difficulties commonly experienced post mTBI, and is an occupation which all participants were highly motivated to resume. There were also persistent changes in driving capabilities, which may be measurable.

The next area of research is to better understand the communication difficulties post mTBI, which persisted when depression and anxiety were well controlled. Many complex occupations were relinquished as participants were unable to deploy skilled strategies to resolve keeping up with the speed of the conversations and make timely interventions to resolve interpersonal conflicts, especially when they were tired. Thus the recent review understanding communication difficulties occurring after exposure to blast related injuries in war situations (Cornis-Pop et al., 2012) need to be considered for civilian populations.

Lastly guidelines for configuring a return-to-work programme need to be developed. A start would be to understand how decisions are made to determine hours of work, post mTBI and what factors influence the incremental increases in the hours of work.

Having explored the implication of my research for practise and further research I will now address the credibility of my findings. As discussed by Thorne (2016), the truth claims with all qualitative research, exploring human problems and making the taken for granted in everyday

life visible to others, remain tenuous. In the following section I will examine aspects of my study impacting on the credibility of the findings.

## **Strengths and limitations**

The strengths of my research were using an interview process to capture the essence of what made it difficult to perform everyday occupations post mTBI, and how these difficulties were mitigated. The exploratory nature of the research and associated analytical process enabled patterns of strategies to be grouped together, revealing patterns that were consistent between the participants. Participants stressed that once they knew why problems were occurring and how to solve them, they could generalise these strategies into novel situations and reconstruct satisfying everyday routines. Knowledge of these strategies is important, as there has been little research into interventions for persisting symptoms post mTBI.

By interviewing participants, months and years after the mTBI, I was able to capture strategies that participants developed in response to the repeated failures they experienced, post injury. Thus my analysis was able to pinpoint strategic times in the recovery process, whereby the use of suitable strategies may have prevented the breakdown in occupational functioning.

Another strength was the occupational nature of the investigation. Participants' accounts suggested an interaction between fatigue, stress responses and capacity changes, all of which impacted on occupational performance. In describing the strategies used to mitigate these difficulties and the contexts in which they were used, I have been able to provide a data bank of strategies which may be of benefit for others, thus creating new knowledge for evidenced based practice.

Although there were strengths in my study there were also limitations. The number of participants were small, and I was not able to recruit people engaged in the range of vocations that I originally planned for. In particular, skilled tradesmen who require good visual motor skills to perform machinery safely and to work at angles requiring constant head movements, which challenge the vestibular and ocular motor systems, were not interviewed. A perspective from people under pressure to perform complex motor skills at speed may have provided important strategies, which were not forthcoming from those in my study who could delay engaging in complex motor sequences.

In addition, the sample was skewed towards those with tertiary qualifications who required high level cognitive processing skills to remain employed. Having said this, the two participants without tertiary qualifications, experienced similar occupational difficulties as the other participants. These included a deterioration in reading and writing skills, delays in returning to driving, difficulties processing complex visual information under speed, multitasking and prospectively sequencing occupations.

One participant had a distinctly different profile of persistent symptoms (i.e., emotional incontinence, sleep disturbance, noise insensitivity, post traumatic anxiety), without the chronic cognitive fatigue and processing limitations that other participants experienced. His profile of occupational performance difficulties contrasted with the other participants. With a bigger sample, there may have been other distinct occupational profiles that presented, with additional strategies developed to address occupational functioning. The symptom profile however was compatible with the longitudinal study by (King & Kirwilliam, 2011), who also used the Rivermead checklist to record persistent symptoms.

The recruited sample, however, met the criteria for the study and demonstrated variation in employment, socioeconomic status, marital status, gender and occupational status. In addition, participants were recruited from different geographical areas and received rehabilitation input at different stages in their recovery. There was consistency in the patterns amongst participants, regardless of their rehabilitation experiences. I concluded, along with my supervisors, that there was sufficient variation in the sample for the study to proceed.

A possible design limitation was the failure to include a sample of people who made a timely recovery. When analysing the data, I recognised it might be useful to compare early coping strategies of the majority who make a good recovery with those recruited for my study. In particular, I would have like to know if those making a timely recovery also experienced strong anxiety response and disabling fatigue while trying to complete everyday occupations in the first few days following their injury. Participants, however, provided examples of family and friends, who “bounced back” within a week of the mTBI, and did not demonstrate a complex sequelae, with capacity difficulties and disabling fatigue, suggesting a higher burden of symptoms, rather than catastrophic thinking and illness beliefs which potentially could impact on recovery.

Another factor that cannot be ignored is the influence that I may have introduced, albeit unintentionally, to the collection and analysis of the data. To guard against this potential bias, strategies to integrate reflexivity throughout the research project were deployed. As discussed

by Carpenter and Suto (2008), reflexivity is closely related to the ethical issues underpinning qualitative research and require the researcher to interrogate their own beliefs and feelings, in the same way that participants' responses become part of the analysis process. Documenting the impact of the researcher in terms of access to data, relationships in the field and data analysis, allows the reader to make decisions about the researchers influence on the findings.

In addition to detailing my methodology, I prepared for the research interviews differentiating between therapy and research. As a novice researcher, the advice from Thorne (2008), to approach the research interview as a person interested to learn as much as possible from the participant, was particularly helpful. I also analysed the first interview together with my supervisors, checking to make sure I remained in the role of a researcher, asked open ended questions and included summaries of my understanding which were presented to the participants, so I could check that my impression matched the participant's intent.

Reflecting on my interviews, I recognised that some of my decisions not to probe for additional information that may have been helpful for my research were based on considerations for the participant. Others were based on avoiding issues I did not want to deal with. An example of the later, was participants' relationship with ACC. On occasions participants expressed a perplexed attitude as to why ACC funders stopped their rehabilitation, before all of their occupational performance difficulties had been addressed. Had I been less focused on my needs (not to provoke angry responses concerning ACC), I may have been able to remain tuned into the participants' experiences and gain valuable information on persisting occupational performance difficulties. Thus, exposing myself to scrutiny was an important part of the process and helped me differentiate my thoughts from those of the participants. In the process, I learned more about myself, which I had suggested may be a positive spin off for participants who volunteered for my study.

Throughout the research project, I made all of my interview data available for my supervisors and had regular supervision sessions. A comparison of the research data with the occupational difficulties presented at a depression management group I was running, together with discussions with colleagues, assisted in the depth of the scrutiny I was able to bring to the analysis. At all stages of the process I checked my conclusions against the actual words of participants.

The final strategy I used to assess reflexivity was to revisit the presuppositions interview I completed at the start of the research project. It was clear that there were research findings

that I had not anticipated, suggesting I had been open to the experiences of the participants who shared different world views.

## **Conclusion**

This small scale qualitative descriptive study, was able to answer the research question, “What strategies do people with persistent symptoms post mTBI use to manage everyday occupations?” Capacity changes in energy levels, emotional regulation and processing abilities were experienced immediately following the mTBI, and persisted albeit with less intensity over time. Strategies to manage these impairments are described which together provide the tools for managing persisting symptoms.

The recovery pattern suggested three phases for re-establishing satisfying occupational routines. The first was characterised by taking off the load and reconfiguring simplified routines to meet essential self-care and productively demands. Secondly “recalibrating” the motor and cognitive components, and deploying compensation strategies, supported the uptake of a greater number of complex occupational sequences. Lastly, giving up the struggle to get better, and incorporating new ways of performing everyday occupations, supported the reestablishment of satisfying occupational routines, minimising disabling fatigue and the triggering of strong stress responses.

Suggestions to improve the rehabilitation experiences for people with persisting difficulties post mTBI are made, and recommendations are made for new research to advance an understanding of the occupational performance difficulties.

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## Appendix 1 - Demographic Data and Symptom Checklist

### Demographic Data and Symptom Checklist



*Project Supervisor: Professor Clare Hocking*

*Researcher: Maree Paterson*

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Age .....

Gender .....

Occupation .....

Occupation (at time of Injury).....

number of children.....

Age of Children.....

#### The Rivermead Post-Concussion Symptoms Questionnaire

After a head injury or accident some people experience symptoms which can cause concern. As many of these symptoms occur normally, we would like you to compare yourself now with before the accident.

For each question, please circle the number closest to your answer.

0 = Not experienced at all

1 = No more of a problem

2 = A mild problem

3 = A moderate problem

4 = A severe problem

Compared with before the accident, do you now (i.e., over the last 24 hours) suffer from:

Headaches..... 0 1 2 3 4

Feelings of Dizziness ..... 0 1 2 3 4

Nausea and/or Vomiting ..... 0 1 2 3 4

Noise Sensitivity, ..... 0 1 2 3 4

Sleep Disturbance ..... 0 1 2 3 4

Fatigue, tiring more easily ..... 0 1 2 3 4



Being Irritable, easily angered ..... 0 1 2 3 4

Feeling Depressed or Tearful ..... 0 1 2 3 4

Feeling Frustrated or Impatient ..... 0 1 2 3 4

Forgetfulness, poor memory ..... 0 1 2 3 4

Poor Concentration ..... 0 1 2 3 4

Taking Longer to Think ..... 0 1 2 3 4

Blurred Vision ..... 0 1 2 3 4

Light Sensitivity, ..... 0 1 2 3 4

Easily upset by bright light ..... 0 1 2 3 4

Double Vision ..... 0 1 2 3 4

Restlessness ..... 0 1 2 3 4

Are you experiencing any other difficulties?

1. \_\_\_\_\_ 0 1 2 3 4
2. \_\_\_\_\_ 0 1 2 3 4

\*King, N., Crawford, S., Wenden, F., Moss, N., and Wade, D. (1995) J. Neurology 242: 587-592

***Approved by the Auckland University of Technology Ethics Committee 10.02.2014  
AUTTEC13/353***

## Appendix 2 - Ethics Approval



A U T E C  
S E C R E T A R I A T

10 February 2014

Clare Hocking

Faculty of Health and Environmental Sciences

Dear Clare

Re Ethics Application: **13/353 Strategies people use to participate in everyday activities when experiencing persistent symptoms following a mild traumatic brain injury. A qualitative descriptive study.**

Thank you for providing evidence as requested, which satisfies the points raised by the AUT University Ethics Committee (AUTEC).

Your ethics application has been approved for three years until 10 February 2017.

As part of the ethics approval process, you are required to submit the following to AUTEC:

- A brief annual progress report using form EA2, which is available online through <http://www.aut.ac.nz/researchethics>. When necessary this form may also be used to request an extension of the approval at least one month prior to its expiry on 10 February 2017;
- A brief report on the status of the project using form EA3, which is available online through <http://www.aut.ac.nz/researchethics>. This report is to be submitted either when the approval expires on 10 February 2017 or on completion of the project.
- 

It is a condition of approval that AUTEC is notified of any adverse events or if the research does not commence. AUTEC approval needs to be sought for any alteration to the research, including any alteration of or addition to any documents that are provided to participants. You are responsible for ensuring that research undertaken under this approval occurs within the parameters outlined in the approved application.

AUTEC grants ethical approval only. If you require management approval from an institution or organisation for your research, then you will need to obtain this. If your research is undertaken within a jurisdiction outside New Zealand, you will need to make the arrangements necessary to meet the legal and ethical requirements that apply there.

To enable us to provide you with efficient service, please use the application number and study title in all correspondence with us. If you have any enquiries about this application, or anything else, please do contact us at [ethics@aut.ac.nz](mailto:ethics@aut.ac.nz).

All the very best with your research,

Kate O'Connor

Executive Secretary

**Auckland University of Technology Ethics Committee**

Cc: Maree Paterson [mareepat@xtra.co.nz](mailto:mareepat@xtra.co.nz)

## Appendix 3 - Participant Information Sheet

### Participant Information Sheet



*Project title: Strategies people use to participate in everyday activities when experiencing persistent symptoms following a mild traumatic brain injury. A qualitative descriptive study*

*Project Supervisor: Professor Clare Hocking*

*Researcher: Maree Paterson*

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Date Information Sheet Produced : 12 October 2013

#### **An Invitation**

Drs Clare Hocking and Kathryn MacPherson, both Professors in Rehabilitation Studies at AUT, together with Maree Paterson an occupational therapist with 10 years experience, invite you to take part in a research project. This project explores how people manage everyday life when they don't make a full recovery within three months after a mild brain injury. A mild traumatic brain injury (also known as a concussion), is defined as a closed head injury i.e., a bang to the head which doesn't penetrate the skull, causing changes to the way the brain functions.

These changes to the brain may result in; a) any loss of memory immediately before or after the injury, b) any change in mental state at the time of the accident e.g. feeling dazed, disorientated, or confused and/or c) any neurological disturbance such as slurred speech, altered sensation, blurred vision, slowed reaction times, coordination difficulties, and sensitivity to light or sound. The injury is considered mild if any memory loss lasts less than 24 hours after the brain injury.

While there is a large amount of research about the complications that follow a mild brain injury, (such as fatigue, memory problems, tearfulness, dizziness, slowness in thinking, visual and balance problems), there is very little research on managing these difficulties while coping with the demands of everyday life.

#### **What is the purpose of this research?**

It is recognised that not all people with a brain injury make a quick and/or full recovery. We want to find out from people who do not make a quick recovery, about how the demands of everyday activities and work expectations are managed. This information may help others working in rehabilitation to gain a better understanding of the facilitators (things that make it easier) and barriers (things that make it harder). It is hoped that the sharing of successful strategies can provide others with "short cuts" for adjusting to the difficulties which can occur post brain injury.

#### **What happens to the information I provide?**

Your information will be considered alongside information from other participants to describe the process of participating in everyday activities. The report of the findings will be written up as the thesis for a Master's Degree. We hope to publish the results of the study in a relevant health or disability journal. All personal information which could identify who

you are will be kept confidential to the researchers and the typist. You will not be identified as a participant in the study in any of the reports.

### **How was I chosen for this invitation?**

My former colleagues agreed to contact suitable people to see if they were interested in participating in this research. You were sent this information as you have experienced ongoing difficulties following a mild traumatic brain injury.

### **What will happen in this research?**

If you choose to take part, you will be asked to spend about 20 minutes completing a short questionnaire about your ongoing symptoms and answering questions which will assist the researcher to understand your needs, e.g. how to manage fatigue or periods of tearfulness. You will then be interviewed for 1-1.5 hours about your experience of managing your usual range of everyday activities after your injury. You are welcome to bring a support person if you would like to. This interview will be audio-taped and then transcribed. A follow-up interview or visit to observe the strategies you use may be requested to clarify information. Observations will only be arranged if you agree.

### **What are the discomforts and risks?**

Adjustment after a brain injury can be a difficult experience. It is possible that you may feel uncomfortable or become tearful talking about your experiences during the interview. I do not anticipate any other risks from participating in this study.

### **How will these discomforts and risks be alleviated?**

You can choose not to talk about subjects that you find distressing, or withdraw from the interview and/or the study at any time. The tape recorder will be turned off during the interview, if time is required to regain composure. In addition, if you would like it, a referral can be made to a health professional to discuss any concerns following the interview.

### **What are the benefits?**

There are no immediate benefits to you for taking part in this study. You will be contributing to information that could help to provide better services for people with mild traumatic brain injuries in the future. In addition, some people find that being interviewed about what they have been through is an enjoyable and/or interesting experience.

### **What compensation is available for injury or negligence?**

Compensation is available through the Accident Compensation Corporation within its normal limitations.

### **How will my privacy be protected?**

Interview recordings and transcripts will only be available to the research team. No information identifying you as a participant in this project will be included in any of the project reports or publications. Transcripts will be kept securely at AUT University for six years, following the completion of the research and then destroyed. The typist transcribing the interviews, will have signed a confidentiality clause and will type onto a computer which is password protected. A code will be allocated to your file and your name will not appear on any of the transcripts. Participants' names and contact details will be kept separate from the transcribed transcripts.

### **What are the costs of participating in this research?**

The only cost to you is your time. If you choose to take part, you will have a 1-1.5 hour interview with a researcher, with rest breaks as required. The researcher will meet you at a place that is convenient for you. Should you incur any travel costs, reasonable costs will be reimbursed to you in the form of petrol vouchers.

### **What opportunity do I have to consider this invitation?**

If you want to take part in the research you will need to contact us directly or give your permission for your details to be forwarded. After we receive your contact details, you will be given at least a week to think about this offer before being contacted. You are able to withdraw from the research at any stage and you do not need to give a reason for doing this.

### **How do I agree to participate in this research?**

You will need to complete a consent form to take part in this research. This will be given to you prior to providing information to us or being interviewed.

### **Who Will receive feedback on the results of this research?**

You can choose to receive a summary of the findings of this research. Once these are available, you can choose to have them sent to you at a physical address you provide, or via an email. You will get details of these options once the study has been completed (about 12 months after your interview). A summary of the research findings will also be sent to the organisations who were involved in recruiting participants. Care will be taken to ensure individuals cannot be identified in the research findings.

### **What do I do if I have concerns about this research?**

Any concerns regarding the nature of this project should be notified in the first instance to the Project Supervisor, Clare Hocking. Clare can be contacted at the School of Rehabilitation and Occupational Studies, Private Bag 92006, Auckland 1142. Phone: 09 921 9162 and email: [clare.hocking@aut.ac.nz](mailto:clare.hocking@aut.ac.nz)

Concerns regarding the conduct of the research should be notified to the Executive Secretary, AUTEK, Madeline Banda, [madeline.banda@aut.ac.nz](mailto:madeline.banda@aut.ac.nz), Ph 09 921 9999 ext 8044.

### **Whom do I contact for further information about this research?**

#### **Researcher Contact Details:**

Maree Paterson, c/o Clare Hocking, School of Rehabilitation and Occupational Studies, Private Bag 92006, Auckland 1142 or

**Phone:** Maree Paterson on 0800 578 423 (free of charge) or

**Email:** [maree.paterson@yahoo.co.nz](mailto:maree.paterson@yahoo.co.nz)

**Approved by the Auckland University of Technology Ethics Committee, 10.02.2014**

**AUTEK Reference:13/353**

## Appendix 4 - Consent for Third Party to Pass on Details

### Consent Form for Third Party

*Project title: Strategies people use to participate in everyday activities when experiencing persistent symptoms following a mild traumatic brain injury. A qualitative descriptive study*

*Project Supervisor: Professor Clare Hocking*

*Researcher: Maree Paterson*

- ☐ I understand that Maree Paterson is wanting to interview people who do not make a full early recovery from a mild traumatic brain injury, for research purposes.
- ☐ I understand that there will be no sharing of information about my case between ACC or staff contracted by ACC, and the researcher.
- ☐ I agree that CNS can forward my contact details onto Maree Paterson, and that Maree can contact me to explain her research further.
- ☐ I understand that I may decline to be involved in this research, without being disadvantaged in any way.

Signature: .....

Name: .....

Contact Details :

.....

Signature of CNS Neuropsychologist: .....

Name.....

.....

Date:

## Appendix 5 - Ethics Amendment



A U T E C  
S E C R E T A R I A T

15 June 2015

Clare Hocking

Faculty of Health and Environmental Sciences

Dear Clare

Re: Ethics Application:

**13/353 Strategies people use to participate in everyday activities when experiencing persistent symptoms following a mild traumatic brain injury. A qualitative descriptive study.**

Thank you for your request for approval of an amendment to your ethics application.

I have approved the minor amendment to your ethics application allowing the invitation for the project to be sent to persons who had previously agreed to be contacted about research.

I remind you that as part of the ethics approval process, you are required to submit the following to the Auckland University of Technology Ethics Committee (AUTEC):

- A brief annual progress report using form EA2, which is available online through <http://www.aut.ac.nz/researchethics>. When necessary this form may also be used to request an extension of the approval at least one month prior to its expiry on 10 February 2017;
- A brief report on the status of the project using form EA3, which is available online through <http://www.aut.ac.nz/researchethics>. This report is to be submitted either when the approval expires on 10 February 2017 or on completion of the project.

It is a condition of approval that AUTEC is notified of any adverse events or if the research does not commence. AUTEC approval needs to be sought for any alteration to the research, including any alteration of or addition to any documents that are provided to participants. You are responsible for ensuring that research undertaken under this approval occurs within the parameters outlined in the approved application.

AUTEC grants ethical approval only. If you require management approval from an institution or organisation for your research, then you will need to obtain this.

To enable us to provide you with efficient service, please use the application number and study title in all correspondence with us. If you have any enquiries about this application, or anything else, please do contact us at [ethics@aut.ac.nz](mailto:ethics@aut.ac.nz).

All the very best with your research,

A handwritten signature in black ink, appearing to read 'K O'Connor', written over a light blue horizontal line.

Kate O'Connor

Executive Secretary

**Auckland University of Technology Ethics Committee**

Cc:

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## Appendix 6 - Full Consent to Participate in Research

### Consent Form



*Project title: Strategies people use to participate in everyday activities when experiencing persistent symptoms following a mild traumatic brain injury. A qualitative descriptive study*

*Project Supervisor: Professor Clare Hocking*

*Researcher: Maree Paterson*

- ☐ I have read and understood the information provided about this research project in the Information Sheet dated 12/10/2013.
- ☐ I have had an opportunity to ask questions and to have them answered.
- ☐ I understand that notes will be taken during the interviews and that they will also be audio-taped and transcribed.
- ☐ I understand that I may withdraw myself or any information that I have provided for this project at any time prior to completion of data collection, without being disadvantaged in any way.
- ☐ If I withdraw, I understand that all relevant information including tapes and transcripts, or parts thereof, will be destroyed.
- ☐ I agree to take part in this research.
- ☐ I wish to receive a copy of the report from the research (please tick one): Yes ☐ No ☐

Participant's signature: .....

Participant's name: .....

Participant's Contact Details :

.....

.....Date:

***Approved by the Auckland University of Technology Ethics Committee 10.02.2014***

***AUTTEC13/353***

*Note: The Participant should retain a copy of this form.*



## Appendix 7 - Indicative Questions



### ***Indicative Questions for Interviews***

*Project title: Strategies people use to participate in everyday activities when experiencing persistent symptoms following a mild traumatic brain injury. A qualitative descriptive study*

*Project Supervisor: Professor Clare Hocking*

*Researcher: Maree Paterson*

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Describe a typical week and the main activities you were involved in just prior to your brain injury?

After the acute symptoms settled (2-3 weeks after the initial injury):

- What did you find easy/difficult with your usual routine?
- What tasks/ activities were particularly challenging? What happened?
- What did you, (or others around you ), do to manage the difficult parts?
- How effective was this?

What changes have been made over time? How did these come about?

Describe a typical week and your main activities now

If one of your friends had a brain injury similar to yours what advice would you give them?

*If people have difficulty answering questions prompts based on their symptom checklist and main activities will be given. For example:*

- Many people after a mild brain injury find concentrating difficult – How do you get on with using the computer at work? Are some times of the day more difficult than others?
- Most of us find it easier to complete things when it is quiet with minimal interruptions, but find it more difficult when the environment is busy. What happened when the children come home from school, or how did you manage chairing the weekly staff meeting?
- Some people experience subtle changes in balance after a mild brain injury. How do you get on at work securing cupboards when you have to climb into confined spaces or how do you get on fishing when there is a bit of a swell?

Project Supervisor's Contact Details:

Professor Clare Hocking

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***Approved by the Auckland University of Technology Ethics Committee 10.02.2014***

***AUTTEC13/353***

## Appendix 8 - Example of Developing Categories'

Plotting a Course to Recovery							
1. Acute Management: , take off the load and get plenty of rest.							
Recognising that all is not well	1.1 Take off the load:	1.2 Get rest and take time to recuperate	1.3 Re-commence activity slowly and without pressure	1.4 Partner up with the good people around you and train other people to help	Barriers	Facilitators	Points for discussion
<p>*Physical symptoms of headaches , nausea , vomiting, dizziness, incoordination and migraines</p> <p>*very tired all the time and not understanding why things were hard to do</p> <p>*having to have breaks all the time and force self to keep going</p> <p>*mismatch between expected and actual performance, ,</p> <p>*couldn't get info from head to hands</p> <p>Tasks that required sequencing over time were confusing and difficult to keep tract of</p> <p>*Not able to keep up with simple conversations and not able to tolerate group discussions</p>	<p>Precursor for accepting the need for naps: seeing for yourself that without rest things got worse rather than better and that 2-3 hours after intensive activity fatigue sets in</p> <p>*Get advice from those that know about mTBI: GP, OT, concussion clinic and later physio if dizziness and balance problems don't settle</p> <p>*Relinquish employment and looking after children while acute symptoms are settling,</p> <p>*Delegate/postpone high effort tasks (requiring decision</p>	<p>*Give self permission to back off and let things heal</p> <p>*Remove self away from social/family interaction as much as possible</p> <p>*sit somewhere pleasant e.g in the garden wrapped in a blanket for several hours if watching TV or reading makes you feel sick, or on the sofa in a nice warm room</p> <p>*listen to advice from the good people around you about the benefits of rest</p> <p>*Start off being rigid with rest times</p> <p>*take note of what happens to mood and processing ability if you don't have a rest</p>	<p>Build up slowly without pressure</p> <p>*recognise improved functioning and gradually take on more</p> <p>*go for a walk –</p> <p>*get some activity but don't make yourself sick and provoke the symptoms</p> <p>*once acute symptoms settled get back into doing small things you like, to get back into normal life</p> <p>*Find things that I could still do to that were small and manageable to do with my work</p> <p>*Don't try and think of a specific word when stuck</p> <p>*Talk around it and find another way to say it</p>	<p>NB some strategies were formed from participants reflections on what they found useful in the acute stage of recovery.</p> <p>*Awareness improved with feedback from family – but only at a time I was rested – otherwise I'd react badly</p> <p>*Needed to rely on partner in the early stages especially with child management and keeping the household running when I couldn't make decisions and my temper was quick</p> <p>*Generating ideas with both health professional and</p>	<p>*People just expect you to be back on top because physically you look fine</p> <p>*People who should know, providing advice, scheduling appointments and interventions which triggered an escalation of symptoms made it difficult to know what advice to trust</p> <p>*2 OTs doing same sort of things – one for home and one preparing for returning to work whilst I was struggling with processing information and making decisions was over the top</p> <p>No information/support for spouse who was</p>	<p>Early Education –</p> <p>*Understanding fight/flight mechanisms– self preservation comes first as a helpful way to understand anxiety and urges to go away and hide.(NB: long term effects of using avoidance as a strategy of managing anxiety, see category 5)</p> <p>*Early advice not to try and think of a specific work when stuck – talk around and find another way to say it – never give up on the conversation</p> <p>Confirmation from others that they didn't think I was skivvying off and</p>	<p>*Awareness and processing difficulties may make it difficult to recognise all is not well and make it difficult to seek appropriate help BEFORE depleting reserves.</p> <p>*Pushing through fatigue/distress, and depleting reserves to achieve RTW targets appears counterproductive</p> <p>*All participants were expecting to make a timely recovery. Further research is needed to understand the repercussions of telling someone that they are expected to make a full recovery, when that doesn't happen.</p> <p>*Anxiety associated with perceptions that those with a mTBI might not be trying hard enough to get</p>

<p>* others around me noticing and reporting on uncharacteristic mistakes and temperament changes</p> <p>* being physically present but not mentally connected to tasks or people in the environment</p> <p>* gave up doing usual tasks e.g. helping special needs son with his reading homework (NB: limited awareness at the time this had occurred)</p> <p>* Uncharacteristic aggression/explosive anger directed at things and people who annoy me. Not taking advice from those that know about mTBI, even when others around me could see that pushing through symptoms wasn't helping</p> <p>* Retarded responses (tears anger/rage) to implied or actual criticism.</p> <p>* cant find the right word when conversing</p>	<p>making) in early stages when everything is difficult.</p> <p>* For those people living alone – only force self to do the things needed to stay independent, and do it the easiest way possible, e.g. sandwiches for dinner rather than not eating or trying to cook a meal</p> <p>* Stop doing the things that cause an escalation in physical symptoms/panic/ confusion</p> <p>* Reduce appointments to bare minimum</p> <p>* Avoid noisy/loud, bright environments – e.g. supermarket, gym,</p> <p>* Relinquish social engagements</p> <p>* become a listener in conversations with more than 2 people</p> <p>* avoid visitors (unless they do all the work)</p> <p>* stop answering the phone</p>	<p>* use self talk and images of what happens if you didn't rest, to help disengage from activity and take a rest</p> <p>* Don't keep pushing through the fatigue – pull back, rest, give yourself time to heal</p>	<p>* Don't give up on the conversation, keep talking (see category... for developing complexity for post acute devt)</p> <p>* Eliminate time pressures</p>	<p>family assisted with developing awareness and solving problems</p> <p>* Teaming up with the OT to educate employer and to help negotiate a return to work (RTW), was useful for some.</p> <p>* Teaching spouse to step and step up fast was vital so they could understand that I was struggling with making decisions and know how to take off pressure rather than add to it.</p> <p>The good people who gave space and make one feel safe: i.e. cooked dinner, did the washing and were quiet and kept out of the way helped to settle things down and reduce anxiety</p> <p>Good people giving feedback helped me understand I wasn't doing as well as I thought I was</p> <p>Using colleague's insights and practical help to support the RTW</p>	<p>left with the burden of caring for the family and coping with injured person and their uncharacteristic aggression/limited awareness and difficulties making decisions and processing information</p> <p>Barrier (at first) – weekly meetings with OT – stranger – busy body telling me what to do with my life – and not understanding the rational for restrictions or directives</p> <p>Pushing through symptoms until energy levels depleted and/or unable to manage conflict without verbal or physical aggression, complicated the recovery process</p>	<p>trying to get out of work was helpful</p> <p>Directives from health professionals were part of plus wife that naps recovery and to stop complaining about were useful after failing to take on board education/advice.</p> <p>NB: Later when participant was able to differentiate between vulnerability and weakness could rest without feeling ashamed – see managing emotions for further details.</p> <p>Need to get family on board in early stages, esp if there are awareness difficulties</p>	<p>better combined with fears that others think (real or imagined) they might not be trying hard needs to be addressed.</p> <p>* All participants took cues from their altered ways of doing things, as an indication that things were not OK, and conversely that functional improvements were an indication they were getting better. May need a functional inventory and scoring system pertinent to mTBI – to better monitor progress / develop awareness with the client and inform the RTW process.</p> <p>* ? need to avoid overloading clients with too much info initially (hard when you have to develop goals and make a plan on initial contact), and take the time to understand any resistance to advice. Streamlining services needs to be considered</p> <p>NB: Participants found it helpful to see for themselves what happens when they get too tired, than simply take advice.</p> <p>* Evidence that people with mTBI, become more aware and concerned with everyday memory</p>
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## Appendix 9 - Example of Refining Categories'

<p>The complex stuff is hardest. Pay attention to where the task breaks down and make a plan</p>	<p>Q24 Noise and interruptions stop me getting the task done Q3A New learning is difficult Q2: Complex stuff is tiring and takes longer to do Q3* postpone non urgent complex tasks *take stuff home to do where it is quiet *I do some work at home and don't charge it out to compensate for being slower to problem solve (? Underlying emotions associated with guilt will contribute to resistance negotiating increased work hours) The complex components in occupations can prevent completion or suck too much energy Pre-empt the difficult parts *partner up with others to get the hard bits done *delegate hard part to others When delegating *Be particular with what the brief is *follow-up if people haven't got back to you *employ some cunning (see cues for taking a break) It takes more time to</p>	<p>Barrier: No flexibility to rearrange hours with OT Q15" Making "rules" about work hours without consideration of dynamics of the workplace, and cognitive load of specific tasks seems counterproductive Precursor for understanding task demands: being under pressure makes it harder Q17 Reading is hard NB: Denied opportunity to keep practising reading as OT prioritised conserving energy for returning to work Q18 Remembering things is OK but sequencing them is difficult Q20 Strategies for sequencing things in the right order: *Write it down and make a bit of a plan *Mark it off as you go *Carry a sheet of paper and pencil in my pocket Word Finding difficulties (strategy continued in the</p>	<p>Q2 Precursor for understanding: everything was different: *putting sentences together *couldn't cope with any kind of complexity *couldn't cope with the phone, *couldn't deal with conversation— *got angry very quickly". Strategies for socialising: *socialise for 10-20 mins —take self out to car for a nap and then repeat the process *partnering alongside someone who does the talking Q13 Facilitator: Extended input from OT, PT and SLT (1-1.5 yrs) Barrier (at first)— weekly meetings with OT – stranger – busy body telling me what to do with my life – too much info unable to assimilate Facilitator: Extended input from OT, PT and SLT (1-1.5 yrs) esp for the generation of ideas and support to try things out and problem solve and Strategies to manage conversations: *acknowledge</p>	<p>Q13 Knows things aren't right – but just carries on (acting instinctively – just carries on- hasn't yet got awareness/skills to try different approaches- isolated from others that know – no support for problem solving Finds navigating difficult, has numerous examples of getting lost, but hasn't relinquished driving like she has with many other dynamic tasks Q18 Strategy: make navigating into a challenge Q19, 20 Realise you are lost going to a known place *stop on the side of the road *remind self of where you are going *visualise the correct route and turn around and go back Precursor to developing strategy: love reading but find it hard to concentrate Q21. Strategy to keep reading: Flick back through the pages, until the story line starts to ring a bell then resume reading. Try to get a few pages ahead on each sitting. have interrupted the</p>	<p>Strategy to improve concentration for reading: *Put on background noise (TV or radio), and with more than one thing happening it somehow calms me down Q4 music overwhelms me as well some how Decision making is tricky Q5 "Decision making is tricky generally. You are asking me to think about thinking and I can't think. I don't know where to go with the thinking..." Precursor for developing new strategies: being passionate about a task, wanting to solve it *checking out planning process with family *recalling old strategies (writing things down) and feeling the urge to use them again to help plan complex sequences-not yet using (NB: previously avoided writing as it was difficult and stressful) Q22 Cooking and simultaneously talking with friends and family – high fatigue activity *plan something easy to</p>	<p>Precursor to finding a strategy: *recognising what tasks are too challenging -holding multiple stands of information in your head long enough to sequence complex tasks Q2 - simultaneously retrieving information and applying it to the current situation to defining the problem, and then selecting and recording the correct remedial action for the future Q3 *realise what you need (task which didn't require decision making) Q4 *step by step without needing to make decisions about options for the next step NB awareness of what was hard only occurred after task breakdown AND reflecting on outcomes Q5 (c.f Bronnie who knew what tasks she couldn't do after failure but no understanding of why the task was hard so didn't generalise) Strategy: *relinquish tasks that you</p>	<p>*Develop a behavioural plan regardless if it was a tiny little thing or if it was bigger Take on new challenges *don't jump to automatic thoughts that it will be too hard, esp if high value occupation (paid employment) Q29 "and when they sent the hours to me I was (inward gasp), I was ummm this might be too long, and already in my mind the big vision stuff was saying struggle – but at the same time I was saying hold on I haven't given it a go, so I said I'll give it a go..." *prepare self and others around me *get agreement if it is too much, help will be available *look at the whole day – prepare things for at home as well as work *introduce more sleep rest times *put effort into learning the requirements – write down the details of what was needed *be prepared to back out if needed *draw on flexibility skills *have a good laugh when</p>
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	<p>process information and things aren't getting done in time to meet job requirements:</p> <p>Get smart about getting things done: Be very clear what the actual performance measures are, hit those and don't do anything extra.</p> <p>Q18 Know the complex stuff is the hardest and may trigger symptoms if you overdo it</p> <p>When you have overdone it i.e. poor sleep, return of nausea, dizziness and increased tiredness</p> <p>• dial it back for a bit</p> <p>Q19* Develop some cunning</p> <p>• ring IT straight away for help even though we are meant to try and fix our own problems first</p> <p>• take it on the chin that everyone thinks I'm a numbee when it comes to technology</p> <p>• Take work home to complete away from distractions</p> <p>• Ask for some extra resources</p> <p>• check you are taking regular breaks (fall back on old strategies)</p> <p>Q22 Develop some cunning –</p>	<p>workplace)</p> <p>• Don't try and think of a specific word when stuck</p> <p>• Talk around it: find another way to say it</p> <p>• don't give up on the conversation</p> <p>Word Finding difficulties</p> <p>• Don't try and think of a specific word when stuck</p> <p>• Talk around it: find another way to say it</p> <p>• don't give up on the conversation</p>	<p>conversations were exhausting</p> <p>• Plan short bursts of conversation with rest in between</p> <p>Precursor to anticipating the need for downtime and deploying rest time: realisation that 2-3 hours after intensive activity fatigue will set in</p> <p>allow 10mins, half an hour or so, or so of zombie time (watch a film but mostly nap), two to three hours after intensive activity</p> <p>Q7</p> <p>acknowledge that I have to do it differently or think about how to do it rather than do it instinctively</p> <p>• acknowledging that my perception is not the ball and end all</p> <p>• plan</p> <p>• use other people</p> <p>perceptions (ie feedback)</p> <p>• plan towards a goal together*consult people who I trust to give feedback (make it a collaborative approach)</p> <p>• learn to trust others (new thing)</p> <p>Strategies for socialising:</p> <p>• socialise for 10-20mins – take self out to car for a</p>	<p>sequence and not got back to finishing the task</p> <p>Use Visual reminders as cues that tasks haven't been completed</p> <p>Strategies to remember appointments:</p> <p>• Ask people for reminders</p> <p>• utilise txt messages to jog memory</p> <p>• write appointment on calendar, and then think back to when the first appointment was made</p> <p>• having two different methods to remember appointments is usually enough to make it stick, - for appointment on that day – not for ones in the future</p> <p>Q24</p> <p>(double reminders for encoding – see also Barry)</p> <p>Precursor to deploying strategies – hate grocery shopping, sit in the car and don't want to go out (impatient waiting in line, isles too crowded and cant think properly)</p> <p>Strategy for shopping: Take disabled mother who will start the shopping and let me to come in when I am ready – I know she is struggling so that motivates me to get in there</p>	<p>cook like a roast when I have visitors</p> <p>Q24</p> <p>Casual conversation in a group of adults is tiring</p> <p>Q25</p> <p>• Go outside with the kids for a while to stave off the feelings of being overwhelmed</p> <p>Strategy for engaging in a complex new activity:</p> <p>• organise not to be pressured by other things,</p> <p>Q16 but at the end of the day – it all seems like a hell of a steep learning curve to me – but if I'm not pressurised by other things – I can meet those things – I can make sure you are excited in what you are doing</p> <p>but it is clear I am passionate about it – I'm excited about those things</p> <p>• relinquished the regular rests to achieve occupation passionate about</p> <p>Q17</p> <p>However once the art works back in New Zealand didn't have a clear idea about how he wanted to distribute the goods – and had difficulty</p>	<p>are not able to do (supervisory work)</p> <p>• identifying jobs that need doing at work within capabilities,</p> <p>Q6</p> <p>Strategy to recuperate after depleting reserves - after ten weeks of trying to return to normal work duties:</p> <p>• Reduce work hours (11.5 to 6 hours – 4 days on 4 days off)</p> <p>• Relinquish tasks with high cognitive load</p> <p>Outcome: improved energy levels, and improved cognitive levels</p> <p>Q7</p> <p>Precursor for recognising improvement; improved achievement of everyday tasks</p> <p>Q8</p> <p>Strategy: monitor performance with achievement of everyday tasks (Would a more formalised process for recognising improvement be beneficial?)</p> <p>Precursor to understanding post mTBI difficulties: comparing preinjury functioning with current functioning:</p> <p>Q11</p> <p>Strategy to improve</p>	<p>things got confused</p> <p>Q30</p> <p>When things go wrong, and the learning routines were getting the better of me and I was doubting myself – push on with planning and preparing knowing with practise things will get easier</p> <p>• practise the difficult things – (writing which had become very messy, and drawing which was much slower)</p> <p>Q31</p> <p>• show the pupils at school what you have to do to practise something that was hard</p> <p>Q32*</p> <p>Quirky habits I have to live with – flipping things around when I am tired</p> <p>my mind- when somebody gives me a question, or wants an answer ill give them the opposite, its inverts – even when I'm taking notes, ill give the opposite of what was intended, – it looks silly when I've done it, and ill apologise that I've given you the opposite answer, – those things sort of happen"</p> <p>• know that it is most</p>
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			<p>nap and then repeat the process</p> <ul style="list-style-type: none"> <li>*partnering alongside someone who does the talking</li> </ul> <p>Q13.....</p> <p>Q17 Learning to see the way forward again – process step by step</p> <p>Q16 Strategies developed to achieve clear communication</p> <ul style="list-style-type: none"> <li>*taking deep breaths</li> <li>*use a set of self talk statements, so can think before reacting: like “my perspective is not the final perspective”, and immediate response is not always the best one</li> <li>*focus on a good outcome for every conversation</li> <li>*set the terms of what a good outcome will be</li> <li>*plan to end in a way we can decide on a positive way forward</li> </ul>	<p>*ask mum what she wants for dinner to help decide on what to buy</p> <ul style="list-style-type: none"> <li>*think of something which I know is simple and I know where the ingredients are and just buy that</li> <li>*go past an isle that is really busy and come back</li> </ul> <p>And later in interview</p> <ul style="list-style-type: none"> <li>*use visual cue at the supermarket – something that I know will be easy to cook and purchase semi spontaneously</li> </ul> <p>Discussed walking past a busy isle at the supermarket and coming back when it was quieter as a strategy to cope with the complexity</p> <p>“Q26 (awareness issues</p> <p>Unable to remember</p>	<p>making decisions about storage – who he would sell to – how he would transport the good etc</p> <p>Q18</p> <p>?? doesn't have the big picture about how he wants the storage and distribution to work in NZ, therefore going around in circles and not able to make decisions and sequence ideas into a plan</p> <ul style="list-style-type: none"> <li>*Starts considering different possibilities –</li> <li>*Listens to others suggestions helps him formulate ideas which he can then evaluate</li> </ul> <p>Q 19</p> <p>Recognises difficulties planning how to store and sell the art work back, once it is back in NZ, and considers delegating the latter part of the process</p> <p>Q 20</p> <p>Strategy for decreasing the</p>	<p>concentration – post acute: Use calm background music to assist with staying on task,</p> <p>Q39</p> <p>Strategies to aid memory</p> <ul style="list-style-type: none"> <li>*Make lists and tick off when task achieved</li> <li>*Log appointment onto phone calendar with a warning half an hour before need to leave</li> <li>*Revert back to paper diary, to keep track of planting and sewing, as cant retrieve this from diary on smart phone (yet)</li> <li>*learning to use memo on phone (need a process to evaluate apps – technology apps not therapy driven as yet).</li> </ul>	<p>likely to happen when I am tired</p> <ul style="list-style-type: none"> <li>*apologise when you notice it happening</li> </ul> <p>Q33</p> <ul style="list-style-type: none"> <li>*don't expect your best work when tired – OK is good enough</li> <li>*get the other adults around you to write the notes if the right words wont flow</li> </ul> <p>When I am tired – driving is affected –</p> <ul style="list-style-type: none"> <li>*If in doubt STOP</li> </ul> <p>Q35</p>
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