

DISSERTATION

Narrative Inquiry Into Family Functioning after a Brain Injury

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## ABSTRACT

The lived experiences of the family of a Traumatic Brain Injury (TBI) survivor is an under represented, yet growing field of qualitative psychological research.

This thesis used a case study approach with a family in which one member sustained TBI thirteen years previously. Using conversational unstructured interview techniques, I participated with the family in eliciting public narratives around their experiences since the accident. These public stories were also thickened by individual interviews, which both supported and contradicted the public narratives.

In the analysis I found two major narrative lines, the first of which was the *baby-narrative* which held that the injured person must not be injured any further in word or deed and must be protected at all time. The second dominant narrative was the *fighting-narrative*, which was characterised by language and actions around fighting/battling on behalf of the injured person against uncaring 'others'. Several important suppressed or counter narratives emerged during the individual interviews, which could not be spoken about publically.

I conclude that the power of the two dominant narratives is fuelled by constant rehearsal and enactment, which actually freezes the family and does not allow it to move forward. Suppressed stories are discussed as a possible avenue for therapeutic growth and for the evolution of the family story as they age.

## INTRODUCTION

This research project focuses on the 'lived experiences' of family members years after one of them has received a Traumatic Brain Injury (TBI). Through interviews with the family we created, rather than discovered, a narrative account of their experiences. The interviews that we took part in together and their subsequent narrative analysis are not vehicles to a 'truth' that the family holds, but instead the stories themselves are their 'truth' (Gergen, 1998).

This section introduces the reader to much of the individual physiological and social reactions to a brain injury as well as the commonly experienced 'phases of rehabilitation'. Literature on the complex and idiosyncratic systemic reactions of having a member of the family receive a brain injury will then be discussed. Finally, this section discusses the need for further research to be focused on the often hidden and private world of a family trying to cope after TBI has taken place years before.

### **Personal effects of Brain Injury**

A traumatic brain injury (TBI) is characterised by any injury to the brain as the result of a blow to the skull when the head collides with another object. The resultant brain injury is then caused by the rapid exogenous acceleration, deceleration or rotational forces (Kay and Lezak, 1990; Foulkes, Eisenberg, Jane, et al., 1991). The severity of a person's injury is usually measured at the time of injury by the Glasgow Coma Scale (GCS) and by length of Post Traumatic Amnesia (PTA). These measures have been shown to relate to longer-term outcomes (Bishara, Partridge, Godfrey, and Knight, 1992). However, this medical conceptualisation cannot account for the myriad social and psychological aspects of the injured person's life, as well as their family system and integration into society (Wilson, Gracey, Evans, & Bateman, 2009).

Whilst all people with TBI will differ in their recovery and rehabilitation, many will have a combination of personal impairments in the cognitive, emotional, behavioural and physical domains. The longer-term implications of impairments may only gradually become apparent over several months and years after the injury. Cognitively, people with TBI often display a decreased ability to plan, organise, remember and reflect. Their relatives may experience these difficulties as the individual 'just not having any insight' into a problem. Emotional changes are often cited as the most distressing type of change for the family to deal with and these include 'changes in personality', decreased awareness, becoming more demanding, as well as possible increases in anger (Bond et al, 2003). The physical effects include limb weakness, increased tiredness, dizziness, and lethargy, which lead to difficulties in concentration and attention. Often reported changes in the continence and libido of the individual are also associated with the physical effects of TBI (Florain, Katz, and Lahav, 1989).

Although TBI affects individuals idiosyncratically, most of their previous levels of communication and social interaction will be affected to some degree. This can subsequently lead to difficulties in areas of social judgement such as empathy, making and sustaining relationships and maintaining mentalizing ('mind reading') skills. The

interaction of all these acquired difficulties can be challenging for others to understand. Functional impairments such as a relationship breakdown and decreased employability also contribute to the individual deficits, which are frequently experienced.

As all people exist within multiple overlapping social systems, the devastating and sudden change to the personality and the functioning of the injured person feeds back into the surrounding interactional familial system. As these changes are felt within the family system, so they in turn feed back to the injured individual which can create a cycle of interactional loops.

## **Phases of Recovery**

Consistent findings from several reviews have been used (Florain et al, 1989; Jumisko, Lexell, and Soderberg, 2002; Oddy and Herbert, 2003; Verhaeghe, Defloor and Grypdonck, 2005, Klonoff, 2011) to track the process of personal adjustment into four phases.

### **The First Phase**

The first phase of TBI is characterised most frequently by an accident which is followed by an emergency admission to hospital of a patient in a state of unconsciousness. This is a complete shock to the family system and this sudden impact on the homeostasis of family life often leaves the family members reeling and unable to function (Williams, 2008). Priorities within the hospital are around the immediate saving of life and stabilisation of the 'medical patient'. This is a period of turmoil for the family who are typically focused on the same 'life and death' questions as the hospital staff. The family often spend time living in the hospital and look at very small signs of recovery as important (Turner, et al. 2007). The sudden and catastrophic onset of the accident means that the family's focus is on the short term, as the period in hospital often changes rapidly. Families often report moving between hope and despair, and engaging in 'wishful thinking' whilst the injured person is in a coma (Brown and McCormack, 1988).

### **The Second Phase**

The second phase begins when the patient starts to emerge from their coma and a period of Post Traumatic Amnesia (PTA) is entered. PTA refers to the period of marked confusion and clouded thinking which is associated with the inability to lay down new memories (anterograde amnesia) or to remember the period before the accident (retrograde amnesia). The injured person often experiences this as a very frightening period in which they perform strange behaviours arising from an inability to understand their situation. The family enters a 'practical mode' phase with support from wider family members and friends. Practical issues are highlighted and often embraced, e.g. such as devising hospital visiting rotas. As the family are aware that the injured person is now unlikely to die, their thoughts move away from mortality and onto other issues such as practical daily tasks that need to be done.

## **The Third Phase**

The third phase of rehabilitation is characterised by hope and optimism about 'recovery'. The patient can emerge completely from PTA and undergo a steep improvement curve and the thoughts of the family may now turn towards thinking that the injured family member is able to make a full recovery and return to normal. Prominent family questions may have changed at this stage to those questions which concern a timeline for full recovery. The family at this stage is still looking at all the positives and expect them to continue as they transition out of hospital (Turner, et al 2007).

## **The Fourth Stage**

The fourth 'long term adjustment phase' is possibly the longest phase for both the individual with the injury and for their family. Adjustment to the impairments of their emotional, cognitive, and physical lives, as well as to the changes in their social and communicational styles all present on-going challenges for the family and for the individual (Man, 2002). At this point, it becomes clear that the family are survivors just as much as the person with TBI is. Therefore, while the family members are the best source of support for the injured person, they are also secondary victims (Bond et al, 2003).

The ability of the family to adjust and to form a new coping identity depends on many factors. These include physical factors such as the site and severity of the injury and the length of PTA. Perhaps more importantly, it also depends on many of the systemic issues outside of the individual which are resident within the family such as the family's 'pre morbid' coping style, the amount of extra familial support that they are able to retain, and the extent to which they are able to integrate the new and old family identities (Palmer, 2010 in Bowen, Yeates and Palmer, 2010).

## **The Family Reaction to Traumatic Brain Injury**

*...there is a body of evidence concerning the impact of brain injury on the family and remarkably consistent findings have been obtained in a wide range of studies over the last three decades... (Oddy and Herbert, 2003, p 270)*

Florain, Katz, and Lahav's (1989) seminal paper summarised the current understanding of the literature written on the effects that 'brain damage' had on family functioning ['brain damage' was the term used by Florain et al, in place of the term 'TBI' used throughout this paper.]

The paper contends that disruption to the 'family narrative' has the greatest impact on family functioning. Family narratives are defined here as stories that represent experience and that are meaningful to a particular audience (Wells, 2011; Gergan, 2009). Wells (2011) explains that narratives are the way in which [the family] restores its violations of normality. Florian et al (1989) contend that the family must acquire a

new and coherent view of their emergent reality to create a narrative that accounts for the TBI.

However, TBI disrupts this process, as it challenges the creation of a new more nuanced and integrative narrative. The authors compare TBI to spinal cord injury (SCI) to make the point that the overall impact of a brain injury on the family is greater than the sum of the individual aspects of the injury. The authors contend that in their sample, the needs of the family with the brain injury were greater than those with spinal cord injury. However, the resources available to the family of a TBI member are often more scarce than those available to the SCI family, despite the extent of the physical injury often being the same or greater with SCI.

The authors highlighted the psychosocial changes that happen within the injured individual, which have both passive and active consequences on family relationships. Family members often report that these psychosocial changes are greater than the physical and cognitive counterparts often found in brain injury. This is a finding which has been supported since this original paper (Man, 2002; Turner et al 2007; Jumisko, Lexell and Soderberg, 2002).

The integration of a new identity for the injured person is often hindered by the injury's effect on executive processing skills. These reduced executive functions cause a consequent reduction in abilities of flexible thinking, self-reflection and abstract reasoning.

Florian et al (1989) show that the emotional distress and disturbance in the family is related more to the psychosocial and identity changes in the injured person than with the site or severity of the injury. As time progresses, these problems can become entrenched and therefore become more problematic for the family system. Tension, fatigue, mood changes, deficits in life skills, social skills, behavioural inhibition and high levels of anxiety within the family are all cited as potential sources of family disharmony.

The authors demonstrated how the “mental health functioning” of family members, psychosomatic changes, social and family functioning, social relationships, sex and parenting were all affected by TBI. Lack of social ‘skills’, and more demanding personality styles, as well as the more embarrassing personal care needs for the individual, can result in an inevitable reduction in social contact for the injured person. This ‘self imposed exile’ can lead to wider family systems not realising the difficulties that are being faced within the nuclear family, and lead to increased levels of depression for family members.

Both sleep disturbances and anxiety are commonly found in family members of people with a brain injury; the authors contend that depression, denial, anger and guilt are all common consequences of this. The social isolation and withdrawal which is common in many brain-injured families can lead to depression and once spontaneous recovery from the injury plateaus, then the family may start to isolate themselves; they may be embarrassed by the person's on going behavioural changes and because the uninjured



family members cannot go out as they are always 'on call' for the injured person. Social isolation can lead to conflict which is hidden from their wider society, and this in turn can remain unchallenged and linger within the family.

Isolation can be imposed on members of the nuclear family by their friends and wider family. During the acute phase of the injury (phases 1 – 3, above) it is common for family and friends to rally around and give support. However, as the post acute phase of rehabilitation progresses, family and friends often diminish (Callaway, Sloan and Winkler, 2005). Often reported changes in character and identity within individuals with brain injuries can lead to social withdrawal by family members (Yeates, Gracey and McGrath, 2008).

This paper also highlights changes which occur in the roles between husband and wife when the husband has been injured. There is a comparison of this role change with mothers of injured adult males, followed by a discussion of Caregiver Burden. There are few published discussions about how dynamics within a whole family have changed post injury.

In their paper, Jumisko, Lexell and Soderberg (2002) qualitatively aimed to explore the lived experiences of close relatives of 12 people who had sustained TBI. The authors used Phenomenological Hermeneutic Interpretative techniques to analyse semi-structured interviews with each of the family members. The interview schedules focused on life pre/post injury, meeting other people and on the care of the person with the TBI. This approach identified the major theme for the interview which they labelled "fighting not to lose one's foothold". This theme was then subdivided into six sub themes: getting into the unknown; becoming acquainted with the changed person; being constantly available; missing someone with whom to share the burden; struggling to be met with dignity and seeing light in the darkness.

These six subthemes were then interpreted in the comprehensive analysis through Eriksson's ideas of suffering, love and hope. The ability of the family member to care for the person with the TBI was curtailed by their own suffering, even though they felt that they had an ethical obligation to care for the person with the TBI.

This paper clearly demonstrated that clear and consistent information and support are incredibly important for the family from the point of the injury and continuing throughout the rest of their lives. However, one major conclusion from those who were interviewed was that professionals did not seem to give a clear and consistent message; they didn't seem to have time for the families and they seemed not to have a clear understanding of what the family was going through. This theme recurred throughout the paper and has been found by other researchers since this article was written (Bond, et al, 2003, Turner et al, 2007).

The family rarely start out being carers for a brain-injured member, and new identities take time to emerge in the post acute phase, long after the confusion of the initial injury. The authors contend that if the families had someone to understand and reformulate their experiences, then this would lead to better outcomes. The participating families

explained that their stories changed over time, as did their subsequently lived experiences through later interpretations of their memories. Due to the continually changing family life that TBI causes, the burden of living with someone with TBI does not decrease with time (Jumisko, Lexell and Soderberg, 2002).

### **Coping with Life in the Long-Term Adjustment Phase of Rehabilitation**

Whilst it is clear that the burden for the family is complex; 'outcome and family coping' style is not consistently described within the TBI literature. Two review papers (Verhaeghe, Defloor and Grypdonck, 2005; Oddy, and Herbert, 2003) on 'outcome and coping' aimed to address this.

Verhaeghe, Defloor and Grypdonck (2005) reviewed the existing literature as being poorly organised, and they attempted to structure the available literature on 'stress and coping in families with TBI,' according to two prevalent theories; the 'stress-coping model' and 'systems theory'.

Lazarus and Folkman's (1984) 'stress coping model' demonstrates that the stress that people might feel given a particular stressor, is dependent not only on the intrinsic stressfulness of the event/situation, but it is also dependent on the internal resources of the person interacting with that stressor. The concepts of subjective and objective stressors are useful concepts when considering carer burden. Lazarus and Folkman separate 'problem focussed' and 'emotion focussed' coping styles. The person engaged in the 'problem focussed' coping style will aim to change the environment or themselves in order to cope with the stress, where as a person engaging in emotion focused coping will attempt to reappraise their situation to find new meanings in their difficulties in order to cope.

The stress-coping model explains the brain injury as the stressor and the way in which families cope with this stressor as their 'coherent coping strategy'. The authors contend that families of TBI will aim to reduce stress with strategies which comprise either a 'problem focused' or 'emotion focused' coping style.

Verhaeghe et al (2005) applied this model to the coping styles of family members of somebody with TBI to the more general principle of caregiver burden. However the authors attest that the distinction between problem focused and emotion focused coping is arbitrary, as many strategies fulfil both mechanisms. Therefore, there may be other ways of conceptualising a family's set of copings strategies – i.e. systems theory.

The second conceptual framework which Verhaeghe et al (2005) address is systems theory. Systems theory states that all systems - of which families of TBI are one - are interconnected amongst all their members, in a bi-directional fashion. This means that father-mother or mother-child interactions for example will each influence each other. These systems are never complete and evolve continuously with time. As one member of the system is affected, the consequences of this effect will be felt throughout the entire system in a new phase of its evolution. These ripples are due to the

interconnected nature of all the participants. Because of this process, all family systems will thus use various and differing ways to process and manage their experiences.

Family systems will often strive for homeostasis and as such, many elements of the TBI including the changes in personality; impairments in social and communication skills and emotional and behavioural life, will act to significantly disrupt the homeostasis of the whole system. At such a time, a new equilibrium can only be achieved if all the family members are able to adapt and evolve towards a new state of balance (Leaf, 1993).

### **A Possible Framework for the Family Adaptation to TBI**

Oddy and Herbert (2003) responded to a perceived lack in the literature of a 'well-articulated conceptual framework' for family adaptation. It is important to appreciate that how families experience the impact of a member's TBI may be processed and managed in different ways.

They explain the need for professionals to have some appreciation and understanding of the internal dynamics of a family which has recently been injured in this way; in particular to the well documented conflicts around the relative roles of the mother and the spouse of the brain injured person. The emotional and personality changes are so often cited as being of far greater distress to the family than the physical changes which cause them.

Oddy and Herbert (2003) propose a possible framework for the family adaptation to TBI. They state that denial of the obvious difficulties and fantasies about possible outcomes could serve as a protective factor against distress, rather than as a negative escape from the reality of life. According to the authors, cognitive adaptation is an important part of the framework for adaptation. Increasing self-esteem, feelings of control and a sense of meaning are all important elements of cognitive adaptation. Interestingly, the notion of cognitive adaptation views 'denial' as a positive way of coping with adversity, and frames it in terms of helping families to view their predicament as a challenge, rather than as a threat.

'Objective and Subjective Burden,' are seen as being important in the framework for family adaptation; the objective burden is the actual extent of the injury and the subjective burden is the family's perceived ability to cope with this burden. Emotion focused coping verses problem focused coping styles are considered at different stages in the process of rehabilitation. Oddy and Herbert (2003), like Verhaeghe et al (2005) attest that when considering families of people with a brain injury, Lazarus and Folkman's (1984) distinction between emotion focussed and problem focussed coping styles are arbitrary. For families, there is the single traumatic event followed by an on-going series of unremitting forms of stress; as such, both emotional and problem focused coping styles are needed according to Oddy and Herbert (2003).

Bereavement and loss are also important elements of adaptation to TBI. Families undergo a similar process to mourning in 'unresolved grief' reactions. The role of the

unresolved loss is explored from a constructivist position by Komonski (2011, in Harris, 2011) and Harris (2011; Neimeyer, Harris, Winokuer & Thornton, 2011). They posit that grief cannot find a resolution if the 'meaning making' of the grief cannot be resolved and if the person has not actually died; the grief that people can then feel for the lost characteristics of their loved one may never reach resolution.

While the person has not been lost, a 'stranger' who has to be looked after in place of the loved one may replace them (Wood, 2005). There is a general sense too, amongst the families of people with brain injuries that 'no-one understands', i.e. GPs, health professionals and social workers cannot empathise with the problems of the family. The loss involved in the family is not simply the loss of the pre-morbid brain injured person, but also the loss of the pre-morbid family unit and their plans, intentions, hopes and fears for the future (Booth and Tyerman, 2001).

A family systems model was used by Oddy and Herbert (2003) to explain some of the role changes inherent in the family adapting to brain injuries, particularly when a child assumes the role of the injured parent, or a partner of the injured person might assume the role of the mother or father.

In attempting to categorise the process of family adjustment and coping, it is important to acknowledge again that all families are unique and that not all families will go through the same adjustment process. Man (2002) found that because coping varied across families, more research was needed to explore the topic further. Man (2002) also found that mastery of the situation, clear personal expectations and flexibility were important factors in increasing the levels of 'coping' in the families that he interviewed for his narrative research.

### **Clinical Relevance**

This research offers the family an opportunity to recount its story of coping and adaptation in the long-term recovery phase, after the TBI. This family narrative is unique in every case although themes from the adaptation literature have emerged. Research papers exploring adaptation of families several years post injury, are relatively sparse and this research paper will enhance public understanding of the family narrative post TBI and add to the qualitative and experiential literature on family lives post-injury. This research is almost unique as it will allow narratives which are concerned with the intra-family relationships as well as the relationships between the family members and the injured person, to arise naturally.

Many difficult and complex processes happen within the family which are hidden from a medical conceptualisation of a brain injury and this is a frequent complaint of families who have experienced TBI (Florian, Katz, and Lahav, 1989; Jumisko, Lexell and Soderberg, 2002; Andreatta, 2008).

Clear advice and information has been cited as an absolute need for the family in the early stages of TBI. The lapse in time between the 'recovery phase' and the development of full and complex problems in the system during the later 'post acute rehabilitation

phase,' may preclude health service participation. However, as the post acute period develops, the family's narrative becomes more, rather than less complex and as such, the advice and support must also change and develop (Bond, et al, 2003). The post acute long term care for the individual and their family needs further consideration from the professionals working in this field, which this narrative enquiry will aim to provide. As with all narrative inquiries, this research will offer a voice for the lived experiences of a family, which would otherwise be hidden (Bond et al, 2003).

Providing a clear 'map' of one family's narrative through the post acute phase of TBI may help to demystify the difficulties within the family. Giving voice to the changes and struggles within the family can provide a clearer picture for both professionals in the field and for other families living in similar circumstances.

Since brain injury rehabilitation and 'recovery' was originally a medically-dominated field, work which looks beyond disability or trauma post injury could provide a deeper understanding for clinicians working or researching in this field. Such an understanding could consider the processes of adjustment; growth and adaptation to change; collaboration between family members; or between families and professionals (or other groups) to broaden the understanding of adjustment.

Finally, as this work is data-led, inductive qualitative research, I am not able to constrain the focus to preconceived concepts of how the family will story their experiences. Therefore, the family are free to tell whichever narratives are most important to them both as a unit and individually and therefore many unforeseen areas of interest may arise through the research. This notion is developed more fully in the methodology section.

### **Research Aim**

To explore individual 'uninjured' family members' experiences of having a brain injury within their family.

### **Why not include the story about the individual's own experiences of the TBI?**

My research project investigates the family's narrative of life in the long-term post rehabilitation phase of TBI. As such, I am only interviewing the family and not the brain injured person because the scope of this research is about the family's narrative alone.

In creating this work I was very conscious that the family narrative of living with a brain injury is often hidden and secret; it is often characterised by suppressed stories and ambivalent emotions. According to Wells (2011) the voicing of suppressed narratives is dependant on whether the speaker is able to feel that they have a mandate for the narrative; however when there are conflicting narratives, then some will be negated and suppressed. Therefore, I felt that by interviewing the family in the absence of the injured person, I would be more able to access these hidden narratives and be able to explore the family's ambivalent feelings with them.

Plumber (1995) demonstrates that stories can only become tell-able when there is an audience to listen to them. I interviewed each of the family members separately as well as together, to create a space in which they could air any narratives which must be hidden from the wider family.

So, by interviewing the family alone, I might be able to access the narratives which needed to be suppressed in front of the injured person. Similarly, by interviewing the family members alone, I hoped to gain access to those stories which they might have felt uncomfortable about airing publicly to the family.

As this work is reliant on co-constructing our reality and creating our knowledge together, I must necessarily interpret the language used in the interviews. Interviews, according to Wells (2011), are sites of knowledge production, and the form this knowledge takes is linguistic (p. 27). Therefore, in the specific case of the family which I interviewed, Leonard (the individual with TBI) was unable to use language, and would not have been able to hold a conversation with me, which is made apparent by each of the family members.

I also felt that it was important that I did not meet Leonard during our interview process, so that my relationship with the emerging narratives from the family members would not be influenced by my own preconceived ideas of Leonard and systemic prejudices (Cecchin, Lane and Ray, 1994).

## METHODOLOGIES

### Rationale for Adopting a Narrative Case Study Approach

Wells (2011) has written very persuasively for the use of both case studies and narrative inquiry with families in social settings. Narrative analysis takes a poststructuralist, post modern and deconstructionist approach to narration within the social sciences.

She argues that because narratives or stories, frame the way that we construct problems and solutions, we therefore need to focus on language as 'emplotment', (Polkinghorne, 1995) or how people make sense of their stories via language itself, not just as a 'vehicle for meaning'. The narrative analytical approach is framed within the social constructionist argument, that suggests that language is paramount and meaning and truth are primarily created through language and how language is storied (Burr, 1995).

Analysing thus focuses on the meaning, content, context and audience, including 'ghost audiences,' within the family and personal narratives. As the stories themselves are the seat of the family's socially constructed reality, focusing on the stories around change and rupture can give a unique insight into how families have 'restored violations of [their] reality'. Therefore, the family of a person with TBI may have a rich and deep number of narratives that they have constructed to account for their 'shattered narratives' following TBI within their family (Williams, 2008).

Unlike traditional approaches to interviewing, narrative interviews accept that they are a co-construction between interviewer and interviewee. The thoughts, feelings, assumptions and underlying prejudices (Cecchin, 1994) of both interviewer and interviewee shape the structure and flow of the interview as it is created. By focusing on this co-created reality, narrative inquiry allows the researcher to examine how and why a story is created and what it accomplishes. The story is considered as a whole rather than as a 'sum of its parts' in its effect on the audience (Wells, 2011).

Bond, Draeger, Mandleco and Donnelly (2003) explain that in-depth narrative enquiries into families of people with TBI can give a 'voice' to the lived experiences of the family that might otherwise be lost. Narrative investigations can also give voice to the 'neglected subsystems within the family' such as siblings, whilst the narratives of mothers and spouse caregivers are perhaps relatively well established (Bowen, Yeates and Palmer, 2010).

Injured individuals can experience long-term emotional, behavioural, cognitive and physical disabilities, which persist beyond the time when neurological recovery has reached a plateau. The presence of cognitive and emotional impairments and the discrepancy between the behaviour of the individual pre and post injury is often a narrative which may be hidden publicly, but held within the family which is otherwise unable to tell their story. These idiosyncratic family groups cannot be studied with

positivist randomised control studies, as these would neglect in-depth experiential processes.

There is thus a gap in research that investigates the lived experiences of the family members (Man, 2002). Narrative analysis based on a social constructionist model seems appropriate to investigate the public family narratives and the personal coping narratives held by individual family members within a family.

Familial experiences following TBI have traditionally been under researched (Chwalisz and Stark-Wroblewski, 1996). The lives of family members from the brain injury family are irreparably changed and the burden of this change is not seen to diminish over time. Several research papers (Florian, Katz, and Lahav, 1989; Jumisko, Lexell and Soderberg, 2002; Andreatta, 2008) have identified the need for more research in the area of the subjective experiences of families in which one member has a TBI.

### **My position in relation to a narrative approach**

At heart I feel that I have embraced the Social Constructionist and Constructivist aspects of the UH DClinPsy course and find that this philosophy infiltrates all areas of my professional life. Since starting training, I have become very interested in systemic and narrative thinking, especially when considering how a personal or family narrative can develop and change on its own course, without being rooted within any so called 'objective' reality.

The lives of the family members in the brain injured family are shaped by the stories they tell. These stories may differ or overlap, creating a shared co-constructed narrative of their lives since the injury. However, stories may also potentially clash and compete for dominance within the overarching family narrative, resulting in some stories being more privileged or readily accessible within the family.

In understanding how such a family creates its story, it is understood that no single story is more correct than another (Burr, 1995) and as such the narratives which the family members create about their lives are likely to be dependent on their own individual life experiences, beliefs and values. The traditional brain injury narrative was initially very firmly rooted in a medical model but, more recently there have been efforts to embrace a broader perspective on ABI/TBI, including individual and family based perspectives on identity change and integration post injury (Yeates, Gracey and McGrath, 2008; Wilson, Gracey, Evans, and Bateman, 2009; Segal, 2010; Bowen, Yeates and Palmer, 2010). Narrative research affords the family the opportunity to express their constructed narrative and present it to the medical profession (Bond et al, 2003; Brown and McCormack, 1988; Turner et al, 2007).

The surveyed research literature illustrates a need for more qualitative understanding of families who have an individual who has experienced TBI and so the focus of my research will be data led on the lived experiences of a single family. This narrative research will hope to both complement and challenge the public and professional discourse on TBI which views the medical-model of disease and cure as dominant



(Halligan and Wade, 2005). Possibly as a reaction to this, my interests have developed within a field of interpersonal, systemic interactions, which either cannot find any current and significant emphasis within that medical field, or can clearly be shown to be at odds with it, (Boyle, 1990; Dallos and Draper, 2000; Johnstone, 2000; Johnstone and Dallos, 2006; Szasz, 1974; Vetere, and Dallos, 2003).

### **Writing from the first person**

Throughout this report I have chosen to write in the first person singular pronoun form for two reasons. Firstly, by saying, 'I...' I make it clear that I am not attempting to convey objectivity or 'truth' in my writing, rather that I am adopting the position of the interviewer for 'whom the interview is a joint accomplishment' with the family (Fontana and Prokos, 2007). Therefore I am keen to 'own' my position during this work, and acknowledge that the work is a co-construction. Secondly, I believe that using the first person pronoun humanises the report and in turn creates a relationship with the reader (Gergen, unpublished manuscript); the post-modernist position suggests that the reader cannot have a relationship with the work which is free from their own (your own) social and political context (Gergen, unpublished manuscript; Gergen and Thatchenkery, 2004).

### **Ethics**

This study received ethical approval from the University of Hertfordshire ethical approval board on 22nd of June 2011, registration protocol PSY/06/11/AB. See the appendices for the ethical approval forms.

### **Informed consent**

The participants in this study were recruited through A Brain Injury Association. The participants were sent the information sheet from appendix A by email before the study. On the first family meeting, they were given a hard copy and were asked to sign a consent form (appendix B) which stated that the family understood that their participation was voluntary and that they had the right to withdraw from the study at any time. They were informed that their confidential information such as the voice recordings would be destroyed after the conferment of my degree.

### **Confidentiality**

The participants were informed via the information sheet that their personal information would be removed from the data so that they would be anonymous. The names that appear throughout this report are pseudonyms. However, it was explained in the information sheet and reiterated in person that there was a limit to any confidentiality through anonymisation. The family were taking part in a case study and therefore they would be likely to be able to identify each other when reading the report. The family were warned that what they were saying could ultimately be read by other family members and they should remember this when taking part in the study. They

were reminded that as the data (in the form of mp3 files and transcripts) was confidential, it would be protected and held securely by me, until destroyed.

## **Design**

The process of qualitative research is non-linear and the data collection, analysis and interpretation are not discrete phases to be completed before subsequent phases can start. Instead, the circular nature of the work means that the research questions, data collection, interpretation and analysis will affect each other and feed back into the aims and collection methods for the study (Mishler, 1986; Wells, 2011).

## **Emergent design**

The process of an emergent design is one in which study aims are flexible and will be defined according to the data that is being produced in the interviews. Emergent design is informed by a process of inductive rather than deductive reasoning (Morgan, 2008). This means that the design of the study aims to produce experiential data, which can be interpreted and commented upon. Alternatively, deductive reasoning would involve using the family to test theory (Morgan, 2008). The study cannot therefore be designed too rigidly, because it is impossible to know beforehand which themes will be important to the family. For this reason, a much less structured interview approach was adopted.

## **Case Study Design**

Wells (2011) argues that case studies are useful research paradigms as they create 'context dependent knowledge and critical cases against which to test a theory and a typical case with which to refine theories'. The more complicated the narrative, the fewer participants are required within the unit of analysis; five may be sufficient for very complex case studies (Wells, 2011, pp. 20).

Given the idiosyncratic nature of all TBIs and the equally unique nature of family life; a case study is very appropriate for this field of study as it allows for a deep and thorough investigation within that single family which can exemplify or challenge current understandings on the topic (McAdams and West, 1997). The social world is continuously changing and so findings from social research cannot be generalised outside of the time and place in which the investigation occurred. Therefore, the findings from case studies should only be treated as working hypotheses. Case studies can also attend to contextual data about where the family is placed within its wider society and so offer a greater and deeper understanding of the underlying meanings and assumptions inherent within the family narratives (Wells, 2011).

## **Sampling methods**

The study used purposive sampling. Purposive sampling is the recruitment of participants who have experienced the phenomenon under study (Starks and Brown Trinidad, 2007) and this sampling differs from probability sampling in that it uses

smaller numbers and aims not to create a representative sample of a target population, but to recruit a sample from which to create an in-depth understanding (Patton, 2002).

### **Inclusion/exclusion criteria**

I aim to recruit a single family for a case study.

### **English Language**

As a major focus of this work is on the language that is used to create the stories within the family and within and between individual family members, I will insist that the family are articulate first language English speakers.

Although I understand that research into ethnic minorities and the non-English speaking population is not explored fully enough, especially within an NHS context, the nature of narrative research means the process of creating a co-constructed narrative strongly influences this inclusion criterion.

### **Time since the TBI occurred**

Because I am interested in the family that has settled into a new 'reality' post brain injury, I am therefore interested in recruiting a family where one member has sustained a moderate to severe brain injury.

The injury would have to have happened at least five years before the start of the research. I chose five years, as it would have given the family time to have settled into their 'new lives'. The shock of the TBI may have subsided by this point and 'a new normal' way of functioning might have emerged.

The severity of injury will influence the time that the injured person is in acute rehabilitation phase; as such, five years may be a useful length of time to wait. The input of healthcare professionals is also likely to have reduced considerably five years after the accident and the family might be experiencing life 'on their own' by this point. However, the extent of the initial injury would mean that there is also an enduring impact from the TBI on the individual (and family) which has become part of the family's narrative.

### **Home circumstances**

The injured person will be medically stable, living in an established environment and will have been out of the hospital for a prolonged period of time. This way the family will be involved in the long-term phase of 'recovery' and less likely to be buffeted by the fast moving, unstable phases at earlier stages of the recovery.

### **Participant recruitment**

The participating family was recruited from a brain injury charity in South East England. I approached the family liaison worker at the charity and introduced my research. She invited me to a monthly family support group where family members and carers meet each other for informal support without the injured person coming with them.

I presented my proposal and left my details with the group. Several people at the meeting were interested in the research but did not meet the inclusion criteria. One man who was eligible gave me his card and agreed to take part in the study. I e-mailed him the following week and asked him to give the information sheets to people in his family and invite them to take part in the research if they consented to. All correspondence was through 'Gareth', the father and he invited those family members who eventually came to the interview.

All the names of individuals and service providers have been changed to protect the privacy of the participants. Some inherent bias in the selection procedure might be apparent because Gareth would have chosen only those people from his family whom he considered worth inviting.

### **Participants (the family)**

The 'family' who consented to take part in the research consisted of Gareth (the father), Kristina (the mother), Terrence (the older brother), Alex (the maternal cousin) and Barry (the family friend).

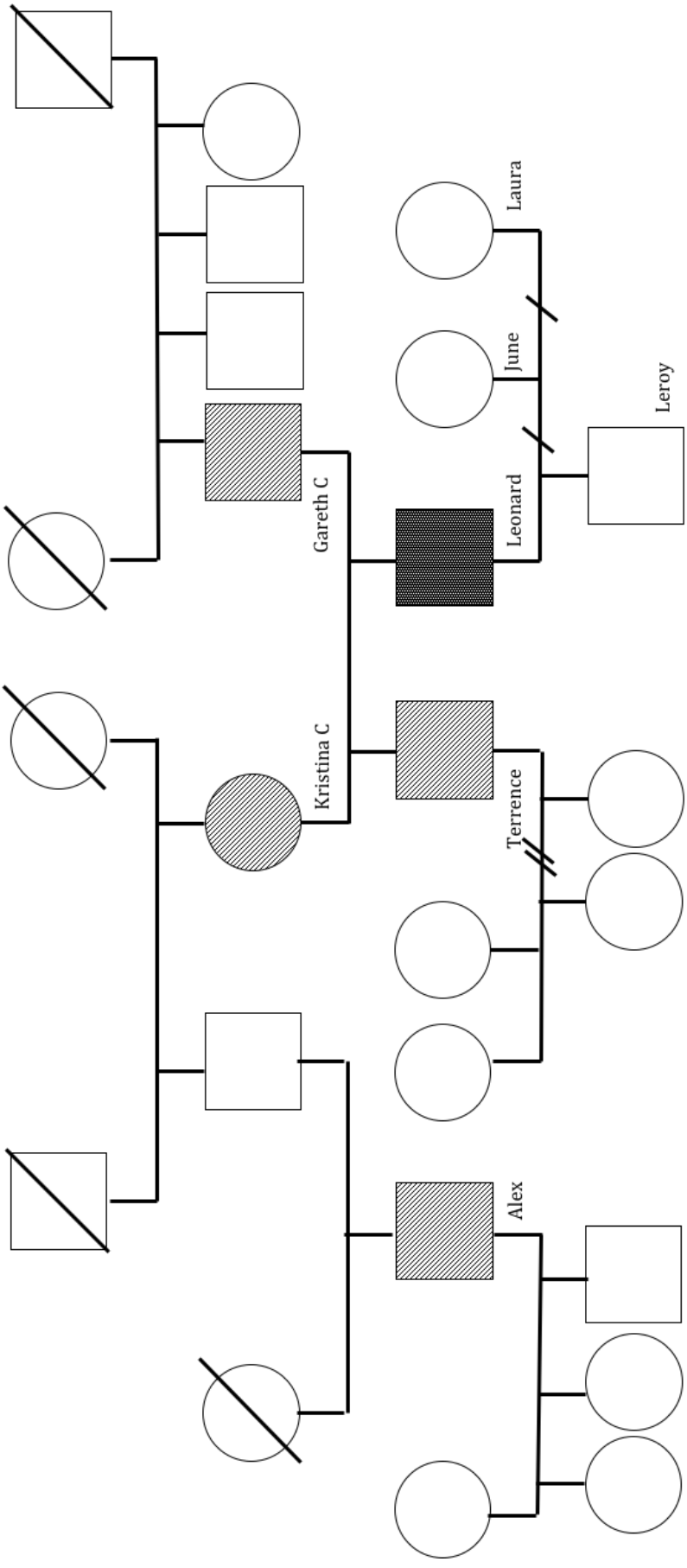
The following genogram (family tree) represents all those people who were mentioned in either the family interviews, or the individual interviews. Those people who took part in the interview process are represented by hashed lines, whereas Leonard, the IP is represented by the dark square in the centre. The genogram follows the standardised procedures (Jolly, Froom and Rosen, 1980; Hartman, 1995) with circles representing females and squares representing males. Boxes which have been struck through represent deceased people. A single line through the relationship is a separation, whereas a double line is a divorce.

Gareth and Kristina are the parents of the injured man, Leonard. Terrence is his older brother by five years. Alex is Leonard's cousin on his mother's side and Barry is a friend of Leonard and the family. As all my correspondence was with Gareth in the early stages of the work, I interviewed only those people who had accepted his invitation. I recognise that this has implications for the research, for example, cousin Alex was invited as he has regular contact with Leonard, and therefore his inclusion in the research is obvious. As is the inclusion of Barry, who although not actually a family member by blood, has also worked with Leonard and continues to enjoy spending time with him. Gareth had initially invited all the care staff to the interviews as well, arguing that they were as close as family by this stage.

## **Injured Person**

Leonard had been injured in 1998, after jumping from an aeroplane in a military exercise in France. His parachute failed to open properly and he sustained a number of injuries upon impact, including severe TBI. His GCS and PTA data was unavailable to the family. Leonard was initially treated in hospital, after which he received a period of in-patient rehabilitation and was discharged to a residential care home, but this placement was not sustainable. Leonard now lives in his grandfather's old house (which is just down the road from his parents' home) with 24-hour care provided by professional care staff. He has very limited movement and very little speech; communicating mainly through blinking or yes/no cards, which he will point to.

Figure 1: Genogram of the participating family



○ Female  
 □ Male  
 / Deceased  
 ---/--- Separated  
 ---//--- Divorced

□ Barry

## **Interview schedule**

No formal interview schedule was produced for this work and an unstructured interview was planned. The social constructionist position states that the knowledge which is co-created between participants and researcher will depend as much upon the researcher's position as the family's position. Therefore, by creating an interview schedule it would have presupposed which themes or topics would be important for the family to address. These privileged positions and narratives might then have prevented other counter narratives from emerging.

The emerging design process therefore starts in a very unstructured way and builds its structure by either narrowing or widening the focus as more information is gathered on the topic.

The narrative question which I used to start the interview was "Please tell me about your experiences of life since Leonard's accident". Mishler (1986) describes stories as being jointly constructed via relatively few and open-ended questions. This very open ended approach to the interview places the emphasis on the family 'driving' the research, as it allows them to focus on what is most important to them rather than to me as the researcher. The important themes and narratives may therefore naturally emerge through this unstructured design.

## **Family and individual interviews**

This study employed two different types of interview procedures. Firstly, I interviewed the whole family together, which allowed the 'family narrative' to emerge naturally with the whole family present. Secondly, I interviewed each member of the family separately in a personal interview. This second type of interview was designed to let each participant elaborate on themes which came up in the family interview but which may not have been fully explored with all the members present. It also gave an opportunity for individuals to voice any stories running counter to, or in disagreement with, the dominant narratives emerging from family stories. Similarly, if the participant felt that they wanted to change or retract their opinion when away from the family group, then they could take that opportunity too. The individual interviews were similarly unstructured with individuals being asked whether they would like to add anything to what had already been discussed.

## **Procedure**

After recruiting Gareth at the 'the brain injury association' family day, I corresponded via e-mail with him to organise the date and time for the family interview. I was concerned initially that many more people than I would feel comfortable to interview would attend as the scope (family interview) and scale (DClinPsy) of the work suggested an optimal number of between 5-8 interviews. The care workers were unable to attend however, which made the interview process more manageable. The first interview took place on 9<sup>th</sup> September 2011 using a stand-alone audio Dictaphone and an iPhone, which has voice recording

capability. Attendant at the family interview were Gareth, Kristina, Terrence and Barry. Cousin Alex was absent, but had e-mailed saying that he would like to take part at a later date. The transcription service did not require the video as I had anticipated, and it was destroyed.

I use the term 'unstructured interview' here in my assertion that to formally structure or plan the interview would be to predict the outcome and bias the direction of the conversation before it had begun, in keeping with Mishler (1986) and Holloway & Jefferson (2008). Instead, I used an interview strategy akin to Patton's (2002) informal conversational interview, whereby my guidance was the simple exploration of the topic, and all subsequent questions which occurred to me came naturally as part of a normal conversation. As a Clinical Psychologist in training, this sort of interview is one which I undertake daily, in aiming to elucidate the underlying emotional and lived experience from a narrative.

At the beginning of the interview I read aloud the information sheet, paying particular attention to the confidentiality part and the participant's right to withdraw at any time. This gave me confidence that they were giving properly informed consent to participate in the work. Each of the participants signed the consent forms and gave me their contact details for arranging the individual interviews.

After securing informed consent, I introduced myself and asked who would like to start introducing themselves. I then asked the only premeditated question of the project "tell me about your experiences of life since Leonard's accident".

Whilst listening to and taking an active part of the conversation, I noted aspects of structure, content and performance of the narratives, which might have aided the analysis of the transcripts.

The Joint Construction of Meaning (Mishler, 1986) demonstrates that interviewers and interviewees both contribute to the understanding which is created during the interview. So, instead of the interviewer's questions necessarily leading to responses, one can usefully understand questions and their answers as a 'circular process through which its meaning and that of its answer are created in the discourse as they try to make continuing sense of what they are saying to each other' (Mishler, 1986, pp. 53-54). Therefore, I tried to remain mindful of any particular path that we were co-constructing during the interview. I tried to give everybody a chance to speak if they chose to accept it. During the interviews, I aimed not to "take things for granted" and questioned all of the assumed knowledge which was presented. By doing this, it fleshed out the narrative and helped to clarify potential points of ambiguity for me. The family interview lasted 90 minutes.

The family interview work was transcribed and listened through twice before I conducted the individual interviews with Kristina, Gareth, Alex (at work), Barry and Terrence respectively. There was no specific reason for this order, other than for our mutual convenience.



At the beginning of each individual interview, I reminded the interviewees that I was holding separate conversations as an attempt to get to know their individual story, as well as the more general 'familial' one. This might also allow them to talk more freely without fear of censure by having other people present at the same time.

The earlier analysis of the group interviews gave me some starting points which allowed an insight into the potentially difficult parts of the individual narratives. I could then use these as prompts in the individual interviews, if they did not arise naturally. The exception to the rule was with cousin Alex, who did not take part in the original family interview.

### **Transcription and analysis**

I hired a professional transcription service for this work ([executivetying.com](http://executivetying.com)) to transcribe verbatim the words used by the interviewees and me, including the number and length of pauses and the disfluent fillers. The appendix includes a copy of the confidentially agreement signed by the service.

I started to analyse the first interview as it became available as this allowed for the emergent design of the research to develop. This process of emergent design allows the analysis and interpretation to feed back into the direction of the study and affect the subsequent questions to be asked.

### **Analysis**

The analysis consisted of reading through the transcripts whilst listening to the interview on headphones and paying particular attention to the structure, the context, and the performance elements of the work. The work was formatted so that it appeared as landscape on A4 paper with large margins and all notes relating to these three elements were added into the margins, with separate sheets of paper used when required. I typed up all the notes into a spreadsheet which pinpointed the page and numbers that each of my interpretations came from. This meant that at the write-up phase, I could locate the direct quotes from the source material to backup my interpretations. I was careful to write down all of my personal reflections as well as my instinctive reactions to the conversations as they happened, both immediately after the interview itself and in the subsequent readings of story.

The write-up aimed to produce a coherent co-constructed narrative of the family story, which we created over eight hours of interview time together. This final text will include the public family narrative as well as the more hidden counter narratives that have emerged throughout the analysis, which appear outside of the dominant story.

In summary, for each hour of interview, I read through and made hand written notes on the transcripts around three times, before the fourth read through which involved typing up the hand written notes that I had made. During the fifth read, I wrote my analysis in draft and finished forms.

## **Quality Criteria**

Elliot, Fischer and Rennie (1999) suggested 'member checking' as a form of quality criteria in qualitative research. At each phase of the process I asked the family to check the transcriptions for accuracy. I was reluctant to show them any of my interpretations though for two reasons. Firstly, because the created narratives are necessarily co-constructed due to my social constructionist position and therefore my understanding of the story may not resonate with their own understanding. Secondly, time will have passed since the interviews were conducted and the stories of the participants may have changed over that time. The constructionist/constructivist position is clear that what is constructed as 'truth' can only be 'true' for a particular time, place and perhaps individual or group (Burr, 2003). My research therefore contends that adding to the work at a later date would change the narrative that was originally created.

Social constructionist research is influenced by the social, theoretical and cultural aspects of the researcher as much as by the data being collected (Yardley, 2000). Therefore, supervision was not used to establish a story which was right, but to check that an audit trail could be followed, and that there was an internal consistency in my argument. (See appendices for a copy of the family transcript and my attached notes on the transcript which informed my thesis).

As a researcher I understand that the way in which I constructed the narrative with this family might have been influenced by my demeanour, age, gender, class, ethnicity and many other variables.

I understand for example that as a white middle class male who is well spoken and articulate, I may construct a different narrative than if I was a woman in the same situation. As the only woman being interviewed, Kristina might have shared a different narrative with me had I been a mother of my own children, as there would be different levels of assumed knowledge. Had there been an obvious class divide between the family and me, that might also have had implications for the research, as would the fact that they might have perceived me as being in an 'expert position' despite my efforts to disavow that relative position.

## **My Reflective Position**

During the course of the research I regularly sought supervision from both my internal and external supervisors. They had different relationships with my work, from either a 'narrative research' or a 'practicing in brain injury' perspective. They were of different genders too and helped me to focus on different aspects of the problems I brought to them.

Being able to reflect with them was critically important during my work. During one supervision session for example, I was able to reflect with my external supervisor my 'annoyance' at Kristina and her attitude towards 'Laura'. This was clearly becoming a block for me and my understanding of her narrative.

Together though, we were able to hypothesise and explore alternative explanations for her actions, which caused me less annoyance and allowed me to see her narrative in a much different light.

Similarly, I found myself very drawn to Terrence's narrative and found that I was very sympathetic toward his pain. I again brought this up in supervision, and related it to my own life and feelings of needing to be seen and supported by my parents. This again helped me to gain more perspectives than my own immediate and unreflective position; upon which to base my interpretations.

Post structuralist approaches to narrative demonstrate the need to produce these competing interpretations (Harrison, 2006; Barthes, 1967). Such approaches to human understanding reject the singular notion of the 'I' self-concept and instead our understandings and interpretations of knowledge will shift depending on our own perceptions of self in relation to Kristina and to Terrence.

## RESULTS AND DISCUSSION

### Introduction the Results and Discussion Section

This 'results and discussion' section will focus on the two dominant narratives that emerged during the family interviews. The family owns these public narratives collectively and therefore they will form the basis of the discussion.

Taking each major narrative in turn, I will explain how these were created and reinforced publically, but how they were also contested within individual interviews. Several times 'supressed or counter narratives' were held by different family members. These points of agreement and contention are contrasted with the two major narratives.

The main stories are the *fighting-narrative* and the *baby-narrative* - these are held mainly by Gareth and Kristina respectively. Gareth and Kristina both rehearse their own major narratives and support each other. It is appropriate that the two dominant narratives are name through these tow most dominant voices in the family.

## Introduction to the *Baby-Narrative*

The following dominant narrative discourse was named as the '*baby-narrative*' as Kristina's story seemed bound up with this infantilising theme.

*"...he has become our baby hasn't he..." [FFI-P16]*

This narrative theme is characterised by an internal focus towards the family rather than outwardly towards society. It is a narrative of hope against the odds and a fight for the protection of what the family already have. This theme uses their internal resources, including an internal faith in God, to help with Leonard's care. Kristina mainly holds the narrative but implies shared ownership with the other members of the family by using the plural pronoun 'we' when describing their actions – she will often say 'don't we?' when looking for confirmation and validation of her actions and story.

In its performance, the *baby-narrative* appears sterile, with few overt emotions displayed. Through repetition and rehearsal, the traumatic emotions have been heavily suppressed. Only very occasionally do they break the surface, and they are quickly denied in favour of the dominant narrative which has an implicit avoidance of emotion.

This narrative positions Leonard as an infant, and also revels in the small achievements which he manages, as if he is a young and helpless baby. The *baby-narrative* maintains that everything is 'okay', and that things are going in the right direction. There is a denial of negativity, which is seen as a thing of the past; a stage from which the family have subsequently emerged. This narrative is fragile; and as its main author, Kristina needs to constantly maintain and reinforce it. The rigidity and fragility of this story means that it is susceptible to contradiction. Therefore, people who may not fully adopt this theme are perhaps implicitly discouraged and their narratives are suppressed.

Implicit within the *baby-narrative* is 'a lack of trust' in others who are seen as threats to the family unit and its continued preservation. As such the *baby-narrative* is one of being very involved in the day-to-day running of Leonard's life, whilst not letting other people such as the original set of carers, or the 'bad care-home' be a continuing part of it. Isolation is a natural consequence of such positioning, although it is not acknowledged within the *baby-narrative*.

The suppression of counter narratives means that anyone holding an alternative story of the shared experiences after the accident has no familial voice. Terrence holds a suppressed story in relation to this major narrative theme as publicly, he rehearses the *baby-narrative* - whilst, in private, he holds strong feelings of anger towards Leonard, as he feels neglected by his parents and resents the fact that Leonard is getting so much of his parents' attention, so long after the accident.

The *baby-narrative* started at the point of the accident; however, its rigidity means that it has had difficulty evolving over time. Gareth and Kristina are

ageing and will soon be unable to continue with their work for Leonard as they have over the last thirteen years. Negotiating this change in life circumstances puts a strain on the *baby-narrative*.

Finally, the narrative seems to have developed with the underlying rationale of meeting Leonard's needs, however, the *baby-narrative* may unwittingly be meeting others' unacknowledged needs as well.

## THE *BABY-NARRATIVE*

### **Factual stories and lack of engagement**

Terrence volunteered to tell the story of Leonard's accident, however, after a short time he paused and Kristina took over. It seemed very clear that Kristina had ownership over the 'facts' of the story, and was therefore deferred to by Terrence. I wondered if Terrence felt that he didn't have a mandate for owning and retelling this narrative.

The story that Kristina related was very factual, and takes little account of her feelings; it sounded very well rehearsed. It is now thirteen years since Leonard's accident and all the bright and sharp meanings of the hospital will have faded and have been altered through rehearsal and the passage of time.

This was a very sterile retelling, the function of which seemed to be that factual accounts don't necessarily lead to strong emotions. By narrating the story in this way it felt 'closed' and I was disinclined to ask probing questions; in reflection I think that this way of telling the story was a defence against the possibly difficult emotions which may be present. It also makes it less likely for anyone to damage the important *baby-narrative* where 'everything is okay'.

### **Protecting what she has from further damage**

During the family interview, Kristina seems to exemplify the *baby-narrative* when she describes the family as being "fighters" and her ideas about the importance of repetition in Leonard's life.

*"...he [the neurosurgeon] didn't give us much hope...but being fighters, we were prepared to keep on looking into the area...we found out that the brain can repair itself in parts...I've always clung to that hope...we've seen very slow but positive improvements...repetition, repetition, repetition...can help to create a new pathway in the brain and I've always clung to that..." [FFI-P5]*

This passage speaks of hope against the odds, and the absolute need to keep fighting for Leonard. This is a very important part of the *baby-narrative* and is related to the fact that she described the family as fighters. Kristina's description of them as fighters here relates to fighting against despair, rather than fighting against an external other. The second major narrative theme presented later in this thesis will address the idea of fighting others external to the system more directly.

Kristina's constant task is to be on the lookout for potential areas of improvement and stabilisation so that Leonard does not slip backwards, in such a way, the *baby-narrative* protects Leonard and the family from further harm.

*"...We've always been the ones to write to the GP..." [FFI-P6]*

*"...Oh yes, we never give up do we? You're always on the look out..." [FFI-P11]*

The *baby-narrative* protects the family through language by understating emotions. This happens throughout the family interview, for example Kristina said that it was “*disheartening...sad*” about Leonard's accident and she used the moderator “*but there's a lot of fight in us*” [FFI-P6].

I wondered if her resolve in constantly looking for new developments and repeating her mantra of “*repetition, repetition, repetition*” [FFI-P5 & 16] and “*stimulation, stimulation, stimulation*” [FFI-P11, 12, 14, 17, & 34] might be as a way of coping with the possibly overwhelming emotions of her situation, by holding onto hope.

*“...we've never stopped looking for those little signs and still to this very day are looking...for any...new developments in brain damage...”* [FFI-P6]

Kristina seems to be fighting against the loss and despair which could have crept into their lives and instead spearheads Leonard's care with all her strength.

*“...We've got hope, it gives us hope and we cling to that hope, because there's a lot of untapped energy out there and resources...”* [FFI-P10]

### **Positioning and performance of the *baby-narrative***

Kristina frequently uses performative techniques when talking in the family interview. She imitates the voice of an imaginary GP here, and adopts a pleading voice in response, which appears to be saying how helpless and powerless she is. Perhaps in doing this; she can uphold the family's position, i.e. as underdogs relative to the authorities.

*“...Even the GP has never come to us, Mr and Mrs C, there's a new development we'd like you to try. Nothing, nothing.'... 'Please could you refer us to a neurologist?'... 'Could we see a new physiotherapist?...'”* [FFI-P6]

However, her performance changed during later parts of the interview, for example she used a much more active voice to describe getting a meeting to be attended by sixteen people for Leonard.

*“...through our complaining we went to a meeting at the Hospital and we had sixteen people, didn't we? Sitting at a meeting at the Hospital, through our own initiation...We had physio, psychologist, nursing team, social workers, nurses, there was a lot of input, occupational therapist...”* [FFI-P7]

Kristina uses the word ‘we’ far more than the word ‘I’. It feels as if she is validating and collectivising her opinions and acting on behalf of the family in this way.

Sometimes when listening to Kristina, it is hard to locate Leonard within her story. It feels as if she is acting on his behalf; the way that one might for a baby, who is unable to hold or express his own feelings; here it feels as if Leonard is a



helpless victim. This might be indicative of Kristina's new relational position with Leonard since his accident. This way of acting towards Leonard, the family and the world seems like a very important coping mechanism for Kristina, and therefore it forms a major part of the dominant *baby-narrative* within the family.

*"...And that is what my next goal is, to find somebody that can do that [implant a microchip in Leonard's leg], so if you find anybody that can do that kind of thing..."*  
[FFI-P11]

### **Dealing with the loss of physiotherapy**

It was "heart-breaking" for Kristina that Leonard's physiotherapy was removed and he wasn't given the long-term physiotherapy care that was recommended for him.

*"...[They] Wrote him off. That was really a heart-breaking experience..."* [FFI-P8]

The family light up when they talk about his speech achievements with the physiotherapist as this represents hope for them. Within the *baby-narrative*, when physiotherapy was denied to them by the NHS, it is as though they were saying 'look at what you are doing to us, look at the progress you're preventing!'

*"...he winds the carers up when he's having his physiotherapy, that being the time when he speaks more easily than at any other time. It's a standing joke now, they ask him how old he is and he will insist that he's thirty eight...A big grin from there to there...he likes to have a laugh...he's got a sense of humour...as well..."* [FFI-P9/10]

It is in speaking about Leonard's strengths that the family liven up, I feel here that the narrative has moved onto talking about hope and achievements as if for a small child who has achieved a small developmental task. The family spend a lot of time responding to his mood and therefore when he seems in a good mood, this shines through them in their retelling. The obverse condition though is when he is in a bad mood and the family suffer with him.

*"...[I reflect to the family] Can I...comment on...what I saw happening...Barry...you said when he's having his physio he can speak more and then the whole room...livened and there were lots of smiles on faces, talking about the things that Leonard is able to do when he's having physio..."* [FFI-P10]

### **Dealing with criticism and dissent to protect the family unit**

Within the *baby-narrative* there is a predisposition to protect the family unit as being strong and reliable, without room for criticism or dissent. This narrative seems to give Kristina a psychological buffer in protecting what she has within her family from further damage.

When Kristina feels some form of implied criticism from Gareth she defends her/their position and repeats her mantra "*repetition, repetition, repetition*".

*“...But then we do that Gareth because we try to encourage him all the time...build up confidence again, repetition, repetition, boosting his confidence, ‘Well done, Leonard’. I mean the odd occasion when he speaks to us, or says something that makes us laugh we applaud him, don’t we” [FFI-P16]*

By way of further explanation of the points, she explains that she has been trying since day one with *“repetition with the carers”* [FFI-P16]. In this way, she continues to protect the family unit as she sees it, from internal inconsistencies and the *baby-narrative* reasserts itself.

### **Consolidation of the *baby-narrative***

Kristina seemed to be narrating her life through the interview, and not wanting it to appear different than the story which she needs to hold on to; i.e. the *baby-narrative*. On several occasions she used performative imitations of talking to Leonard during this section of the interview:

*“...‘Well done, Leonard’ for the slightest thing...‘Well done, Leonard!’ You know, that’s when I say he’s like a baby...” [FFI-P17]*

*“...‘Well done, Leonard’ and we applaud him [slaps], you know...” [FFI-P18]*

It seemed as though Kristina was taking an opportunity to consolidate her position in relationship to Leonard and the *baby-narrative*, confirming her story and herself within the narrative.

The *baby-narrative* is fragile and feels like it needs constant repetition and consolidation to protect it from potential counter narratives. Kristina seems to have taken on the role of the person driving the *baby-narrative*. The other family members offer no counter narrative publically, which appears to reflect their accepted role in implicitly maintaining and supporting the *baby-narrative*.

### **Dealing with possible threats to the *baby-narrative***

Threats and challenges to the *baby-narrative* are potentially very damaging for Kristina and the family, given the fragile and brittle nature of the narrative and therefore they must be dealt with carefully.

Laura was Leonard’s girlfriend at the time of his accident and when she is discussed in the family interview and during Kristina’s individual interview, she appears to be talking about how she deals with Laura as a potential threat to the control of the dominant narrative.

Kristina and Laura appear not to have met before the accident, and from Kristina’s narrative, they were only in a casual relationship.

*“...it was just a casual thing as far as we know...don’t think Leonard wanted to settle down...” [K-P12]*

It seems that because there was not a relationship between the two women, Kristina appears not to have liked her very much. She seems to have been edged out of the family frame when Kristina took the central role in caring for Leonard.

*“...I think she was pushing...I don't know for sure but under the circumstances...there was something written into the law that if you've lived with the person for a year or so you become...[common law wife]...we wanted to avoid that...” [K-P12]*

Kristina speaks as if she was doing Laura a favour by removing her from Leonard's life, but also highlights her own motives as well.

*“...Yeah, yeah, yeah and I think we did her a big favour by...Letting her go or not encouraging her too much in making decisions...it would have been awful for her...all the time...” [K-P20 Q1]*

So Laura, who represented a threat to the dominant *baby-narrative*, was removed from the family, as if for her own good.

*“...because Leonard had a responsibility to his son and if Laura had come in on the scene it might have changed things radically...” [K-P20 Q2]*

In reflecting on this section of the narrative with my supervisors, I realised that I found it very difficult to analyse and write up this section. On a personal level, I experienced Kristina as being very dismissive of Laura, acting on her behalf and on Leonard's behalf, whilst giving the outward impression of simply being a conduit for Leonard's wishes.

The way that Kristina describes dealing with Laura was a clear example of how possible counter narratives are implicitly dealt with in the family.

### **God and the church in relation to the *baby-narrative***

God and the church play an important part in the *baby-narrative*. When Kristina and Gareth heard that Leonard was on the 'danger list' Kristina called for the priest at once.

*“...I said he was quite on the danger list really. And I said, 'is there a Chaplain here', and being a Catholic country, 'Yeah, no problem' and he came and he anointed Leonard...” [FFI-P23]*

I consciously didn't want to engage greatly in conversations about God and the church with Kristina during the family interview and tried to keep the conversation terrestrial. I am for practical purposes an atheist in outlook, after having been brought up as a Roman Catholic. I am aware that this will have impacted on the co-created reality that we shared together and will have affected the resultant story that Kristina told. The extent to which I validated discussions

about religion, might have affected the amount that she was willing to talk about it.

She did spontaneously return to religion in our individual interview though, reflecting the power of this theme for her. During our individual interview, Kristina had made several more mentions of her relationship with the church and so I asked her quite directly how she coped.

*"...[short pause] sheer determination and the help of God [yeah] my faith is everything to me, without that I couldn't cope at all..." [K-P14 Q1]*

*"...the church sustained us very much...all the way through ever since we've had some very...difficult times...not least of all with care, carers, the NHS saying... 'we've washed our hands', we're not going to look after him, Social Services..." [K-P16 Q2]*

The church was a very important support for Kristina in the beginning. She described a nightmare situation with Leonard being "wired up to machines". She was able to find solace in the Latin mass, which was how she communicated with the French priest and during this story the Latin mass felt like only way in which Kristina was able to make sense of her trauma at that time.

*"...my first reaction was to – they told us it was touch and go – was to if there was a priest who would come and anoint him within the sacrament of the dying and the priest came the very following morning..." [K-P14 Q2]*

Leonard had been flown to the neurological hospital in France, Kristina said that there was a large expatriate English population living there who had overheard her talking with Gareth and put her in touch with an English priest. The priest said that:

*"...he would get his community praying for Leonard...so immediately we felt embraced in a cocoon of Christian love...which was what we needed at the time, that was all we had to support us you know..." [K-P16 Q1]*

When Kristina talked about the church, it felt like it was the only institution which had not let her down over the last thirteen years. Kristina described the happiness and support she felt when people would come up to her and say *"we pray for your son"* [K-P16].

When Kristina talks about the church, her story feels like a sanitised version of events. It is clear that she receives a lot of support from them and it seems that in some ways she can let go of and give her pain to her God, or to the community of the church.

*"...I've got a very deep and profound faith and I think the Lord in his, in his wisdom has used this to bring us closer together, used this trauma to bring us closer together..." [K-P21]*

This seems like another way that she can make the story into a positive, and to remove the negative parts of the story. The fragility of the *baby-narrative* is strengthened when comparing it with the Passion, when the NHS “washed it’s hands of him” then the image of Pontius Pilot is evoked. The narrative therefore has a wider cultural source, as of Madonna and child. Here Kristina says ‘what right do I have to be unhappy when Mary went through this pain?’.

*“...it wasn’t easy for the Lord, Jesus didn’t have an easy time of it...and his mother...she saw her son being crucified, whipped, spat at, scorned, what had he done wrong? She must have knelt at the cross and felt very sorry, very sad, disappointed and...abandoned so I can liken to that...that’s a great support...and it wasn’t easy for her so who am I to expect anything better? That’s it...” [K-P21/22]*

### **The development of the *baby-narrative***

It seems that whilst the *baby-narrative* started when Leonard was injured, it was developed and thickened through the experiences of the ‘bad care-home’ and the ‘useless carers’. Leonard was sent to the ‘bad care-home’ after his acute rehabilitation. However, the family had a very difficult experience there.

*“...Leonard was confined to his little room...neglected...wasn’t hydrated...teeth weren’t brushed...his urine was like the strongest shade of tea...pressure sores...Nobody noticed...” [FFI-P29]*

This story was also very sterile and ‘unemotionally narrated’. In this way, the *baby-narrative* was stated as fact without room for dissent or questioning the dominance of the narrative. This is another example of how Kristina finds it very difficult and unwise to trust other people. In the *baby-narrative*, people will let you down and therefore it is better to be more ‘hands on’ and ‘do things yourself’.

*“...We escaped, it was quite exciting [laughter] really...Straight from Colditz [laughter]...” [FFI-P34]*

When the family did take Leonard home from the ‘bad care home’, Kristina confided that the care package they got in place, provided carers who were ‘lazy and lethargic’.

*“...the first agency that we were given by Social Services that we were recommended too were an absolute waste of space, they were hopeless...weren’t trained, didn’t have a clue...” [FFI-P38]*

She seems here to be confirming the validity of her own choices and giving examples of her positioning in relation to the rest of the family and the care workers.

*“...I was doing it all and saying trying to persuade the carers ‘oh let’s take Leonard out for a walk this afternoon’...” [FFI-P39]*

Because she feels that the care workers initially provided by the local authority were so hopeless, it seemed logical to her that she and the family take over Leonard's care

The *baby-narrative* therefore is built upon the family's desire to take Leonard's care into their own hands. I reflected that Kristina's overarching narrative seems to be confirmed by these stories of care workers who were not good enough for a mother who wanted to re-parent a child who had been infantilised by his injury.

### **Reaffirming the *baby-narrative***

After discussing negative emotions from the past, an important part of the *baby-narrative* is to reassert and reaffirm the positive story. So at the very end of the initial family interview, Kristina consolidates this position by saying that, while there was a period of difficulty, there are now some good care workers and "the world is his oyster now". This is such an odd phrase to use about someone who was so badly injured, but it again seems to concord with her theme that everything is okay, and will continue to be so as long as she is in charge.

*"...we've got an excellent team of carers...who have been specifically appointed and trained to look after Leonard...and well the worlds his oyster now...they are fantastic..." [FFI-P40]*

So, as the family interview closes, all of the negative feelings that have been around regarding Leonard's care are dispelled as the world is now his 'oyster'. This is yet another example of the *baby-narrative* having to re-establish itself and finish on a positive note, which however, seems out of keeping with his condition and may reflect her sense of hope that somehow he will regain his faculties and abilities.

### **Kristina's Individual Interview**

The following sections of the *baby-narrative* are those created from Kristina's individual interview.

#### **All time high**

Kristina had prepared notes for the individual interview, which seemed like a performative aide which might add strength and consistency to the narrative which she wished to present – the *baby-narrative*.

*"...we're on an all time great at the moment because...everything is in place...and Leonard seems to be showing signs of improvement...albeit slowly but he is...thank god he is better now than he's ever been...what more could we [wish for]..." [K-P2]*

It seems that Kristina is very reluctant to show negativity during the interview, and seems to be striving to make sure that 'everything is seen to be okay'. In telling the *baby-narrative*, Kristina was presenting a fixed position towards her family without inviting or encouraging any discussion.

She does not like going to 'the brain injury association', and it seems difficult for her to verbalise why. She gives several examples such as:

*"being an old lady" and having to "look after the grandchildren" [K-P3]*

One way of coping for Kristina is to keep her emotions under control, and by going to 'the brain injury association' meetings she would be less able to control her emotions and maintain a positive outlook in the way that she would like.

By attending 'the brain injury association' meetings, Kristina would also be looking outward, rather than be inwardly focussed, as she prefers to be. The *baby-narrative* is about focusing time on Leonard and the immediate surrounding of the family, and not looking further afield for help and support.

*"...oh what I'd give to just put my feet up...close my eyes and have a little sit...and then you think, 'no I've got to go'...because I still like to keep my finger on the button...and make sure that things are going the way I want them...there's always a little something that I might think 'oh why don't you try this', 'why don't you try doing that with him'..." [K-P4/5]*

This is a very important theme for Kristina as it reveals that she is still very much involved in Leonard's day-to-day care after thirteen years, even with the 'good carers' who they now have employed. By saying that she would like to put her feet up, she is also asserting she has taken on this role unwillingly and that it is a drain on her – but she perseveres, this self-sacrifice seems like an important factor in the *baby-narrative*.

### **Changing care demands over time**

Kristina could not foresee a time when she might not be as hands-on with Leonard's care, because she is the only person who is constant and consistent in Leonard's life; only she can know all his needs.

*"...Not really...I'll tell you why...because carers come and go...at the moment we've got an excellent team...but who knows...when a new carer comes...they don't know all the little details...I mean even the best carers they don't know Leonard in and out..." [K-P6]*

When Kristina described having to pop in and *"keep her finger on the button" [K-P5]* it felt like an organisational feat that she has to maintain. This is a very slavish position that she is in, because she feels that it is her responsibility now to play this role and never let it go to anyone else.

*"...I try not to be bossy...I encourage them...whenever I leave, I always 'thank you for all you do for Leonard, you really are appreciated'..." [K-P7]*

It seems that Kristina is trying to walk a very difficult line in organising the carers and perhaps she finds it difficult to accept that they are employed in a professional capacity and cannot give him the love as she does.

### **Getting older - Evolution of the *baby-narrative***

I suggested that Kristina's narrative of wanting to 'put her feet up of an afternoon' was at odds with her other more often repeated narrative of organising and being the overseer for Leonard's care.

*"...Well I'm sure the Good Lord will let me know when it's time that I can't do anything...thank god I'm blessed with good health and when the time comes I'll know, won't I? but...while we can...with every fibre of my being I will do everything I possibly can..." [K-P8/9]*

Kristina seemed quite content about it and didn't seem to get angry or feel hard done by in her retelling. She simply felt that God would tell her when her time had come and she couldn't do any more. The overarching cultural source for her story seems to be a religious one – i.e. she has been put there by God to 'save' her child.

I am continually struck throughout her interview that when she talks about Leonard she's acting for him and on his behalf but without his consultation. This feels like it conforms with the *baby-narrative* that Kristina is positioning Leonard in the place of a helpless infant who must be acted for and on behalf of by the family.

*"...Well we're doing slightly less because we've set everything up...and the carers...they are absolutely fantastic...they are so good, they are the same ones who know Leonard's every need..." [K-P10]*

While Kristina said that she was happy to abdicate responsibility for Leonard's care when the time comes for it, delegating to other people, I felt that she was actually finding the prospect very difficult; especially as they have been so involved with Leonard's care for thirteen years and are constantly fighting for their position.

So the *baby-narrative* conceals difficulties about moving into the future, because the public narrative must be that "all is okay".

### **The important public narrative**

I think the most important public narrative for Kristina is that which sets out to reassure that 'everything is okay'. The fragility and rigidity of the *baby-narrative* means that it is open to contradiction and internal inconsistency, when competing demands within the narrative meet for instance:



*“...the carers, as I keep repeating, they are absolutely fantastic...they are so good, they are the same ones who know Leonard’s every need, even to a certain extent better than we know them now after thirteen years...” [K-P10]*

Kristina contradicts herself here by saying that the carers are very good and might know Leonard better than she does after so long. This appears to be an example of trying to maintain the public narrative that ‘everything is okay’ and nothing negative can be uttered, even if it contradicts her earlier tract that she has to ‘*stay hands-on because even the best carers cannot know Leonard as well as she and Gareth do*’.

The dilemma between what Kristina ought to do and what she wants to do may be long standing and probably reflects the difficulty that she is coping with. It is perhaps emphasised increasingly as she and Gareth age.

*“...the carers won’t allow us to do anything ‘no, no, no, no, I do that, that’s my job’...when we’re going out to put him in the van...I try to help moving the – ‘no, no, no, let me do that Mrs C.’, pushing the wheelchair...‘no, no, no, my job to push’ and I think for goodness sake let me do something, he’s my son...and that really hurts...” [K-P10]*

“It hurts,” is one of the few emotional phrases that Kristina has used in the whole interview process. It also lends weight to my conjecture that she is unhappy with relinquishing her role to the carers. This feels like genuine pain and highlights a difficult position of conflict that she holds in relation to the *baby-narrative*. She is stuck in a dilemma as a mother with an infantilised child, but also aware of her own creeping mortality – a painful position to be in and one she seems to be fighting hard to contain or minimise.

When Gareth recounts a similar story during his individual interview, he laughs, saying that the carers are so much faster at doing these things than he and Kristina are, so that’s why they do it rather than for any other reason.

*“...the carers always put him in, so they...‘oh no Mr C. I’ll do that’ [laughter] that tells you something doesn’t it? [laughter]...they jump on the tow-lift and they...have him tied in securely before we’re still thinking about it [laughter]...” [G-P18 Q2]*

This differential positioning between Gareth and Kristina may be why this story does not hurt Gareth in the way that it hurts Kristina. It could also reflect the different positions that Gareth isn’t dealing with “*his baby*” in the same way that Kristina is.

### **Kristina’s contradictions within the *baby-narrative*: A ladies man**

Kristina seems to be conflicted in herself about Leonard. When describing him at a birthday party that had been laid on for him by some old female friends, Kristina described him in the present tense as a “*ladies man*” [FFI-P16].

*“...He loves the girls, though doesn't he, Barry? He's a ladies man and he's a handsome man...” [FFI-P16]*

It feels here as if Leonard's pre injury qualities are being projected into the family's narrative of his post injury life. As a coping mechanism, it seems as though Kristina is employing the 'denial' part of the adjustment process, to recite a public narrative with reference to pre-injury personality traits.

There is a complicating factor in her description of Leonard though, because I go on to ask the family how their relationships with Leonard have changed since the accident and Kristina answers with *“he has become our baby hasn't he?” [FFI-P16]*. It is a common narrative for mothers of brain-injured adult children to claim that they have “become a child again”.

Therefore, Kristina seems to be have cast Leonard into two seemingly contradictory positions simultaneously. Firstly, she is speaking in the active and present tense about him being (and therefore continuing to be) a ladies man, yet secondly claiming that he has become a baby again to the family, and therefore presumably unable to hold the position as a ladies man.

This may perhaps be understood as different ways of inviting care or affection as either a ladies man or as a helpless child, albeit from potentially different sources.

Different family members may be using various ways of understanding his newer post-injury identity, based on projections from his past, 'pre-injured self'. Perhaps these positions are based on a difference between an observed position of Leonard within the family, and an openness to future possibilities based on continued hope against the odds.

### **Gareth's individual interview contributing to the *baby-narrative***

Whilst Gareth's main contribution to the interviews consisted of the *fighting-narrative*, discussed in the second part of this thesis, he does also influence the *baby-narrative* as well.

### **Letting go for a second time**

Gareth made the point that as you grow, you let go of your children when they reach eighteen. Gareth and Kristina seem to be once more saying goodbye to Leonard as he again leaves them. This time though it is not through growing into adulthood and the natural course of leaving home, but because they are getting older and they cannot remain as involved any longer.

This seems to be Gareth's attempt to move this beyond the *baby-narrative* by acknowledging that they have to move on. As such, it's a way of curtailing the narrative by looking at ways of bringing it to a natural and resonant end.

*“...Well...its nature just taking its course isn't it...you've been to 'the brain injury association', most people at 'the brain injury association' have mums and dads wondering and worrying about what's going to happen to them when they're gone...” [G-P24]*

As the *baby-narrative* is brittle and inflexible, Gareth's influence on it helps to insert ideas about change and adaptation to the future life of the family. Gareth recognised that to move the *baby-narrative* forward, he must learn to let go again.

*“We still haven't learned to stop trying” [G-P30].*

The mood of the family really lightens when Leonard is having a good day, but the obverse of that is also true, that so much of their emotional well being as a family is interwoven with Leonard's moods which are very clearly reflected in the family unit.

Gareth says that he must learn to let go of the difficult emotions so that he doesn't become too overwhelmed. This narrative is very trapping, because their happiness is so reliant on Leonard's mood, which was so variable.

*“whenever Leonard is okay, we are okay” [G-P30].*

### **Alex's Interview**

Although Gareth invited Alex to the initial family interview, he was unable to attend as he was out of the country. He did agree however to take part in an individual interview. I was interested in Alex's relationship with the dominant narratives upon which he both articulated and contributed.

### **Feelings towards Kristina and Gareth**

Alex supports the *baby-narrative*, but doesn't become over involved. He feels very deeply for Kristina and Gareth, which is a focus throughout his individual interview. He mentions that he too has children and that this makes it easier to empathise with their pain, knowing the level of devastation that he would feel were he in their position. Therefore, he is motivated through the desire to help Kristina and Gareth relieve some of their suffering.

*“...it was a different focus... feeling very much for Kristina and Gareth...having got kids of my own...trying to imagine what they were going through which...seemed unimaginable...” [A-P11]*

When we started to talk about negativity and the possibly difficult feelings that he might be having, he quickly dismissed these potentially complex emotions. He described this as a protective function when he is with Leonard, and they will go to *“being in the moment”* [A-P12] because to do anything else, to dwell on what has been lost for Leonard and the pain that this causes for his parents every day would be too much for Alex to bear. This form of self protection via

disengagement with the potential difficult feelings associated with loss is a significant part of the *baby-narrative* and Alex advocates it as the best way to be with Leonard.

### **Not dwelling on loss**

When Alex and I started to investigate the losses inherent in the family, he turned to me and sharply said *"okay anything else?"* [A-P13]. This made me rather apprehensive and abashed. In reflecting after the event, I think that what I might actually have been doing is addressing and reflecting on the pain of the situation, which provoked his protective coping strategy.

This position is supported by the dominant *baby-narrative*. Therefore, when I tried to probe into Alex's uncomfortable feelings, I came up against the *baby-narrative's* protective elements and was repelled.

Alex seems to have his role with Leonard in perspective, he does not have the desire or the time to think constantly about Leonard:

*"...Leonard is, is very important to me...but I won't be dwelling on Leonard every minute of the day..."* [A-P16]

Given this sense of perspective, Alex does not dwell on the difficulties of the situation. He remembers feeling very sad when the accident happened but while he sometimes still becomes sad, he usually thinks that he wants to have a 'good time with Leonard' and he thinks that that 'this is the new Leonard now'.

### **New relationships with Leonard**

Alex feels that to have a relationship with Leonard, one would have to be very determined because of the amount of work that was needed at the beginning without any reward. For many people that would mean working with Leonard on a child's level, which they might feel uncomfortable about. Therefore, it would be appropriate for Kristina to hold the *baby-narrative*, but not for other people.

*"...its not a normal relationship either...it's probably treating Leonard a little bit like a child in some respects..."* [A-P15]

This seems to be an important point; it is obvious, but as yet unsaid that Leonard must necessarily form a new relationship with everybody in his life. It might follow therefore that the ability to cope depends on how well those friends and relations have been able to adjust to their new relationship with Leonard, or how much the new relationship resembles the old one.

## Important Counter Narratives to the *Baby-Narrative*

The *baby-narrative* is therefore a powerful story to which the whole family subscribe publically and support in different ways.

There is little dissent in the public sphere, however there are some very important counter narratives which were not voiced at the public family interview, but which were voiced privately in the individual interviews.

Terrence and Barry both hold the major suppressed counter narrative to the *baby-narrative*, whilst Kristina herself reported one important counter narrative.

### Barry's Individual Interview

During Barry's individual interview, he described the joke telling and kidding by Leonard as being the actions of an adult; whereas many people treat him as a very young child in keeping with the dominant *baby-narrative*. This implies that Barry has his own version of this story; he experiences Leonard as an adult, who can sustain attention and make jokes in an adult way.

*"...he's very adult, and sometimes...people speak to him...like they are talking to...a very young child...'come on now, come on, eat this one, come on, do this, or do that'...I don't know if...they realise they are doing it, but I sometimes wonder..." [B-P13, Q2]*

This is an alternative story to that of Kristina 'having her little boy back' and it demonstrates that there is another way of being with Leonard as an adult. Barry wonders how Leonard feels about being treated this way and imagines asking whether he sometimes feels as though he is being treated like a child.

It struck me that Barry frequently takes the position of the curious person rather than the person who acts on Leonard's behalf. By doing this, Barry is not assuming that he knows automatically what is best for Leonard, as other family members seem to do.

*"...'I wonder how Leonard feels about that' again it's one of these questions I'd like to put to him, on paper...'Do you feel like sometimes you are being treated like a child'..." [B-P14]*

Throughout the interview, I perceived Barry as only being interested in Leonard as he is; rather than either trying to change him, or worrying about the relationship between them. He is very accepting of him in all his guises and the power of the *baby-narrative* distresses him as it infantilises Leonard.

### Terrence's version of the *Baby-Narrative*

During the family interview, Terrence's contribution felt like a demonstration in acquiescence at the expense of his own suppressed narrative. Throughout his recital he is publicly affirming his allegiance to the dominant narrative,

regardless of whether he actually holds private counter narratives. There was little space within the family to hold public alternative stories, and it was very difficult to contradict such an established major narrative as the *baby-narrative*.

It is interesting that he didn't use words such as 'I' or 'we' during the family interview, and did not seem to have any ownership of this family story; instead he was almost reading from a script and being very careful about what he said in this public forum.

It is important to note that Terrence was there upon his father's invitation rather than mine and so could have been following his father's wishes which were clearly set out (and against which he has already fought and lost) rather than my less formalised structure for the interview.

### **Relationship with his parents and the development of the *baby-narrative***

Although Terrence was very quiet during the family interview, when the *baby-narrative* was being created, he spoke more when we met individually.

Terrence was very aware of his parents' changed attitudes towards Leonard. Gareth said that he "*made up his personality than it was*" while Kristina said that he had "*become our baby again*" [FFI-P16].

Terrence said that when Leonard was injured he actually saw more of him than he had done previously. Particularly in the early stages of the injury with the:

*"...just the whole, the ups and downs of the rehabilitation process..."* [T-P6].

Terrence said that during the process of his moving from the acute rehabilitation centre he'd become increasingly aware and worried about his parents' plans to set Leonard up in his own home. It was a major concern:

*"...that Mum and Dad would, that too much responsibility for Mum and Dad's shoulders..."* [T-P7]

The experience that I'd seen of Terrence at the family interview as holding a suppressed narrative and no mandate for his beliefs became clearer during the next phase of our individual interview. Terrence explained that out of concern for his parents he wrote to Leonard's consultant and that this:

*"...caused a rift [between him and his] Mum and Dad...they were very hurt that I was kind of, err, seen to be opposed to Leonard returning to his own home..."* [T-P7].

As the *baby-narrative* was emerging for the wider family, Terrence was narrating the coming events differently. His story was more related to the potential loss of his parents and the change of his own identity.

I suggested to Terrence that some of his fears were justified, as Kristina and Gareth had become very involved in Leonard's care. This part of his narrative doesn't seem to have been acknowledged by his parents though as Terrence is set apart from his parents and their wishes and is exiled from the *baby-narrative*. Instead, Terrence seems to have apologised for *being*, or having done something *wrong*.

*"...I did say to them, you know I was, I was wrong, I am sorry..." [T-P7].*

I wondered if having his story publicly rejected by his parents meant that Terrence was left feeling rejected and abandoned because he did not validate the dominant family narrative. He might have felt punished for 'betraying' the unity of the family narrative.

### **Relationship with ambivalence**

Terrence is full of ambivalence during this interview. He says that while he was acting for his parents' interests, he was also acting for himself as he didn't think that he would have the time to be with Leonard if that was what was required and seemed to be part of the developing *baby-narrative*.

*"...I was concerned for Mum and Dad, and I was...about me and my situation in that I had a young family...I couldn't pick up... any pieces you know...they weren't purely...Altruistic concerns..." [T-P8]*

Terrence discussed attending 'the brain injury association' meetings a few times and said that he identified a lot with the people there and what they were going through, saying:

*"...[it is] Not easy, and eh, eh (short pause)...[Can I push you on that one, and just ask you to expand on]...It's quite depressing really..." [T-P9]*

He was not happy about being placed in that situation. When recounting the story it felt as if he was watching his own bleak future, his voice changed, his eyes widened and he appeared fearful.

*"...there were people there that...as a result of their injury, you know their behaviour, personalities had changed to some degree, and they just didn't fit anymore...they were going to have difficulties...all the way through in relationships..." [T-P9]*

It seems that at the time of the accident Terrence was trying to look after his nuclear family and his own young family, whilst he was concerned about the role which he might be required to play in supporting Leonard.

*"...later on...when my parents are...frailer and...unable to do what they do now, that I'll need to step in and become more involved..." [T-P10].*

## Relationship with detachment

I asked Terrence directly whether he and his parents had settled themselves since the rift and he did not answer, saying:

*"...I can see that this is the best situation for Leonard absolutely..." [T-P10]*

This felt as though Terrence had succumbed to the dominant narrative, even within the individual interview. However, a very important theme emerged from this question, which was that:

*"...I suppose emotionally, I've...pulled way...I've ...detached, from him somewhat, in the knowledge that he's...being well cared for, and that...my parents are very attentive to him..." [T-P10].*

So, it appears that Terrence's major coping mechanism is to emotionally detach and pull away, in the face of a bleak future full of duty and obligation. The power of the dominant narrative is such that this seems his only option.

This is a coping mechanism employed by many of Leonard's old friends and people in the wider family. However, Terrence cannot do that fully because of his position within the nuclear family and so he is full of ambivalent feelings.

*"...You know, I'm entitled, I'm entitled to feel angry, eh, and, but, you know, I have to keep it in some perspective..." [T-P14]*

He is also very angry that there is the implicit assumption that when Kristina and Gareth have gone he will take over the responsibility for looking after Leonard:

*"...which could conceivably be at any time now..." [T-P10].*

He is very resentful of this, especially as he was originally opposed to Leonard moving home. Terrence said that he had *"mixed feelings"* [T-P11] about having to take responsibility for Leonard when his parents are too old to do so.

*"...Yeah, I feel very mixed about it...I work full time...I'm in the middle of my working career..." [T-P11]*

He will also be expected to look after them too as the only reason that they would give up the responsibility is if they are too frail.

*"...it, is implicit that because they are more frail, and therefore they are going to need...More support...there are going to be a lot of demands from my family ..." [T-P11]*

Terrence feels there are too many demands from his family and qualifies his ambivalence by saying that because his family will demand more from him later, he should take the time now to be less involved while he is able to do so. It is the



implicit nature of this imposition which he objects to. In which case, the only relationship that Terence can have with it is avoidance.

### **“Getting her little boy back”**

Terrence implies that one reason why the family can't talk about anger towards Leonard is because of his feeling that Kristina has her little boy back. The unforeseen consequence of a narrative in which a mother 'has her baby back' is that for Terrence, he has become the lost son.

*“...in some respects, in my parent's, Leonard has become a little boy again...he was further removed from them than I was...and in some ways they've got him back...”*  
[T-P14]

Terrence lived with his parents for a year when his marriage broke down and they helped him to move into his new house. Throughout Terrence's conversation it felt to me that he was moving back into the parental fold; re-establishing his attachment bonds, which felt skewed towards Leonard.

Terrence seemed very introspective and sad when he said that his parents' conversations are never far from Leonard. He described the personal and emotional effect on him as

*“...Eh, well, (11 second pause) it leaves me like this...you know, talking about it...it's difficult sometimes...it's something I have to work on...leaves me like this, you know...struggling to keep it in some sort of perspective... it's difficult, it's difficult...”*  
[T-P16]

Terrence understands that for a long time Leonard was very unsettled and his parents were trying very hard to create a stable environment for him with good carers. However, there seems to have been no readjustment now that Leonard has become settled. Terrence seems to find it difficult to voice these concerns and so his conversation comes through in a stuttering and stammering way when he speaks during the interview.

*“...But now things are sss stable, and, you know, and of course, you know in that situation, which is kind of being, you know, you are focused on a particular goal then, you know, you go all out to achieve that goal...”* [T-P17]

Terrence has a fragmented and incoherent narrative, which speaks of traumatised stories of loss and fear. He is conflicted because he understands that Leonard needs help and support and doesn't want to seem in any way neglectful of that, but at the same time he feels neglected himself.

*“...Eh, eh (slight pause), in some ways, you know, there hasn't been a readjustment in, in, in the, you know, eh, it's still an awful lot about Leonard...”* [T-P17]

## **Holding a suppressed narrative within the family**

I think that Terrence's resistance to speak publicly may be due to feeling that he doesn't have the right to tell his story and that his story doesn't have any legitimacy in the family and the wider family narrative.

To maintain their relationship, Terrence has to suppress his counter narrative from his parents as the implication of challenging the dominant narrative is that it would sour the relationship.

*"...they represent the differences between us in a way...the different stories...I don't voice it really...don't try...make the relationship with us more difficult, you know, it will sour the relationship, ..." [T-P21]*

Having lost the ease of communication with Leonard, he can seldom see past the TBI and see the core person who is still in there.

*"...there was just this...look in his eye...it was that, I think, fleeting moment of...being able to see, or connect beyond the limitations of the disability..." [T-P25]*

This last happened at his parents' wedding anniversary. Terrence said that there were some massive grief and shame feelings that occurred when this happened regarding his ambivalent feelings towards Leonard. This is very important to note as family members vary widely in how they manage their feelings in relation to the terrible accident.

*"...Yeah, the loss, and I, also I think, you know, I think some guilt and shame really for the, you know, the ambivalent feelings, the difficult feelings I had as well..." [T-P26]*

## **Kristina's own Counter Narratives**

Although Kristina is very supportive of the *baby-narrative*, there was an instance where she showed a brief counter narrative of her own, which is very illustrative of how she deals with counter narrative internally.

*"...when we were a little bit younger our friends...were all going off...on their holidays...we couldn't – a little bit of resentment there that we weren't free, we had to be around...resentment, yeah resentment...that we didn't have our freedom..." [K-P18 Q1]*

This is the only indication of any negative feeling that Kristina expressed in almost two and half hours of interview both privately and with her family. I reflected this back to her in the individual interview, and she said that these feelings were "*down there*" [K-P18] as if not for public consumption.

I found it very interesting that Kristina does hold a suppressed counter narrative herself. She was very reluctant to explore these suppressed narratives, given the

difficult emotions they cause, and which the dominant *baby-narrative* has been constructed to avoid.

*“...that’s past now because we are freer now that we’ve ever been...albeit we haven’t got the energy now...well that’s a pay off isn’t it...” [K-P18]*

Within four transcribed lines of her small counter narrative, Kristina's *baby-narrative* had re-asserted itself. She negates all that has been said, and returns to asserting the dominant public narrative that ‘all is okay’. It is a very powerful response which protects against the necessity of feeling pain and difficult emotions.

*“...we’re quite happy, we’re contended, we’ve got a comfortable home, food in our tummies, friends, grandchildren...got my God, what more could I want?..” [K-P18 Q2]*

## **THE FIGHTING-NARRATIVE**

### **Introduction to the *Fighting-Narrative***

The second major narrative theme running throughout this work is the *fighting-narrative*; so named because of the frequency of language employed around 'fighting' and 'battling' on Leonard's behalf. Gareth mostly holds the *fighting-narrative*, supported by Kristina.

The emotions associated with this narrative are frustration, anger, intolerance and personality change. As Leonard's personality has changed, so have that of Gareth and the family. Relationships with Leonard have changed and the battling is the result of changed relationships between themselves and the 'external' world. The *fighting-narrative* centres on having to do battle with the authorities, in a world where people in charge appear uncaring and unhelpful.

The *fighting-narrative* is mostly couched in a language of inevitability, of having no choice, and the fights mostly stem from frustrations. Because of his position as Leonard's father, it is Gareth who takes on the role as Leonard's protector and advocate.

An important theme running throughout the *fighting-narrative* is that 'other people do not care' neither do Leonard's old friends and many family members. The frustration generated by family and friends staying away from Leonard leads to anger. One particularly important story for the family members as a whole, is that they help people who are less fortunate than themselves both through organised church charities and individual acts of kindness; they become frustrated when they feel that this caring attitude is not reciprocated back to themselves.

The *fighting-narrative* is similar in some ways to the previously reported '*baby-narrative*' in that neither narrative involves any choice for the family as the concept of choice is for non-family members only.

Both narratives involve members of the family not fully engaging with emotional responses and reactions; more value is placed with just 'getting on with things'. The two narratives also involve family members acting on Leonard's behalf rather than with his consultation.

The narratives strongly feature his protection and safety, however differently the family members approach this task, (which may be associated with the societal constructs around gender divides). This function of the battling seems to have a purpose, i.e. it provides some way of making sense of the world now and reconstructing the shattered narratives of the past.

The residing difference between the *fighting-narrative* and the *baby-narrative* can be exemplified by the two different answers that Kristina and Gareth gave to

my question regarding how relationships have changed with Leonard since the accident.

Kristina's said that "*he has become our baby again*" [FFI-P16] whereas Gareth said "*[I am] making his personality bigger*" [FFI-P16].

For Kristina, she might want to protect her 'vulnerable and fragile infant' from any further harm, and so she addresses the world in that way and focuses inwardly to protect him. Alternatively, Gareth seems to be approaching many of his interactions with the world in a way that looks outward and fights for Leonard on his behalf.

There are hidden narratives to the *fighting-narrative* too which will be illuminated during this section. Barry holds particularly touching stories centring around Leonard's lack of a current social circle. However, rather than his narratives being driven from a sense of frustration and incredulity like Gareth, they are instead coming from a place of gentle shared understanding and intimate communication.

There are complicating factors within this narrative too, as Barry is an exemplar of 'the good person' who stays with Leonard, while for his own reasons, Terrence is not able to assume that role.

As with the *baby-narrative*, Terrence's story is completely suppressed in relation to the public *fighting-narrative* and I expand on his different feelings towards the dominant *fighting-narrative* with him.

## THE FIGHTING-NARRATIVE

### Gareth's Major Narrative Theme

#### "Personality change"

At the very start of the interview I asked the family to introduce themselves; Gareth took the opportunity to state that they had had a ten-year fight or battle for Leonard's quality-of-life. I felt that this had become such a part of his identity now, that he would comment on it when simply asked to introduce himself.

*"...To start...as you know I'm Leonard's father...Leonard's accident was in 1998...until the last...two or three years...it has been a struggle to get a quality of life for our son and...we've both had a ten year fight...battle...with the authorities to get him...a quality of life..."*

Gareth said early in the interview that he has changed and become more intolerant since Leonard's injury. He feels that because Leonard is unable to fight for himself, he has to do Leonard's fighting for him. This then, has the inevitable consequence of making Gareth's character:

*"...more aggressive and rude...because of the difficulties that come your way..."*  
[FFI-P3]

Gareth might be experiencing the anger that he thinks that Leonard will be feeling at his predicament which has become manifest within the family story in the *fighting-narrative*.

*"...But no one worried. It's just that they couldn't be bothered and even the...health authority...they were not interested...they didn't want to rock the boat..."* [FFI-P4]

Gareth might be dealing with his new relationship with the authorities in what he describes as an intolerant and forceful, manner.

*"...because of...what's happened to Leonard, I've got very intolerant...I think the character's changed...I found that if you were complacent...you didn't get anything..."* [FFI-P3]

It may be that Gareth has simply learnt through experience and storying his narrative in a particular way that he has to be this "new person" and justifies his changed view of the world by his new feeling that he has to be Leonard's protector and defender. I wonder if Gareth's experience at the 'bad' care home 'taught' him and the rest of the family that they had to fight to do anything; and that to do anything else would be to give up; therefore there is no other choice.

I continually had the sense from the family interview, that they felt that there was never a choice for the family and that they were the only people not giving up on Leonard.

In our individual interview, Gareth expanded on how his relationship with Leonard has changed his personality.

*“...because Leonard can't speak for himself you've got to speak for him...Well I think...I'm trying to interpret...So I'm his voice cos he can't voice his...frustration...”*  
[G-P9]

Here Gareth is describing what he perceives to be a universal law, where he simply has to act on Leonard's behalf. He is acting on Leonard's behalf by interpreting his actions, which is necessary because he is unable to reliably communicate his intentions and desires. Therefore, battling for Leonard is an important sub-theme of the major *fighting-narrative*.

He feels as though he worries more for Leonard and this makes him intolerant and irritates people, *“because I told them the truth”* [G-P9]. The frustration that Gareth experiences, seems to be directly correlated to the frustration that he believes Leonard is feeling.

Another source of frustration may be due to the culture shock that he felt when leaving the high-pressured world of private fast moving business where he worked as a manager, to dealing with the NHS where he perceived that nothing moved at all, as he reflected on how little has moved for his son too. He feels that the professionals working in the NHS are good, but that the *“admin is appalling”* [G-P10].

### **Nobody else cares**

Gareth affirms his sense of on-going responsibility that “there is no choice” when it comes to caring for Leonard and that things simply have to be done for him.

*“...just get on with it, or what else can you do you can't ignore it can you, you can ignore it but we can't ignore it ...”* [G-P4]

This positing of a black and white position for the people related to Leonard's care (eg the NHS /Social Services and ‘the brain injury association’) whereby “people don't care about Leonard and we have to act for him”, may be a strategy which Gareth uses to cope with the situation.

*“...the immediate family knew...that's what I thought. But no one worried. It's just that they couldn't be bothered and even the Hertfordshire health authority who the jurisdiction of the home came under, they were not interested...”* [FFI-P4]

This seems to create a situation whereby Gareth is able to create a role for himself, within this new post-injury system, as he is displaying the drive to defend the parameters of this new role as defender/protector. By adopting this role, I wonder if it protects Gareth from the difficult emotions that would need to be faced if he didn't position himself as somebody who was fighting the authorities for Leonard. In positioning himself as somebody inside the system

looking outwards, he can experience his frustration and anger with other people rather than as existential anger at his and Leonard's own inescapable situation.

At one point during the interview I noted that the family are spearheading Leonard's care as well as fighting against the authorities on his behalf.

*"...The spearhead should come from the neurologists...or the people who used to look after him...Nothing, nothing..." [FFI-P6]*

However, while it is important for the *fighting-narrative* to emphasise publically that other people should be doing the work for Leonard, I think that 'doing' the actual spearheading for Leonard serves a very important function within the family; by spearheading Leonard's care, the family might be consolidating their own position as Leonard's essential fighters rather than handing over responsibility to other people. The family therefore maintains a position of unity in holding onto Leonard, and their 'us verses them position'.

Within Gareth's narrative, Leonard's life is cast as precarious and fragile Gareth's way of coping with this might be to try to do everything alone for example he described a situation where he was trying to get some financial support for Leonard at a meeting and described having to 'sell' Leonard's case to a committee of care providers

*"...who had already prejudged him..." [FFI-P8]*

Gareth feels this is very unfair which leads to feelings of not trusting the authority figures and therefore fighting against them. Leonard seemingly needs to play a role for the family, and one which they know that he is capable of; however, within a short meeting he might appear differently to the people assessing him.

*"...it's like selling Leonard, when you go there you've got five...or seven minutes with a neurosurgeon...and you've got to sell your son within that seven minutes, otherwise you've lost...If Leonard just has a bad day...you've lost it..." [FFI-P7]*

Throughout the interview, this emerging narrative function appeared to be that because Gareth and his family were the only people who cared for Leonard they could not possibly leave his care to anyone else, even though they were ostensibly asking for exactly that help and support.

*"...you've lost it if Leonard isn't on form for the five to seven minutes when selling him to people who have already prejudged his case..." [FFI-P7].*

By repeating the theme that *"...the authorities don't listen..." [FFI-P8]*, Gareth is feeding his "truth" into the family system and therefore the family may adopt it as part of their story, which they carry with them. By dismissing the authorities in this way, Gareth may be telling the family that there is no other way of interpreting the actions of the authorities. In this way, Gareth is powerful in



shaping the dominant family discourse of battling against the authorities for Leonard's care.

### **Fear of TBI leading to isolation**

For Gareth, people are scared of people with TBI, this is very painful and causes him both hurt and anger.

*"...I think people are scared of brain damage..." [FFI-P14]*

At a recent family event Gareth reported that only ten of 120 guests actually greeted Leonard.

*"...there was about 120 people there. What and about ten went and saw Leonard?...wouldn't be more than ten would they? Wouldn't have been more than ten..." [FFI-P14]*

Gareth felt that even family members are scared of people with brain injury and people in a wheelchair. Gareth reported this leading to Leonard's social circle dwindling, which Gareth cannot understand, especially given the numbers of people that he must have known when both a Para and a Policeman.

*"...But how, how many paras did Leonard know?...How many policemen did Leonard know?...But if they haven't got to go, they can't face it can they..?" [FFI-P14]*

Again this seems like a simplified view of others and is a view which might lead to the reinforcing of the black-and-white image of other people's intentions, searching for information with confirms or denies the dominant narrative. Gareth takes the incredulous position about Leonard's old friends and implants the ideas that they are embarrassed or that they think it is the best thing to do to avoid Leonard. This is a further example of the *fighting-narrative*, and one of being misunderstood. In this version of the story, Leonard is pushed aside by friends, family and society as a whole, so Gareth seems to be losing the battle to keep Leonard's social circle.

*"...You know, a lot of the family are just 'well he's had his accident, best way of us coping with it is to stay away' and they do. Well that happens to a lot of people that Leonard knew, they stay away..." [FFI-P14]*

In our individual interview, Gareth elaborated on this theme of isolation by saying how disappointed he is in his siblings and extended family. He remarks that they have never invited him and Kristina on holiday since Leonard's accident which he says hurts him.

*"...Perhaps they think it is all we talk about...[laughter]...So that might be the only topic of conversation...Yeah but that would be bored...[laughter] bored to death with it I might be, I don't know...That hurts...That so hurts..." [G-P12 Q1]*

Gareth's explanation of this story is that other people will be afraid that his only source of conversation will be about Leonard. He continued by saying that at his recent 50th wedding anniversary party; many of the family members stayed away from Leonard.

*"...some people accept brain damage and other people will steer away from it...as if I had a leper in the wheelchair...people don't know how to cope with it...and that hurts...we have lost friends because of Leonard's accident or we've lost friends because I'm always talking about Leonard..." [G-P12 +13 Q2]*

Gareth had raised his voice and I could see that he was more animated/frustrated/angry that he had been. I felt that this was because we were coming onto an important theme for him, that people have been dropping away from the family. He feels that it is because he bores people with talk of Leonard. With his anger Gareth seems to invite capitulation into his story as his forcefulness seems to invite you to agree with his point of view; his anger and performance might also have the effect though of scaring people away too.

I reflected my feeling back to Gareth that he was describing the process of isolation. In response to this he described how the neighbours regularly go inside to avoid the family coming in if they are with have Leonard.

*"...The neighbours...have seen me coming out, I bring Leonard home here and I'm out working in the garden in the front...they disappear...people will disappear...I don't know why, I think they feel uncomfortable..." [G-P13]*

It is very difficult for Gareth to have any affinity with these family members and neighbours who find it hard to be with Leonard as he has spent much of his life working with and relating to disabled and disadvantaged people. So, his reaction to people ignoring Leonard is one of frustration and incredulity, because he is unable to empathise with them. He compares his understanding to the social narrative surrounding attitudes towards disability.

*"...It's a society thing isn't it?...that someone in a wheelchair or someone who has had a stroke whose...face has dropped at one side...they can't cope with that, so the way they cope with it is to ignore it..." [G-P15 Q1]*

### **"We should have done more"**

Gareth also holds a story of guilt at needing to have done more for Leonard all the way through, from the early days after the accident.

*"...we should have done more, or have done things differently..." [FFI-P26]*

Although they are actually fighting all the time, it feels as if they should be doing more. This seems to be an image of Gareth conforming more to his relational-sense-of-self as the advocate and protector for Leonard, stretching backwards in time to the beginning of the *fighting-narrative* which started at the point of Leonard's injury.

This is particularly felt in relation to the initial period of the accident; Gareth became more animated than he generally was through the rest of the interviews when he imagined asking the other servicemen for their accounts of the accident and taking their names and numbers for future reference.

The sense of needing to do more is a subtheme of the dominant *fighting-narrative*. Gareth illustrates this by suggesting how he should have addressed Leonard's soldier friends.

*"...I would have gone to those soldiers and asked for their name, their number, 'could I contact you' and press you to tell me exactly what happened? But I wasn't emotionally able to do it...because of what had happened to him..." [FFI-P24].*

Here, Gareth casts his position as a protector/saviour/only ally for Leonard. In doing so, he makes no account of possible feelings of shock, trauma or loss, therefore the associated emotions of guilt, disappointment and regret seem not to find purchase within this fighting story.

### **Anger**

Gareth describes Leonard as being *"a full-time job"* [FFI-P37] and says that he would not have had the time to put into Leonard if he was still at work. This struck me as a rather depersonalised way of describing Leonard, which is possibly related to his coping style. Gareth seems to operate by doing 'tasks' related to Leonard's care and so he feels as if he is 'accomplishing' in this way.

At that point in the interview he then asked angrily whether all other people have to go through what he went through when their child had a brain injury?

*"...have all those families got to go through the same thing? Mmm?..." [FFI-P37]*

In feeling Gareth's anger, it feels like a summons to share his opinions about the absolute unfairness of the family's position. It also opens the possibility of sharing across families and of mobilising change due to the weight of collective stories.

This reminds me of the angry person whom I met when trying to recruit for this project. Gareth usually kept his emotions controlled, although at points during this interview his anger seemed to be just beneath the surface. He mentioned anger the first time during the interview towards the later stages, but it had been very present throughout the interview even though it wasn't named.

*"...Em what's it mean, that...what's the right word for it...anger...anger which I should have I'm still angry, still angry. Anger, anger..." [FFI-P38]*

## **The 'Army cover-up' leading to the development of the *fighting-narrative***

When discussing the phase after the Army 'cover up' as they see it, Kristina says "*it was us against the system*" [FFI-P27]. Kristina offers her support to the *fighting-narrative* here as she explained that the family story is that the Army covered up Leonard's accident and the details surrounding it and that the Colonel:

*"...wanted to get this exercise over and done with and get back to Britain..."* [FFI-P25].

This is perhaps the first example of when Leonard's needs were not considered - when the authorities were making decisions about his life. So the family narrative was shaped by 'people letting you down' from the very start of their journey.

Kristina does not usually put these intentions into other people's voices and in doing so here could show how very entrenched the story has become in the family psyche. So that it no longer seems like something that can rightly be questioned, and has instead become a "truth" for the family.

### **Adapting to Leonard's TBI**

During our individual interview together, Gareth continued to expand on the *fighting-narrative*. He said that the family are always planning for Leonard, and while the authorities can ignore him, Gareth does not have that choice. Even the care team that they have employed and are respected are not employed to show initiative with Leonard; that has to come from Gareth and Kristina.

*"...We're always sort of planning things, planning things for Leonard...and getting things for him to make it improve his quality of life, going to exhibitions..."* [G-P4]

Gareth said that he would still be volunteering with St. Vincent de Paul Society (SVP) and working in the community, even if Leonard had not been injured, therefore life might not be too different. Other people have also commented that their relationships with Leonard are helped by their previous experiences with helping out disadvantaged people.

*"...I was just talking about...what we...would've done with our life if...Leonard hadn't of had his accident...Well...we would try and support other people as well as...trying to do something with our own retirement..."* [G-P5]

I felt at the time that this narrative could be seen in terms of a life goal or something that occupies every moment of the day for Gareth; I reflected this back to him at the time. He recalled going around the local area campaigning for Leonard, going to different organisations and raising awareness of his case and the way that he was being treated. When Gareth talked about this time it was with real gusto and emotion. So rather than it being the memory of the pain and

trauma of the accident that causes him to become emotionally engaged, this is triggered instead by his fighting and campaigning.

*"...I used to go round [locally] telling people about the way my son was treated to get his case recognised...wives clubs and different...organisations...I would tell them the whole story of what happened...and say look this is what's happening out there..." [G-P6 Q1]*

I suggested that if Leonard hadn't become injured, he would have found a cause to support anyway and would have approached it with the same gusto.

*"...When I became redundant...I decided that I wasn't going to sit back and do nothing..." [G-P6 Q2]*

He agreed with my suggestion that he wasn't likely to sit back and relax in retirement and related a story about taking people to Lourdes with the SVP and organising Christmas lunches for 80 to 90 people. Looking after the church and working as a hospital driver are examples of the activities that he did in retirement before Leonard was injured.

### **Emotional reactions to stepping back**

The *fighting-narrative* is similar to the *baby-narrative* presented in the previous section as there are some complicating factors relating to the story which involve moving forwards and stepping back from Leonard's care.

Gareth seems to be constantly working and finds it very hard to 'step back'. I asked about abdicating some of the responsibility for Leonard's care. He knows that they have to start this but it is very hard, for example he said that he used to be able to help Leonard into the van and strap him to the lift very quickly, but that now they don't have the energy and that the carers can do it faster. The importance of having less energy might be a reflection of facing up to their own mortality and fading strength. This anecdote was more fully elaborated during the *baby-narrative* section.

*"...Well we've got to do it because...cos we're getting older and haven't got the energy..." [G-P18 Q1]*

Other younger and fitter carers could do all the work in the loading, handling and securing of Leonard in the van in much less time than he and Kristina could. This anecdote was told with laughter and humour, as opposed to the heartbreak with which Kristina told the story.

Gareth does seem to accept that he has to move away from Leonard's direct care. He has seen parents' anxiety when he has looked after their children and understands that he must put his trust in other people in the same way that he was trusted in his turn.

*“...I’ve seen this so much in life when I’ve been to somebody’s house and collected someone disabled and the parents on the doorstep with anxious looks in their eye, eyes, their letting their son in my hands...” [G-P18]*

The worry that Gareth feels seems to be managed by concentrating on the details of Leonard's care. These expressions of concern feel very genuine, especially considering that for thirteen years he has been a fighter, a planner, a voice for and campaigner for Leonard, which are all very involved, active positions and may be very difficult to be ceded from.

### **Ambivalence about Leonard’s life before his accident**

Gareth explained that Leonard had a very dangerous job and that he could have died at any time. He believed firmly that he should have been putting his family first. He then speculated that perhaps because he was not married to Leroy’s mother, that he might not have been as close to him as he might otherwise have been.

*“...He...had a son who I...well what he wanted to do was going to be dangerous and he could’ve lost his life, anywhere... I thought that was selfish to go and do that...” [G-P21]*

Generally parts of the *fighting-narrative* appeared fragmentary and were hard to piece together, as if Gareth had difficulty building a coherent picture of his ‘lost’ son.

Firstly, he told the story of being very proud of Leonard's achievements in both the police, the military and his undercover work in narcotics. He detailed a very idealised story about Leonard’s work.

*“...He stayed in the Savoy hotel, Claridges all the posh places, one day he would drive a Jag, a Ferrari, you know, upstairs he’s got Giorgio Armani suits he used to wear, hand-made shoes, shirts, everything, the bees knees...” [G-P21]*

Secondly, he implied his unhappiness with Leonard's life choices to do with this work at all, because he had a young son and the girlfriend who “was madly in love with him.” This unhappiness at Leonard’s actions was greatest when it was revealed after the TBI that Leonard would have left the country for five years and worked undercover. It must have been hard for Gareth to articulate criticisms given the injury his son suffered.

*“...we didn’t know the background to all this he never told us anything, Leonard. So she had, we had her with staying, with her we thought he was dying. She had been rejected by him...” [G-P22]*

Thirdly, he was explaining to me that when I settle down and have children, that I would in the natural course of events see them grow up and say goodbye to them, and at that point, I would no longer know what was going on in their lives, and instead only hear about them in an indirect way. This was his experience of

Leonard leaving home, and therefore according to Gareth's narrative the same thing would naturally happen to me in my fatherhood. Here Gareth seems to be reinforcing his own narrative about fatherhood, in justification of the fact that he did not know what was happening in Leonard's life when he was injured.

*"...well you know, the same thing will probably happen to you when you settle down and you have a family and you have children..." [G-P21]*

The level of ambivalence between these two conflicting positions that Gareth felt between pride at the 'good' and anger at the 'bad' is striking. Gareth seems to be struggling to grasp who his son used to be, and who he has become now. I reflected to Gareth that he sounded very conflicted between his feelings of pride and anger at what Leonard was doing.

I was struck again about some differences of interpretation that sometimes occur between Gareth and Kristina's version of events. Gareth is able to use Laura here as a person who *"was madly in love with Leonard"* [G-P22] whereas Kristina could only see her as somebody who *'had her feet under the table'*.

I was struck by the apparent contrast between Gareth's own position in relation to his family and his description of Leonard's position in relation to his family. According to Gareth's narrative, he had put great resources into his own family whereas Leonard had significantly abandoned his.

## Counter Narrative to the *Fighting-Narrative*

### Barry's alternative position to the *fighting-narrative*

Barry introduced an important theme to the family interview, which is that he is able to be with Leonard because of his past experiences of his cousin. This may not have been the case had he been brought up without these experiences.

When Barry offered the counter narrative to the family's dominant story of 'people afraid of losing that bounty from the TA', he did it in a polite and matter-of-fact way. Given his time in the Paras he was in an expert position and could speak here with some authority. The family did not openly disagree with him, but neither did they embrace this story. This gave some possible insight into the way that alternative explanations are either integrated into the family story or not.

*"...I'd like to say something about...the accident, they wouldn't have been in fear of losing their bounty, not at all. I'm sure finances wouldn't have come into it at all. They would have been under strict orders..." [FFI-P26]*

Kristina and Gareth had previously said that the soldiers jumping that day would have been tight lipped due to the possibility of losing their bounty; however, Barry interjected that that was unlikely - instead the men would have been under the much greater threat perhaps of court marshal if they had spoken to the family.

*"...So they're more likely under threat of court marshal if they speak when they're not supposed to, you know, under orders not to speak. ..." [FFI-P26]*

I wonder if it is very difficult to remember alternative stories within this family if they are not acknowledged and valued. This feels like a live example of how counter narratives to the dominant story within the house are suppressed by the family.

### Barry's positioning towards Leonard

During our individual interview, Barry was more able to speak freely. Even from its outset, Barry seems to take a different stance towards Leonard compared with the rest of the family in their individual interviews. I was struck instantly that Barry's conversation put Leonard at the centre of his story; he is concerned about Leonard's feelings and affairs throughout, whereas other members' stories are often about how those concerns in turn affect themselves.

*"...he's got feelings, he must get stressed and everything like that. I've said...to him "Leonard, would you...prefer that I go" when I visit him...and he pointed to yes, I said "don't worry, I'm not upset about it"...it won't stop me coming again..." [B-P1]*



When Barry talks about Leonard smiling it is very clear that it gives him a lot of pleasure to see it. His narration shows that he sees Leonard as a three dimensional person, as an equal, brother or a friend.

*“...it’s great to see him smile...I asked him just prior to his holiday, is he looking forward to his holiday, and he pointed to...no. I said “you’re having me on”, and a big smile came on his face...and he was beaming...” [B-P13]*

*“...when you get a smile...it’s warming isn’t it...” [B-P28]*

Barry’s total demeanour changes when discussing it, such that it lights up his face.

When Gareth and Kristina both talked about “decorating” Leonard’s house when he was in America on his holidays, however Barry discusses the story differently. He used the words “*clearing out*” [B-P2] and noticed that Leonard might have been shocked to see it looking so different.

*“...I’m not too sure if he likes, a lot of his bits and pieces have gone missing...because they’ve had a good clear out...” [B-P2]*

Judging by his physical attitude during the early phase of this interview, Barry did not seem happy either that the room had been changed so dramatically. I wondered at the time whether he might have been reflecting the upset which he thought that Leonard would have been feeling towards the decorating/changes.

*“...he’s a little bit shocked by that...bearing in mind...we’re talking about his home...and everything’s changed while he’s away...he was aware that all this was happening, but then to come back and suddenly find there’s probably a third of the things that were on the wall...” [B-P2 Q2]*

Barry noticed particularly that while the religious iconography remained, his parents had removed much of the Parachute Regiment and Police memorabilia. This seemed to be an expression of Leonard’s parents’ avoidance of the reminders of the past which had hurt him or damaged him, but which Barry would have had a very different relationship with. This feeling of loss on Barry’s part may however be due in part to the fact that Barry was a paratrooper and this is one of the things which connected him to Leonard.

*“...There was a lot of photos, there was parachute regiment badges...Religious...Bits and pieces, like crosses and...perhaps a sacred heart and things...most of the religious things are still there anyway...” [B-P2 Q3]*

This section of Barry’s interview feels as if he is describing ‘another way of being’ with Leonard. Barry’s position is one of acting more slowly and considering Leonard’s feelings more directly than the dominant *fighting-narrative* seems to allow. So, while both Gareth and Barry are assuming a role of advocating for Leonard, they seem to do so in very different ways.

## Carers

Another example of Barry's differing attitude towards Leonard is that he wondered about the work and attitude of a particular carer. Although other family members have spoken about the carers in general, during his conversation, Barry spoke about one person in particular.

It seems that while other family members might have assumed that they were Leonard's advocates in dealing with this person, it was Barry's first thought to ask Leonard for his own thoughts and then to 'put it in writing' so that he could understand Leonard's point of view more easily.

*"...I want to ask him about these things...I'd like to know how he gets on with his carers..." [B-P3]*

Although it seems that Barry is aligning himself into the position of an advocate/protector here for Leonard, he never acts on his behalf without consulting him; which seems proscribed by the *fighting-narrative*. Barry recounted an incident that he was unhappy about and a carer who he is unsure of as the carer was acting in such a way to impress Barry, which he inherently distrusted as it:

*"...makes you wonder, if they do those kind of antics while you're there, what will they get up to...when you're not there..." [B-P5]*

Barry has experience of care workers in other settings as his cousin lives in a care home for people with learning disabilities. He perceives that some carers have a better relationship with his cousin, which he can tell because of his cousin's body language and ease around them.

*"...my cousin...would respond to him...He wouldn't say words associated with what he'd just said, but would respond to him...Like 'I want a biscuit or a bit of cake' or something like that, which is...[his] favourite sentence...I can see the difference..." [B-P6]*

The carer that Barry is unsure about uses the phrase "*you're my friend*" which piques Barry because Leonard does not seem to react to him in a way which would suggest a close friendship and mutual feelings.

*"...he's always saying to Leonard "my friend, you're my friend", he'll repeat it over and over...but then doesn't act like a friend..." [B-P4]*

Barry learnt to notice body language because his cousin once showed distress when a particular carer entered the room. I think that Barry has used these experiences and transferred his "skill set" when supporting and befriending Leonard.

Because Leonard is so central to Barry's story, it seems that he is able to notice things that other people did not report. Some of his feelings regarding the carer

may be due in part to Leonard's reaction to him and the feelings that Barry has from Leonard's reactions. Barry says that he is very experienced about judging people.

### **Barry's cousin and spending time with Leonard**

During this part of the conversation, Barry showed a great deal of compassion when he spoke about the fact that his cousin had never said his name. This resurfaced towards the end of our interview regarding his wish that Leonard would be able to say "thank you Barry".

Barry described his cousin as having been very 'poorly' recently and demonstrated the implications of not being able to communicate properly when having major health difficulties. During this time his voice is strong, yet quiet and thoughtful. He is not trying to avoid its emotion power.

*"...[I was] reduced to tears...[my cousin was] crying out in pain...I was in a state..."*  
*[B-P10, box 10]*

Barry is narrating an alternative story to the *fighting-narrative*, where the loss, grief and sadness associated with life are able to be felt. He presents this story as a counter to the dominant narrative and does not avoid or sanitise difficult emotions. The dominant *fighting-narrative* is that the emotions are best dealt with by channelling them into practical ends.

Parallels can perhaps be made between this recent period in which Barry nearly lost his cousin and Leonard's accident thirteen years ago when he very nearly died. Barry described the difficulties of his cousin's experience in the hospital, as being unable to talk, and the doctors not having the skills to properly communicate with him. Again this seems to parallel with the confusing and disorientating states which Kristina and Gareth would have been in when Leonard originally had his accident. Barry's voice is sympathetic and compassionate when he talks about his cousin and these experiences might help him empathise with Kristina and Gareth and may therefore become part of the family narratives.

### **Experiences and communicating with Leonard**

Barry summarises the thought processes of Leonard's friends as he imagines them:

*"...I might be like a lot of the friends of Leonard and think I'm getting nowhere here, I'm not getting any response, or he's not communicating, and out of embarrassment probably, or, you just think, well I won't come back anymore..."* [B-P12]

Barry's previous experience of being with people with disabilities is also true of Alex, Kristina and Gareth and may be an important predictor of good coping strategies of people who care for or befriend somebody with a brain injury.

Barry seems to pay particular attention to Leonard's body language, and interacts with him through eye contact. Barry is very touched by the joke that Leonard pulled as this was the second time that he spoke about it, which I understand as a measure of its importance for him.

*"...He couldn't shake off the smile before they saw him...So yeah, that's great..." [B-P13, Q1]*

When telling the story, Barry seems very happy and pleased within himself. He enjoys this story a lot as it seems like a spontaneous and genuine communication between them. This is an important theme and an important quality of the interaction between Barry and Leonard. Barry is very happy to have eye contact from Leonard and thereby go into his world; he looks to advocate for Leonard, rather than change him in anyway and he is able to find his connection and reach his place of normality. This seems again in contrast to the major narrative theme of advocating *for* Leonard, whereas Barry seems to be also advocating, but doing it *with* Leonard.

### **Communication**

The communication between Barry and Leonard seems very important. He mentions the importance of shaking hands as a means of communication. It is an important leveller within their interactions, as handshakes are the mark of an equal relationship, rather than that of a career and his charge.

*"...when you do actually get your hand into the palm of Leonard's...He tends not to let go...He gets a firm grip and eh...I feel a little bit uncomfortable about forcing my hand away..." [B-P16]*

It is easy to see that this is a form of communication that Barry is reluctant to break, given how important these exchanges are with Leonard for him.

I suggested that he positions himself as an advocate or protector for Leonard. Barry did not directly answer this question but instead talked about two personal stories regarding Leonard.

The first example was that Barry explained how he was very actively trying to cajole somebody who had known Leonard in the Paras to visit him, who unfortunately would not come. In telling this story, I think that Barry is adopting his role of friend and protector for Leonard versus the other people who are seen by Barry as letting Leonard down.

*"...I've tried and tried to get this young guy, I keep saying...'are you going to come and see Leonard with me', he keeps saying he will, but...I know Leonard will be pleased to see him...but then if it was a one off and he doesn't come again...it would just hurt Leonard..." [B-P18]*

It is a similar narrative to that expressed by Gareth but in the gentler way with less incredulity. The second story that Barry told was that he was upset on Leonard's behalf that the Royal British Legion seemed to ignore him because he was injured whilst training and was not the victim of a war-injury, despite the fact that he had toured in war zones in the past such as Northern Ireland.

*“...On Remembrance Day, when they go back to British Legion, they speak up about other guys with...War injuries, but they blank Leonard, because his was...a training accident, although he was...in Northern Ireland for quite some time...as a paratrooper, very, very dangerous...” [B-P18-19]*

Barry reported that Gareth finds this particularly hard too; I wondered if Gareth views the Royal British Legion as another service or authority that seems to have let Leonard down within the family narrative. Barry remarked on the unfairness of this situation, as the RBL seems to make the distinction here between a veteran who has lost three limbs and Leonard who cannot use the limbs he has. But importantly, Barry feels that the brain injury which Leonard sustained is hidden from public view and is therefore the far greater problem, as the far more visible physical injuries are given more public recognition, whereas the TBI which is often a far more debilitating injury for the person and their family is given relatively little public recognition.

*“...there was two guys in a wheelchair...one had lost three limbs...But he's no different to Leonard, Leonard...can move his legs just a little...But obviously he can't walk and things like that...what difference is it...He can't do anything with this arm...but the other guy had...no brain damage...but Leonard...has got brain damage too, which is an even worse situation...” [B-P19]*

So, while Barry did not directly answer the question of being Leonard's advocate, he did then offer stories of his advocacy. It might be a measure of Barry's different relationship with Leonard, as he is not a blood relative (and never knew him as a child) that he is more able to have a different position towards him than the family do.

As he has no blood ties, Barry has the most choice about whether or not to spend time with Leonard. He must therefore be very committed to continue to spend time with Leonard as he has the freedom to choose and Leonard is only one part of his life. Therefore, his different relationship with him might simply be a measure of the desire to spend time with Leonard in an adult relationship, which might offer him more freedom from the *fighting-narrative*.

Towards the end of the interview, Barry explained how he and Leonard had met for the first time six or seven years ago, which was several years after Leonard's injury. I was surprised at this, because I had assumed that Barry and Leonard were friends before his injury, I was more surprised that this had led to a genuine friendship as reported by Barry.

I think I had incorrectly assumed that the only relationship that anyone could have with a TBI person is one of sympathy and depersonalised 'caring', so it was

a shock when Barry explained their meeting and his explanation of their relationship. It seemingly wasn't important for Barry whether he and Leonard had had any crossover in the Army before they had become friends.

### Terrence's Counter Narratives

As with the *baby-narrative* section where I interviewed Terrence, he held some very powerful and suppressed counter narratives to the *fighting-narrative*, which briefly stated were that he feels very angry towards Leonard for the pain that he has caused the family and the subsequent impact of taking his parents away from him.

#### Relationship with Barry

The fragmented narrative that Terrence holds seems consistent with idea that he is traumatised by the experience, and the lack of public recognition for his internal inexpressible narrative means that he speaks in a disfluent and disorganized voice.

Barry seems to represent a rivalry to Terrence's preferred position, presenting almost an ideal position against which Terrence is forced to compare himself.

*"...I felt that [Barry's presence] in some ways that, you know, that misrepresented the significance...over time..." [T-P1].*

Terrence knows that Barry is one of the few consistent male figures in Leonard's life now, apart from his cousin Alex. Terrence might be expressing guilt at not being more engaged with Leonard's life now, and that having Barry at the interview seemed to highlight this for him.

*"...[Barry]...is very involved at the moment...Barry will be Leonard's only consistent male friend right now...he is someone that's only really been around...in quite recent times..." [T-P2]*

Barry is the exemplar of the consistent friend for Leonard, whereas Terrence has withdrawn from him and this was highlighted by Barry's presence at the first family interview.

The disfluent way in which Terrence speaks seems to attest to the idea that his is a very suppressed narrative which has had little room for familial recital, and therefore is not presented in a very coherent or rehearsed way.

I was interested in Terrence's account of the narrative that 'Leonard has too few consistent friends' left and wanted to know about Terrence's role in that dynamic which is a fundamental part of the *fighting-narrative*. Terrence described his relationship with Leonard before the accident as

*"...Not being particularly close...my role with Leonard is quite limited to be honest...I've probably not seen him for...at least a month or so..." [T-P4].*

## Relationship with anger

Terrence found it “shocking” that Leonard was considering doing counter surveillance work which would take him away from his family life, girlfriend and his young son. Interestingly, this is similar to Gareth’s reaction, which he shared in our individual interview, but did not share when we had the family interview. Terrence’s conversational manner was very stilted and very stifled; he frequently paused for over ten seconds when offering his narrative.

*“...he planned to go...on the selection course...to do this counter surveillance work...that was quite disappointing. No, not disappointing, it was quite shocking that he was...he was considering doing that...” [T-P5/6]*

This is the only time that this anger has been so explicitly mentioned throughout all eight interviews, which highlights just how hidden the narrative is within the family. Terrence's anger seems to be about the flippant way that Leonard put his trust in other people that they would pick up the slack if he was injured.

*“...I have felt intensely angry with Leonard...over time, for...bringing this about...engaging in a high risk sport...repeatedly, possibly it was him taking too many chances...” [T-P12]*

*“...I’m entitled to feel angry...I have to keep it in some perspective...” [T-P13/14]*

For Terrence it is almost as if that price is far too high, given the massive impact that Leonard’s injury has had on all those around him and will continue to have.

*“...had a young son...responsibilities...obviously he didn’t do it intentionally, but the consequences being that he’s...had a dramatic impact on...those around him...” [T-P12]*

In fact, given the earlier conversation, Terrence is yet to experience the full impact of Leonard’s TBI, because he will at some point inherit that burden of looking after Leonard, as well as having to look after two fragile parents at the same time.

The personal impact of the TBI on Terrence is striking. When discussing what happened to his anger, Terrence says that:

*“it fuels the detachment, and the detachment in turn fuels anger” [T-P13]*

His anger has now reached the point where his girlfriend is warning him about it and telling him that he *“has to attend to it” [T-P12]*. He is ambivalent though because he expresses guilty feelings at the anger he feels towards Leonard. Terrence seems to be holding and suppressing the anger for the whole family.

*“...I also feel bad, I feel bad that I feel angry about it as well...” [T-P13]*

Because of the suppressed nature of the story of anger towards Leonard, Terrence did not know if he was alone with his anger; only that within the family, it cannot be addressed. Perhaps because talking about being angry with Leonard in the family might make it 'more real' and hurt him further.

*"...I don't know what his son thinks...or how his girlfriend at the time felt...I don't know...they [Mum and Dad] may well...feel angry, I don't know...it's not something that's talked about...I've not tried..." [T-P14]*

The *fighting-narrative* is so powerful and dominant within the family that Terrence is completely unable to voice or to share his feelings. Anger at Leonard is not acceptable publically.



## CONCLUSIONS

This study was unique in the literature because its aim was to gain a deep insight and understanding of the lived and socially constructed experiences of a family through their created narratives.

### Summary of the findings

The major finding from the thesis was that the TBI affects all members in the family system and in different ways. This is a very consistent finding, from the research literature (Andreatta, 2008; Florian, Katz, & Lahav, 1989; Jumisko, Lexell, & Soderberg, 2002; Verhaeghe, Defloor, & Grypdonck, 2005). The narratives told within this family however are unique to it and to our joint construction (Mishler, 1986; Gergen 1998).

This research has focused exclusively on the two major narratives which emerged naturally; the *baby-narrative* and the *fighting-narrative*. These positions were held mainly by Kristina and Gareth and only the contributions from other family members which either supported or contradicted this narrative were included in my discussion. However, there were other 'minor' narrative positions within the interviews, which have not been illustrated here. The overwhelming power of the two major narratives within the family demanded equal dominance in the discussion.

### Stuck stories

Both narratives - although particularly the *baby-narrative* - are stuck and frozen in time, with little room for evolution and integration of new stories. These stuck stories can be understood as a process of dissociative narrative distancing, whereby the stories are emotionally distanced by the storytellers (Gallagher & Cole, 2011). In narrating her *baby-narrative*, Kristina often 'sanitised' her story and removed herself emotionally from it, insisting that everything 'was okay,' rather than engaging with it. The counter narratives were, however, characterised by a degree of emotional responsiveness, which could not find purchase whilst Kristina was distancing herself emotionally from the pain.

Verhaeghe, Defloor and Grypdonck (2005) demonstrate that focusing on the unemotional and practical aspects of care reduces the stress of the accident on the family in the short term, after the accident; whereas emotionally focused coping styles would have to create a new relationship with the distress. Oddy and Herbert (2003) demonstrated that both emotional and practical coping styles are usually present in families that have good coping strategies. However, as Kristina and Gareth seem to have dissociated from the emotional aspects of Lenard's accident, they seem to have become 'stuck' within their on-going and current narratives.

Throughout the *baby-narrative*, Kristina uses religious metaphors to explain her position. She uses the church and her relationship with God as a 'defensive dissociation' (Lamothe, 2004). Intolerable anxiety is kept at bay in this way,

thereby allowing Kristina one method of engaging with the world, but it prolongs the narrative distancing (Gallagher & Cole, 2011) and hinders the full integration of her experiences, which is necessary for a 'forwards' movement in her narrative.

Another possible influence on the stuckness of the two major narratives is the obvious rigidity of Leonard's life; both dominant narratives within the family seem to have a systemic link with Leonard's on-going experiences. Although we may perhaps be unable to understand what is happening in Leonard's mind, rigidity and inflexibility of thought are often reported consequences of TBI (Kay & Lezak, 1990). A possible consequence of the rigidity within Leonard is a familial mirroring of their lived experiences, being narratively more 'rigidly' in turn. Kristina and Gareth's lives are so bound up in his day-to-day care that their internal narratives might have 'frozen,' reflected in the rigidity of Leonard's daily life.

### **Homeostasis versus moving forward within the narratives**

Gareth seems to be moving to a realisation that he is unable to do everything for his son. During the interviews, his understanding of his new position seemed to be initiated by his own self-reflection on other people's reactions, particularly in relation to letting the carers do more and stepping back himself.

At times the *fighting-narrative* was hard to piece together, which might be because it is starting to change and evolve slightly, as Gareth incorporates new ideas. This change might be categorized by the realisation that while he has created the *fighting-narrative*, it is a battle that he cannot win, given their ageing and mortality. This self-reflection might be seen as Gareth getting in touch with his own emotional experiences, which he has denied for so long because of all the 'battling' that he has been doing.

Both major narratives perceive Leonard's life as fragile and precarious (Andreatta, 2008) and as such, it might be understandable that they have both developed relatively simplified narratives to make sense of this new constructed reality. The dominant narratives within the family have a simple 'good versus bad' dichotomy and this is the way that this family have made sense of their shattered and violated reality (Williams, 2008). Florain, Katz, and Lahav's (1989) suggest that a more nuanced and integrated narrative is challenged by the action of the TBI on the family. It is also interesting systemically that the simplified family narratives could be easily understandable by a young child, which is how Kristina invites people to view Leonard. It is possible that the family have internalised their constructed identity that they have created for Leonard in terms of the narratives that they hold about him.

The frozen narratives that the family maintain may also be seen as a feature of the type of ambiguous loss that they are dealing with (Betz, & Thorngren, 2006). The wider societal discourse around 'a death in the family,' would allow the family to grieve and 'move on,' in their constantly evolving lives. However, Lezak (1978) argued that the wider societal narratives do not allow the family to grieve

the loss of the person with TBI because their body remains. This lack of a wider social discourse on the nature of the bereavement caused by TBI means that the family are isolated from society and without a common or supportive narrative (Neimeyer, Harris, Winokuer & Thornton, 2011).

Families caring for a member with a chronic illness and TBI move between positions of hope and despair (Cesa, 2005; Brown & McCormack, 1988). Within this family, the position of 'hope against all odds' seems to have been permanently secured by Kristina, whereas Terrence seemingly holds the corresponding position of despair. Moving forward as a family would perhaps involve establishing roles and positions away from these two extreme poles (Cesa, 2005).

### **Trauma**

The major differences between Gareth and Kristina's narrative will probably be influenced by several important factors. Amongst these is the way in which the trauma narratives were initially constructed (Tuval-Mashiach, Freedman, & Bargai et al., 2004). The immediate time after Leonard's injury would have been crucial in developing a narrative around the accident and much research has demonstrated that the initial thoughts of the family are on life and death situations (Williams, 2008; Turner et al, 2007; Brown & McCormack, 1988), i.e. the significance of the injury for the family doesn't become clear until later (Oddy & Herbert, 2003). In terms of a trauma narrative, it is perhaps understandable that the family members have created different narratives because they may have different constructions about the consequences of the accident. For example, in their later recollections with me, Kristina demonstrated the initial preface to her *baby-narrative* in wanting to have *last rights* performed, whereas Gareth's *fighting-narrative* started when he wanted to *collect evidence* for a possible tribunal.

At times during the interviews, there was a striking difference between the ways in which Terrence presented his narrative when compared with the rest of the family. Whilst Kristina's narrative often appeared sterile and devoid of emotional context, Terrence's interviews often gave the opposite impression. He seemed to struggle with creating a coherent, organised narrative (Dimaggio, 2006). Autobiographical interviews are dialogical processes which are co-created between the story teller and the audience, and as Terrence's narrative has been suppressed from the family, it seemed fragmented and incoherent (Hermans, 2000).

### **Sibling relationships**

A very important finding from this research is that this is a story about the whole family system, not just Leonard and his parents. Sibling relationships are badly neglected within the TBI literature at the expense of the more usual parental or caregiver relationships (Bowen, Yeates & Palmer, 2010). However, this thesis spent much time elaborating on Terrence's suppressed narratives in comparison to both the *baby-narrative* and the *fighting-narrative*. Terrence reported strongly

mixed feelings towards Leonard, which were mainly an ambivalent blend of anger and guilt. His own wellbeing was affected by his inability to have his own feelings recognised within the family, and as such, he found some limited solace in detaching himself from the family story.

Perlesz, Kinsella, and Crowe (1999) found that as these sibling relationships are neglected within the family, so they are also least likely to come to the attention of the health services. Therefore, the suppressed or absent sibling narratives are echoed at a greater societal level too.

### **Simplified narratives**

The two dominant narratives are simplified and concrete, with neither room for much subtlety or dissent within them. It might be narrative simplification of the lived experiences of the family could be related to the simplified way in which people might communicate with young children. Such simplified communications work their way into the family narrative in such ways as Gareth's 'black and white' thinking and in Kristina using language as though relating to an infant. Problems for families exist when the stories that they narrate about themselves become stuck and unhelpful (White, 1989; White & Epston, 1990).

All family narratives are likely to be influenced heavily by dominant societal discourses, such as gender roles. The *fighting-narrative* seemed in some ways to confirm to the stereotypical role of the man fighting externally for his son's advancement, approaching and fighting the obstacles in his way, such as the NHS and social services that are unable to perform to the standards required by the *fighting-narrative*. To some extent the father continues the (military) battles his son is no longer able to fight, carrying on his son's legacy as if it might somehow 'magically revitalise him'. The *baby-narrative* alternatively is a stereotypically female position, of looking to nurture what has already been lost and to re-parent the infantilised Leonard, in her ways Kristina is protecting him from further harm. These overarching gender constructs suggest social mores influence the thematic nature of parental stories. There is thus also a need to be aware of the social context that both shape and constrain stories.

### **Clinical Implications**

The clinical implications for families which have had a member sustain a TBI, as well as the medical and rehabilitation professionals who care for them, are multiple and significant.

#### **This family**

The clinical implications for this and potentially other families, might be to investigate the small counter narratives in the story or the 'unique outcomes' (White and Epston, 1990), which are apparent within the overall narratives. For example, Kristina was at one point, able to say that she felt resentful at sometimes not having more time for herself. Narrative therapy (White and

Epston, 1990) might help to explore the meaning of these unique outcomes and thicken an alternative and perhaps more adaptive narrative for her (e.g. which incorporated some 'letting go' and self-care).

Currently it seems as though their narratives are frozen and stuck, and that for Kristina particularly, any change to her dominant narrative seems negative and threatening. According to Strong and Tomm (2007) the social constructionist nature of family therapy would highlight familial differences in outlook and conversation, so that multiple possible narrative threads could be understood together and help to move the family forward to mutually preferred alternative narratives.

An alternative narrative that the family might be able to explore is the idea that it is '*okay to stop*'. The volume of work that the family are doing for Leonard and the narratives that they have created might be maintaining their emotional absence which has frozen them as they have not been able to express their emotions freely; however by learning to 'step back' (and feel), they might be able to free themselves from their trapping overarching narratives, both of which require considerable and costly investment to maintain.

### **Professionals**

This research potentially further increases the medical professions' awareness of family members' propensity to over work and perhaps create rigid narratives for survival. Through increasing awareness of family narratives, people working with the families might be able to feed this message back to families or address their developing stories at the early stages – and perhaps less entrenched or 'rigid' stages - of their narrative journey through rehabilitation. Professionals may thus learn to encourage perhaps more subtle, varied and adaptive stories that more accurately reflect the complex nature of the families' experiences over time.

Additionally, the fact that this family is continuing to feel the very significant effects of the TBI thirteen years after the TBI is important. Clearly the need for support has not diminished as the years have passed. Educating GPs in the systemic impact of having a TBI family member might help families to continue to access support long after the medical necessity of limited rehabilitation has ended.

Another important service related use of this work might be as an entrance into discussions about the attitudes of NHS professionals towards families with TBI. In the current thesis, the family clearly had a perception that they were not listened to or supported by health and social care services. However, as with all narrative accounts, this thesis has been presented only from the perspective of those who chose to share their narrative. I feel that it would be useful to have a debate with policy makers and commissioners about whether they feel that they are paying adequate attention to this section of society.

In discussion with my supervisor who works in brain injury rehabilitation residential unit, she felt that I should not necessarily take the family's opinion of the healthcare providers as the 'whole story'. Therefore, by presenting this picture to healthcare commissioners I might enable the debate.

An alternative hypothesis for this family who believes that they are not supported enough, might be that they actually are being given all the support that they can receive from an over stretched and under budget health service. The family's perception may very understandably be based on the fact that no matter how much support they received from public or private services, it cannot be 'enough'.

Given the current family's internal conflicts and traumatic narratives, it might be another useful service related implication of the work, if it aided the thinking of and public recognition of the possible consequences of TBI in a family. For example, GPs might be able to consider that whenever there has been a monumental trauma in the family such as a brain injury, that the family are likely to be suffering in silence, and would value any support that they might be offered, without actually asking for it themselves.

### **Connecting the hidden stories and islands of people**

Although Kristina reported choosing to stay away from organisations such as 'the brain injury association', they do offer opportunities for families to get together and share their experiences, and therefore create a shared understanding of life after TBI. These family narratives are hidden and suppressed from the dominant societal discourse and so research such as this might potentially help to link together stories of people who have themselves become isolated. Sharing these stories help families share the 'load' of such narrative experiences and as these become more visible to wider society, they potentially enable a degree of public education, helping develop more sympathetic societal discourses around how families (including siblings) are left to manage TBI.

### **Methodological Issues**

The major strength of this study is that it was able to gain a unique access into family functioning after a brain injury. I was able to explore relationships not traditionally available to TBI research, because we constructed narratives between the designated family members themselves and not simply via the carers and the brain injured person, which is often the structure of research in this field (Andreatta, 2008).

Through allowing a very conversational and unfocussed interview style (Wells, 2011), the family members were able to create their own narratives with me, without a prejudged favouring of particular stories or events, which might be the case if a more formal and structured interview schedule had been employed (Mishler, 1986).

During this research I took a co-constructionist position, which means that I understand that my presence at the interview affected the interview to co-create the narratives (Pedlock, 1991). In taking this position, I feel that I was a genuine part of the conversations. The family was able to relate to me in a far less formal way, than if I had used an interview schedule which might in its own way have created narrative dissociation (Gallagher & Cole, 2011), and therefore made it harder to connect with the participants.

As with all narrative research practices, this research has not aimed to prove or disprove theories, rather it aimed instead to explore those lived and storied experiences of the family which were important to them. As such, it would not be appropriate to uniformly generalise this family's experiences onto all families who have a TBI, especially given the socially constructed nature of the presented narratives. However, it should be noted that anecdotal evidence from the clinically based supervisor, a clinician of much experience in TBI, is that such large and 'stuck' simplified narratives, are certainly not atypical within the field.

The selection of the 'family' in this research was very important. It was discussed in the report that this was a created family at Gareth's behest. He was my initial contact into the family and so it was Gareth who chose whose narratives would be given voice. It is also important to note though that the family that Gareth chose to invite necessarily excluded other people who would have given a different narrative and changed the story that was created. The familial narratives that have emerged are thus shaped by the sampling process of how 'family members' were validated as safe to 'access', by the father.

### **Recommendation for further research**

In supervision with psychologists experienced in the systemic implications of TBI in the family, we discussed future research possibilities. We examined the area of 'grand trauma narratives' such as those discussed in this thesis being created and defended in other families. Grand narratives such as the *baby-narrative* and the *fighting-narrative* have very little room to grow and evolve, having become frozen. So while the practical and unemotional style of the family might have been a constructive coping strategy initially, it seems to have become counter productive in integrating and evolving the narratives as time progresses (Verhaeghe, Defloor, & Grypdonck, 2005). The immediate period after the traumatic event is very important in the construction of new family narratives in (Tuval-Mashiach et al. 2004).

This seems like a natural progression of the work, i.e. to see how soon after the TBI such narratives start to coalesce, and how might professionals act to help to develop less destructive and rigid narratives around the TBI and the family role. A longitudinal study, perhaps looking across a good number of families, may aid our understanding of the developmental nature of such stories and how they may best be aided and shaped.

Finally, I am aware of a central character's voice not being represented, i.e. Leonard himself. More research can perhaps extend work such as Uprichard

(2010), looking in particular at people with TBI and *their own* experiences of their family.



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## **APPENDICES**

Appendix A: Approval from UH

Appendix B: Form ER2

Appendix C: Ethics Application form

Appendix D: Consent form

Appendix E: Participant information sheet

Appendix F: Debrief sheet

Appendix G: Transcription service agreement

Appendix H: Transcription of the family interview

Appendix I: Notes on the family interview

# Appendix A: Approval from UH

Revised (September 2006)

## SCHOOL OF PSYCHOLOGY ETHICS COMMITTEE APPROVAL

**Student Investigator: Andrew Bamber**

**Title of project:** Narrative inquiry into family functioning after a brain injury.

**Supervisor: Nick Wood**

**Registration Protocol Number: PSY/06/11/AB**

**The approval for the above research project was granted on 22 June 2011 by the Psychology Ethics Committee under delegated authority from the Ethics Committee of the University of Hertfordshire.**

**The end date of your study is 1 June 2012.**

**Signed:**



**Date:** 22 June 2011

**Professor Lia Kvavilashvili  
Chair  
Psychology Ethics Committee**

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**STATEMENT OF THE SUPERVISOR:**

**From my discussions with the above student, as far as I can ascertain, s/he has followed the ethics protocol approved for this project.**

**Signed (supervisor): .....**

**Date: .....**

SCHOOL OF PSYCHOLOGY

*This form accompanies a submission by a member of staff, a PhD student or a particularly problematic undergraduate research proposal for ethical approval. It will be seen by yourself and all other members of the Ethics Committee. Please respond promptly and please give enough detail to enable the Chair of the Ethics Committee to take the appropriate action.*

*Please email the form to [psyethics@herts.ac.uk](mailto:psyethics@herts.ac.uk). Thank you.*

**Investigator**            **Andrew Bamber**

**Title**                      Narrative inquiry into family functioning after a brain injury.

**Date submitted**        **13 June 2011**

**Considered by**

**Date ER2 returned**

1(a).....Can proceed under the named protocol without amendment.

1(b) .....YES..Can proceed, but please take into account the following suggestions/comments:

The information sheet should state that the project has the approval of the University of Hertfordshire ethics committee and give the protocol number.

2. .... More information needed for making a judgment about ethical soundness of the study.  
*Please be as specific as possible about what your concerns are and what information you require.*

3. ....This proposal raises ethical issues which I think should be further considered before approval is given

*Please be as specific as possible about what your concerns are.*

SCHOOL OF PSYCHOLOGY

*This form accompanies a submission by a member of staff, a PhD student or a particularly problematic undergraduate research proposal for ethical approval. It will be seen by yourself and all other members of the Ethics Committee. Please respond promptly and please give enough detail to enable the Chair of the Ethics Committee to take the appropriate action.*

*Please email the form to [psyethics@herts.ac.uk](mailto:psyethics@herts.ac.uk). Thank you.*

**Investigator**            **Andrew Bamber**

**Title**                      Narrative inquiry into family functioning after a brain injury.

**Date submitted**        **13 June 2011**

**Considered by**

**Date ER2 returned**

1(b) .....Can proceed, but please take into account the following suggestions/comments:

The Information Sheet may be unnecessarily long. Could this information be expressed more succinctly? In addition, the researcher is sometimes referred to in first person and on other times in third person. This may be confusing.



Appendix C: Ethics Application form

**SCHOOL OF PSYCHOLOGY ETHICS APPLICATION FORM**

**Status:** DClinPsy

**Course code (if student):** 09212270 DClinPsy

**Title of project:** Narrative inquiry into family functioning after a brain injury.

**Name of researcher(s):** Andrew Bamber

**Contact Tel. no:** 07725073276  
**Contact Email:** ab09act@herts.ac.uk

**Name of supervisor:** Dr Nick Wood

**Start Date of Study:** 1/6/2011

**End Date of Study:** 1/6/2012

**Number of participants:** 5

|    |  | YES | NO | N/A |
|----|--|-----|----|-----|
| Q1 | Will you describe the main experimental procedures to participants in advance, so that they are informed about what to expect?                     | X   |    |     |
| Q2 | Will you tell participants that their participation is voluntary?  | X   |    |     |
| Q3 | Will you obtain written consent for participation?   | X   |    |     |
| Q4 | If the research is observational, will you ask participants for their consent to being observed?   |     |    | X   |
| Q5 | Will you tell participants that they may withdraw from the research at any time and for any reason?  | X   |    |     |
| Q6 | Will you tell participants that their data will be treated with full confidentiality and that, if published it will not be identifiable as theirs? | X   |    |     |
| Q7 | Will you debrief participants at the end of their participation (i.e., give them a brief explanation of the study)?                                | X   |    |     |

**IMPORTANT NOTE:** If you have indicated **NO** to any question from **1-7 above**, but do not think this raises ethical concerns (i.e., you have **ticked box A** on page 3), please give a full explanation in **Q19** on page 2.

|    |   | YES | NO | N/A |
|----|---|-----|----|-----|
| Q8 | Will your project involve deliberately misleading |     | X  |     |

|            |   |   |   |  |
|------------|---|---|---|--|
|            | participants in any way?  |   |   |  |
| <b>Q9</b>  | Will your project involve invasive procedures (e.g. blood sample, by mouth, catheter, injection)?   |   | X |  |
| <b>Q10</b> | Will the study involve the administration of any substance(s)?  |   | X |  |
| <b>Q11</b> | Will the study involve the administration of a mood questionnaire (e.g. BDI) containing a question(s) about suicide or significant mental health problems? (If yes, please refer to Psychology Ethics Guidelines for a standard protocol) |   | X |  |
| <b>Q12</b> | Is there any realistic risk of any participants experiencing either physical or psychological distress or discomfort?   | X |   |  |

|            |   |   |  |   |  |
|------------|---|---|--|---|--|
| <b>Q13</b> | Does your project involve work with animals?  |   |  | X |  |
| <b>Q14</b> | Do participants fall into any of the following special groups? If they do, please refer to BPS guidelines.<br><br><b>Note that you may also need to obtain satisfactory CRB clearance (or equivalent for overseas students)</b> | Schoolchildren (under 18 years of age)                  |  | X |  |
|            |   | People with learning or communication difficulties      |  | X |  |
|            |   | Patients  |  | X |  |
|            |   | People in custody                                       |  | X |  |
|            |   | People engaged in illegal activities (e.g. drug-taking) |  | X |  |

**IMPORTANT NOTE:** If you have indicated **YES** to any question from **8 - 14** above, you should normally **tick Box B** below. If you ticked **YES** but think that your study does not raise ethical concerns, please, provide a full explanation in **Q19** in the section below.

**There is an obligation on the lead researcher to bring to the attention of the Psychology Ethics Committee any issues with ethical implications not clearly covered by the above checklist**

Please answer **Q15-19** below. Provide appropriate information with sufficient detail. This will enable the reviewers to assess the ethical soundness of the study without asking you additional questions and will speed up the review process **(PLEASE, PROVIDE AT THE END OF THIS FORM AN EXAMPLE OF THE INFORMATION AND CONSENT FORMS, QUESTIONNAIRE(S), IF USING, AND ANY OTHER RELEVANT FORMS, E.G., DEBRIEF SHEET, ETC.)**

|                   |   |
|-------------------|---|
| <p><b>Q15</b></p> | <p><b>Purpose of project and its academic rationale (preferably between 100 - 500 words):</b></p> <p>The effects of brain injury are chronically under researched and research papers into the family experiences of a brain injury are even fewer (Chwalisz and Stark-Wroblewski, 1996). The lives of family members from the brain injury family are irreparably changed, and the burden of this change is seen not to lessen over time (Florian, Katz, and Lahav, 1989) and several research papers (Florian, Katz, and Lahav, 1989; Jumisko, Lexell and Soderberg, 2002; Andreatta, 2008) have identified the need for more research in the area of the subjective experiences of families in which one member has suffered a brain injury.</p> <p>There are many different possible outcomes for individuals with a brain injury due the myriad factors around the site and severity of the injury. These range from mild, nearly imperceptible problems which are characterised by difficulties with return to work and ‘normality’ to severe damage to brain structures and a complete change in life structure. Severely injured individuals can experience emotional, behavioural, cognitive and physical disabilities for the remainder of their life, long after the brain and body has reached its optimal level of recovery. Due to the brain injury population being very heterogeneous, they do not easily fit into large scale RCT designs; rather I would like to create a study to investigate the lived experiences of these people.</p> <p>Although the current study will acknowledge the site and type of brain injury, it will mainly investigate the impact of the injury on the <b>family</b>, rather than on the <b>individual</b>. As I have explained above, the brain injured population is a heterogeneous group, based on the factors of the injury itself and the many pre morbid factors that make up a person’s life. When contemplating research with a family, this is another level of complication in considering the pre-morbid functioning of the family, in addition to the individual and the type and severity of the injury.</p> <p style="text-align: center;"><b>Aims</b></p> <p>To explore individual ‘uninjured’ family members’ storied experiences of having someone with a brain injury from within their family.</p> <p style="text-align: center;"><b>Research Question</b></p> <p>Have family member identities changed over time from before and after the injury?</p> |
| <p><b>Q16</b></p> | <p><b>Brief description of methods and measurements:</b></p> <ul style="list-style-type: none"> <li>• I will recruit a family who are willing to take part in the study (See participant recruitment below).</li> </ul>   |

|                   |  |
|-------------------|--|
|                   | <ul style="list-style-type: none"> <li>• I will use the open ended question to start the family interview such as “Tell me about your experiences of brain injury within the family?” Such questions have been suggested by Mishler (1986) as ideal for eliciting free narratives. Follow up prompts may be provided to assist interviewees as needed.</li> <li>• According to Wells (2011), a family of 4/5 should provide sufficient numbers for narrative analysis, given the complex analyses required to gain insight into individual and family experiences and stories.</li> <li>• I will interview the family together for the first interview, and then interview each family member separately in subsequent sessions. Each interview will last 60-90 minutes.</li> <li>• I will transcribe the interviews verbatim, including the pauses and interjections (er, um, hmm etc). <ul style="list-style-type: none"> <li>• I will analyse the interviews for the narrative experiences of the family.</li> <li>• Data analysis will use the transcribed interviews and elicit a plot, or narrative sequence, it will also focus on how the stories are told or performed. It will explore those themes which are underlying and less evident.</li> </ul> </li> </ul>  |
| <p><b>Q17</b></p> | <p><b>Participants: recruitment methods, study location, age, sex, exclusion/inclusion criteria:</b></p> <p><i>Inclusion/Exclusion Criteria for the study</i></p> <p>I aim to recruit a single family for a case study. As a major focus of this work is on the language used to create the stories within the family and within and between individual family members, English as first language is a necessary inclusion criterion.</p> <p>I understand that research into ethnic minorities and the non-English speaking population is not explored enough, especially within a health context. However, the nature of narrative research and the process of creating a co-constructed narrative determine this inclusion criterion.</p> <p>I am investigating the family that has settled into a new ‘reality’ post brain injury. I am therefore interested in recruiting a family where:</p> <ul style="list-style-type: none"> <li>• One member has sustained a moderate to severe brain injury according to the length of post traumatic amnesia.</li> <li>• As suggested in discussion with my field supervisor, an experienced clinician in TBI, four to six years post trauma would be an ideal range to capture a sample which has settled into their ‘new lives’ after the brain injury. The site and severity of injury will determine the length of time that the injured person is in acute rehabilitation phase; as such four to six years may be a useful length of time to wait. Also the work of healthcare professionals is likely to have reduced considerably by this time after the accident and the family might be experiencing life</li> </ul> |

|                   |  |
|-------------------|--|
|                   | <p>'on their own' by this point.</p> <ul style="list-style-type: none"> <li>• The injured family member is living permanently back at home.</li> <li>• The injured person is no longer at risk of his/her life due to the effects of the initial injury.</li> </ul> <p><i>Recruitment Path</i></p> <ul style="list-style-type: none"> <li>• I will approach several charities with this proposal for help in recruiting the case family.</li> <li>• I will create information sheets (see attached) regarding the project to which an interested family could reply.</li> <li>• We would then set up a meeting to discuss full and informed consent to take part in the study.</li> </ul> <p>This recruitment strategy gives the power to the family, and removes any pressure on them to take part in the study. As I only need a single family, I am confident that this recruitment strategy will succeed.</p> <p>Part of the recruitment strategy is to invite the family to co-author the report with me. Co-authoring the report also challenges the ethical dilemma of possible identification of the family. The family could instead embrace their story and tell this openly, instead of remaining anonymous.</p> <p>In doing so the family could have the possible incentive of 'empowerment'. This paper could offer the family a way of expressing their views and feelings to a professional audience from which they might previously felt ignored. Service user involvement and collaboration in research has increasingly been encouraged by the Department of Health (Read and Maslin-Prothero, 2011).</p> |
| <p><b>Q18</b></p> | <p><b>Consent and participant information arrangements, debriefing:</b></p> <p>I have created consent forms, participation and debriefing forms; see attached.</p>   |
| <p><b>Q19</b></p> | <p><b>Any other relevant information:</b></p> <p>This proposed project is a single family case study and therefore, while I will anonymise the family for the purposes of the DClinPsy, the family members will be able to identify each other in the final report. This will be fully explained during the initial meeting regarding full and informed consent.</p> <p>The family will also be given the opportunity to co-author the journal ready paper. Whereby they may feel empowered by the research in being able to tell their narrative to a professional audience. It is also important to explain to the family that we will be co constructing a narrative and</p>  |

|  |  |
|--|--|
|  | <p>therefore, my interpretations of their family story may be different to their own. There may be potential conflictual dilemmas involved in co-authoring the report with the family though and while I would aim for full collaboration, I would at least agree with the family to share transcripts to confirm member validation of interviews if they were uncomfortable with my narrative analysis.</p> <p>References:<br/> Mishler, E.G. (1986) <i>Research Interviewing: Context and Narrative</i>. Cambridge MA; Harvard University Press.<br/> Read, S. &amp; Maslin-Prothero, S. (2011) "The Involvement of Users and Carers in Health and Social Research: The Realities of Inclusion and Engagement." <i>Qualitative Health Research</i>, 21(5), 704-713.</p> <p>Wells, K. (2011) <i>Narrative Inquiry</i>. Oxford: Oxford University Press.</p> |
|--|--|

PLEASE TICK **EITHER** BOX A **OR** BOX B BELOW AND PROVIDE RELEVANT ADDITIONAL INFORMATION IF YOU TICK **BOX B**. THEN PASS THE FORM TO YOUR SUPERVISOR

**Please tick**

|   |   |
|---|---|
| <b>A.</b> I consider that this project has <b>no</b> significant ethical implications to be brought before the Psychology Ethics Committee.   |   |
| <b>B.</b> I consider that this project <b>may</b> have ethical implications that should be brought before the Psychology Ethics Committee   | X |
| <p><b>Please provide a clear but concise statement of the ethical considerations raised by the project and how you intend to deal with them.</b></p> <p>The participants may experience some distress talking about their experiences but as a trainee clinical psychologist, I will be able to deal with distress appropriately. I will offer the participants a break if needed and will not insist they continue unless they are feeling contained and willing to do so. They will also be reminded they can withdraw at any time without giving reasons and support information would be made available should they wish to follow this up.</p> <p><b>If a YES answer has been given to any of the questions 8-12 above, please state previous experience of the supervisor, or academic staff applying for a standard protocol, of investigations causing hazards, risks, discomfort or distress. If it is likely that medical or other aftercare may be needed by participants, please, indicate who will provide the aftercare, and whether they have confirmed that the aftercare can be provided free of charge to the participants.</b></p> |   |

*This form (and all attachments) should be submitted (via your Supervisor for MSc/BSc students) to the Psychology Ethics Committee, [psyethics@herts.ac.uk](mailto:psyethics@herts.ac.uk) where it will be reviewed before it can be approved.*

**I confirm I am familiar with the BPS Guidelines for ethical practices in psychological research.**

**[For those using a shared online data collection account such as Survey Monkey]:**

**I have discussed with my supervisor and am aware of the issues concerning anonymity and confidentiality in using online data collection. I confirm that I will access no survey or data other than my own.**

Andrew Bamber  
(Researcher(s))

Date 13<sup>th</sup> June 2011



Dr Nick Wood  
(Supervisor)

Date 13<sup>th</sup> June 2011

**CHECKLIST FOR REQUIRED APPENDICES (appended at the end of this form)**

Sample forms can be obtained from Psychology Ethics Committee website at:

<http://PsyNeS.herts.ac.uk/ethics/index.html>

1. YOUR CONSENT FORM
2. YOUR INFORMATION SHEET
3. YOUR DEBRIEF SHEET
4. QUESTIONNAIRE(S) IF USED
5. SAMPLE MATERIAL(S) USED (e.g., pictures, stories, etc)
6. A SAMPLE OF ADVERTISING MATERIAL (e.g., email sent to staff and students, or external organisations)
7. LETTERS TO HEADTEACHERS (if the study is conducted in schools)
8. A SAMPLE LETTER TO PARENTS (if the study is conducted in schools)

Appendix D: Consent form

**Project Title: Narrative analysis of the family experience of life after a brain injury**

**Statement by Participant**

- I confirm that I have read and understand the information sheet for this study.
- I understand what my involvement will entail and any questions have been answered to my satisfaction.
- I understand that my participation is entirely voluntary, and that I can withdraw at any time without prejudice.
- I understand that all information obtained will be confidential.
- I agree that research data gathered for the study may be published provided that I cannot be identified as a subject.
- Contact information has been provided should I wish to seek further information from the investigator at any time for purposes of clarification.

**Participant's Name:**

**Participant's Signature**

**Date**

**Statement by Investigator**

- I have explained this project and the implications of participation in it to this participant without bias and I believe that the consent is informed and that he/she understands the implications of participation.

**Investigator's Name** Andrew Bamber

**Investigator's Signature**

**Date**



## **Narrative analysis of the family experience of life after a brain injury**

### **Part One: Invitation to take part**

You and your family are invited to take part in a piece of research being conducted by Andrew Bamber, Trainee Clinical Psychologist.

Before you decide if you would like to take part, it is important that you understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Please feel free to talk to others about the study if you wish.

Part 1 tells you the purpose of this study and what will happen if you decide to take part. Part

2 gives more detailed information about the conduct of the study.

This information sheet hopes to answer any questions you might have about the research. If there is anything you are unclear about or want more information about, please feel free to contact me on the telephone number below.

### **What is the purpose of the research?**

This research hopes to gain a deeper understanding of the lived experiences of the family members several years after a member of that family has sustained a brain injury. This research is being carried out as part of a doctoral training programme in Clinical Psychology at the University of Hertfordshire.

### **Why have I been invited to take part in the study?**

Several family members of people who have sustained a Brain Injury have been invited to take part in this research. It is hoped that those who agree to take part will share with the researcher their experiences of life after their brain injury.

### **Do I have to take part?**

It is up to you to decide. We will describe the study in this information sheet and you will have an opportunity to discuss it with the researcher. If you agree we will then ask you and your family to sign a consent form to show you have agreed to take part. You are free to withdraw at any time, without giving a reason. This would not affect the standard of care you receive in any way.

### **If I agreed, what would be involved?**

If you agreed to take part in this research you and your family would meet with Andrew Bamber, Trainee Clinical Psychologist. He would talk to you about the research, to make sure you have all understood what it would involve. He would ask you to sign a consent form, which would show that you have agreed to take

part. You would then agree a time and place to meet for the initial family interview.

At the beginning of this next meeting, Andrew would check to see if you had any further questions and to see if you have changed your mind. If you feel ready to continue, he will interview your family as a whole initially about your experiences for about 60-90 minutes. This interview will be recorded.

Andrew will then meet you and each of your family members separately for one further interview along the same format as the family interview.

### **What kind of questions will he ask?**

This research is interested in understanding what your family's experiences are of adjusting to life after the brain injury.

Andrew will ask you to talk about your experiences of life since the brain injury, including your thoughts and feelings about it. He will not have a detailed, structured interview schedule, meaning that he will respond primarily to help to elicit your family story regarding the brain injury.

### **What will happen to this information?**

The recording of the interviews will be typed out so that the information can be looked at in detail. The aim of this is to uncover common themes that are important in understanding the process of family adjustment to a brain injury. A professional transcription service may be used; in this case, confidentiality agreements will have been signed. Both the recordings and the typed out transcripts will be made anonymous.

Andrew will be supervised throughout this research by two supervisors (Dr Nick Wood, Clinical Psychologist, University of Hertfordshire and Dr Siobhan Palmer Clinical Psychologist, Brain Injury Rehabilitation Trust), this means that they will have access to all the information he has collected and will oversee the research. The only access that these supervisors will have is via anonymised versions of the original tapes and transcripts. This information will remain in a locked and secured place until it is destroyed.

Anonymised sections of the information collected from the interview may also be looked at by representatives from academic and professional assessment bodies in order to assess the quality of this doctoral research project. The audio tapes from the interview will be confidentially destroyed on conferment of degree.

As part of the doctoral programme, Andrew will write up a report of his research. Within this report he may include anonymous extracts of the interview to illustrate themes that have been discussed. These extracts will not include any information that could identify participants. The researcher, Andrew, will also write a shorter article for publication in an academic journal, this may also include brief anonymous extracts of the interview. Again, these extracts will not

include any information that could identify participants. Andrew will ask you if you would like to hear what he finds from his research, if you do he will arrange to meet with you to share this.

### **Confidentiality**

This proposed project will interview members from a single family, in a 'case study'. I will anonymise the family details for the purposes of my thesis; however, the family members will likely be able to identify each other in the final report. The researcher Andrew Bamber will fully explain the implications of this during the initial meeting regarding full and informed consent.

The family will also be given the opportunity to co-author the journal ready paper if they choose to do so.

As a minimum, the family can check the transcripts and they will be invited to help with drafting a journal ready paper if they desire and it is feasible. However, it is also important to explain to the family that we will be co-constructing a narrative and therefore, my interpretations of their family story may be different to their own.

#### **What are the possible disadvantages and risks of taking part?**

You will be asked to discuss your views about life after the injury, and to think about the changes that the injury has brought. This could be potentially distressing for you and your family and every measure will be taken to minimise the risk of distress. If during the interview you feel distressed, you will be given the choice of not answering a particular question, taking a break or stopping the interview altogether.

Following the interviews, Andrew will be available if you feel you need some time to talk about any issues raised. Andrew will be able to advise you of who you can talk to if you need further support.

#### **What are the potential benefits of taking part?**

We cannot promise the study will help you, but the information we get from this study will help improve the experiences of families who have suffered a brain injury.

#### **What if there is a problem?**

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on this is given in Part Two.

### **Part Two:**

#### **What will happen if I don't want to carry on with the study?**

If you decide you want to withdraw from the study you should let the researcher (Andrew Bamber) know. He can be contacted on the phone number given at the end of this information sheet. If you have completed the interview you will be asked what you would like to happen to the data. It can either be included in the data, or destroyed. Either option is perfectly acceptable. Your decision of whether to take part or withdraw from the study will not affect the care you receive.

### **What if there is a problem?**

If you have a concern about any aspect of this study, you should ask to speak to the researcher (Andrew Bamber) who will do his best to answer your questions, alternatively you could contact Andrew's research supervisor, Dr Nick Wood through the University of Hertfordshire (see contact details below). If you remain unhappy and wish to complain formally, you can do this through the university.

### **Will my taking part in this study be kept confidential?**

All information which is collected about you during the course of the research will be kept strictly confidential.

As with any health professional, there are limits to confidentiality. If during your meetings with the researcher (Andrew Bamber, Trainee Clinical Psychologist) you disclose any information which suggests that either you, or someone else, is at risk of harm then he is obliged to breach confidentiality and inform someone, possibly your GP. Andrew will do his best to discuss this with you before following such a course of action.

### **Contact Details:**

#### **Andrew Bamber**

Trainee Clinical Psychologist

Messages can be left for him through Cathy Lambert or Wendy Figg, team administrators on the DCLinPsy course at the University of Hertfordshire (01707 285282)

#### **Dr Nick Wood**

Consultant Clinical Psychologist

Academic Supervisor, University of Hertfordshire, (01707 284767)

#### **Dr Siobhan Palmer**

Clinical Psychologist - Field Supervisor; Brain Injury Rehabilitation Trust;

Kerwin Court

Five Oaks Road; Slinfold

Near Horsham

West Sussex; RH13 0TP; Tel: 01403 799160;

## Appendix F: Debrief sheet

**PROJECT TITLE:** Narrative analysis of the family experience of life after a brain injury

### **Debriefing information**

Thank you very much for making this study possible. By sharing your own and your family experiences, it is hoped that your story will help our understanding of how families react and learn to cope with life after a brain injury.

Research findings suggest that families who have sustained a brain injury often experience changed lives and disrupted personal and family stories, which take many years to regain order. We are still not able to fully account for the nature of these changed narratives, and this is what is being investigated.

The aim of this research is to gain a better understanding of any distress that families experience. The information you provided may also help other families who have a similar experience

The information you provided will be confidential, and after analysis the tapes will be destroyed. As a participant, you have the right to withdraw the information you have provided at any time.

Below is listed some resources that you may find useful:

#### **The Samaritans**

Website: [www.samaritans.org/](http://www.samaritans.org/)

Tel: 08457 909090

#### **Headway**

4 King Edward Court

King Edward Street

Nottingham NG1 1EW

Tel: 0115 924 0800

Helpline: 0808 800 2244

<http://www.headway.org.uk/>

#### **Local counselling services (GP surgery).**

If you have any further questions or would like to be informed as to the outcome of this study, then please contact me at the email address below.

If you have a complaint to make about your involvement in this research, please contact Dr. Nick Wood whose details are below.

Name of researcher: **Andrew Bamber**; Email: [ab09act@herts.ac.uk](mailto:ab09act@herts.ac.uk)

Name of supervisor: **Dr Nick Wood**; Email: [n.1.wood@herts.ac.uk](mailto:n.1.wood@herts.ac.uk)

Department of Clinical Psychology

University of Hertfordshire  
College Lane Campus  
Hatfield  
AL10 9AB, Tel: 07738 169 705 Tel:

**Thank you for participating in this study.**

Appendix G: Transcription service agreement

**Doctorate in Clinical Psychology  
University of Hertfordshire**

**Transcription confidentiality/ non-disclosure agreement**

**This non-disclosure agreement is in reference to the following parties:**

**Andrew Bamber**

**And**

**Executive Typing**

**The recipient agrees to not divulge any information to a third party with regards to the transcription of audio recordings, as recorded by the discloser. The information shared will therefore remain confidential.**

**The recipient also agrees to destroy the transcripts as soon as they have been provided to the discloser.**

**The recipient agrees to return and or destroy any copies of the recordings they were able to access provided by the discloser.**



**Signed:**

**Name: Margaret Clow - Executive Typing**

**Date: 13<sup>th</sup> February 2012**

Appendix H: Transcription of the family interview

| <b>First Family Interview, 9<sup>th</sup> September 2011, 3pm</b> |   |
|---|---|
| Int   | So I wonder could we, could we start, whoever would like to start, just with um, introductions. So if I just very briefly start with myself. So, I'm Andrew or Andy um, I'm, yeah, a trainee clinical psychologist and my role here is as a researcher, researching err family reactions to brain injuries. So would anyone else like to  |
| G   | To start, I'm um as you know I'm Leonard's father, Leonard's act, Leonard's accident was in 1998 (short pause) until the last two – the last two or three years it's been a, it has been a struggle to get a quality of life for our son and care and what – isn't it and, we've both had a ten year fight, [mmm] battle, well not fight, a battle with the authorities to get him erm a quality of life which is, I think the best that he he's enjoying now, which we didn't think we could do anymore than what we've done for him. So em, Is the camera on at all, is the camera on? Sorry. [pause] Who was that? Someone upstairs? |
| K   | Hello?  |
| T   | Hi it's me mum  |
| G   | Oh he sneaked in, do you want to wait a minute now he's just arrived?   |
| K   | It's warm. We can't open the door because the dog'll come in. You signed yours Barry,   |
| B   | Yes I have  |
| K   | I'll collect them, get them in. That's that, That's that.   |
| Int   | Now that battery said that it had 200 minutes on it ??? completely to me.   |
|   | [some discussion going on but unclear and presumably not about interview]   |
| K   | Well I put a jumper on because you know, in the evenings I can put the fire on if I'm so cold, sitting around as you do. Well I came home this afternoon, I was dripping you know so I put a thin blouse on. Oh dear. I told you I'd do it for you  |
| G   | What?   |
| K   | Fix that  |
| G   | Yeah, you haven't been near it and it's not working. (laughs)   |
| K   | Well you can't blame me then can you?   |
| All   | Hi  |
| T   | Hello (over speak)  |
| K   | Sit down Terrence.  |
| Terrence  | I'll just get a drink of water  |
| K   | Yeah, do you want a cup of tea?   |
| Terrence  | Er, no, no thanks.  |
| K   | Talk among yourselves [laugh]   |
| G   | Haha yeah, I lost my train of thought now   |
| K   | Oh, well start again then   |
| B   | The News of the World always discuss the fee first, so I wonder if we could talk about the fee (laughter)   |



|          |   |
|----------|---|
| Int      | We can do   |
| Me       | We'll just wait for Mr Murdoch to come in... have you been introduced yet to Terrence   |
| K        | Terrence, this is Andrew [over speak]   |
| Terrence | Hello Andrew  |
| Int      | Hi, nice to meet you. Erm Terrence, can I fill you in, just about where we are. Erm, we just, we're just kind of starting with introductions. So, I'm Andy, I'm a researcher looking at the family reactions to brain injuries within the family. Erm, and what, what's going to happen today is we're gonna have a, just a kind of a very broad interview about how things have been since, er, since Leonard's accident.                          |
| T        | Yeah  |
| Int      | Erm, and I've got an information sheet and a consent form, if I could get you to sign that  |
| T        | Sure  |
| Ibt      | Afterwards, and that'll be great, thank you. Now Gareth was - we were just kind of doing an introductions and guess it started by talking about erm, you think the words you used were a ten year struggle, it had been a ten year struggle, do you want to kind of..   |
| G        | Yeah, i-i-it has been a ten year struggle, erm, because, I think the main reason is nobody will ever tell you anything. You know, perhaps we come, perhaps we come from a different environment. We came from a military environment [mmm] into the NHS, if we had been in the NHS from the beginning, perhaps we might have known more than we did when we first started.  |
| Int      | Yeah  |
| G        | I don't know. But that's something that's happened and you know, I think erm, I've got because of this, what's happened to Leonard, I've got very intolerant. [next sentence said slowly with some pauses] I think the character's changed coz I, if I found that if you were complacent with what was going on, you didn't get anything.   |
| Int      | Right   |
| G        | You had to be aggressive. Aggressive or rude to get anything done.  |
| Int      | Wow   |
| G        | Because they were very reluctant to do anything, because it, it costs money [yeah] to do things.  |
| Int      | So the words aggressive and rude, the way that you're having to describe yourself, in order to get what it is that you want for   |
| G        | For Leonard, I got aggressive and I got rude because of all the difficulties that come our way. Because we, we, we, we felt that you are, you, are on your own against a, against everybody because you could see the injustices of Leonard's care in the homes that he has been in and how he has been looked after, and it was appalling. And that, as you know, luckily that ended up with us, through Channel 4 Television closing a home down. |
| Int      | I remember you saying when we..   |
| G        | We closed it, we managed to get the home closed down. But, before the home closed down, the same thing is happening today, people   |

|     |   |
|-----|---|
|     | report these homes as being bad and report it to the powers that be but nobody does anything about it. Like the BBC have been in, for example, haven't they, to that home in Bristol [that's right] and the place is shut down. But people were complaining before then but no one was listening to them.   |
| Int | That home in Bristol, is that the sort of experience that you -   |
| G   | Yeah  |
| Int | It sort of resonates with   |
| K   | Yes   |
| G   | Yeah, oh Yeah   |
| Int | So, I wonder Gareth that's your, it's kind of a similar story but we've talked about when, we talked about together when we met at 'the brain injury association', erm, it's a few weeks ago now isn't it? I wonder if it's, is it a similar story for the rest of you, that feeling of, the words that kind of jumped out were injustice, that it felt very unjust?  |
| T   | [pause something going on in background] Yeah, yeah. It felt, it felt that um, the er, the services, the services weren't there for Leonard and that there, you know, they were trying to, you know, slot him into what was, what was available rather than, than, than what he needed and er,[short pause] yeah, there was layers and layers of bureaucracy that Mum and Dad had to negotiate. (Coughing) Excuse me. And er, you know, had to understand, understand that adult social care and adult health are different, different entities and er you know operate different funding criteria and an awful, awful there's a massive learning curve |
| Int | Yeah, yeah, Just as you were speaking that's the word that kind of jumped into my head about having to learn about new systems, learn about things that you didn't know about before. Is that...  |
| G   | What was worse, the PCT were paying £3000 a week for Leonard to be in this care, a week! That was what they were paying. And when we told them what was going on in the care home, they didn't want to know. They didn't, they were not interested in doing anything about it. We got blamed for being troublemakers.   |
| Int | Right, so in this, this was your experience then of the, so the PCT were paying £3000 a week for this, for this home that you as a group felt was inadequate and was  |
| G   | I must say that Barry wasn't involved in Leonard's care, Leonard had just come, Barry thank god has come on the scene since Leonard has been at home.   |
| Int | Right   |
| G   | So he wasn't, he didn't know anything about what the immediate family knew what was er but that's what I thought. But no one worried. It's just that they couldn't be bothered and even the Hertfordshire health authority who the jurisdiction of the home came under, they were not interested. Oh yes, OK, you know, they weren't, they didn't want to rock the boat. Like they didn't want to rock the boat in Bristol, that is, and all these people knew this was going on at   |

|     |   |
|-----|---|
|     | this home and they didn't want to rock the boat.  |
| Int | That's really the sense that I'm getting as you're talking that it feels that you're butting heads against a bureaucracy that is quite big and faceless and doesn't want to know. Sort of in for an easy life. Terrence, earlier you said that it felt as if Leonard was being slotted in, rather than, so slotted into existing cases rather than sort of being given the care that he needed. Is that right? So does that sort of fit in with that idea about the bureaucratic system unable to   |
| T   | Yeah, yeah and there, there's a lack of provision for, you know, young, young people, young adults with er, recovering from traumatic brain injury. [15 second pause]   |
| Int | I think, often, often when I talk to people about, about brain injuries erm, what I hear is that similar sorts of things have kind of come up. Erm, often I find that the people that I'm talking to are very knowledgeable now, years down the line about a system, about quite a complicated system. Erm, is that, so have you felt that you've had to do that kind of fighting and do that kind of work that should have been done for you? Is that the kind of experience that you've had?  |
| K   | Well when he was first diagnosed at Headley Court in Leatherhead, at the military establishment, we saw the consultant neurologist, er, who had read the brain scans and interpreted them for us and erm, his diagnosis was very very disheartening in that there was not much hope for any improvement.  |
| Int | OK  |
| K   | And erm, he showed us the brain scans erm and the dark patches on the brain scan, scans indicated that the brain was dead [ok] and you know, as non-medical people erm, that was all we understood, that a large part of the brain was damaged. [yeah, yeah] And he didn't give us much hope, he was being honest but being fighters, we were prepared to keep on looking into the area [yeah] and seeking what [mmm] could be done and we found out that the brain can repair itself in parts, albeit to a lesser degree. But um I likened it to a spider's web, the brain, [yeah] with broken transmission lines [mmm] but then the brain can find other channels [yeah] to reach the goal, to reach the target. Albeit would take a long time and erm, I've always clung to that hope and erm, yes, we've seen very slow but positive improvements and another thing that I learned from reading 'the brain injury association' and other resources continuous input, repetition, repetition, repetition, that in my understanding can help to create a new pathway in the brain and I've always clung to that. [right] And we do see [mmm] small signs of improvement, albeit he can't do, well he can't do anything for himself. But with encouragement, [mmm] 'Do this, Leonard', 'Point to this', 'Blink', 'Shake hands, Leonard', little commands like that and he will follow them. It takes him a little longer [yeah] but he will do it. |
| Int | It's really interesting that you used the word hope there, that when you were telling me that story there, just in that sort of couple of minutes, it felt like a positive thing, but sort of little things were  |

|     |  |
|-----|--|
|     | happening. At the time you used the word disheartening and the word dead as well, so you said sort of large areas of his brain were dead and this was really disheartening. What kind of things, I know that talking about that time now might be quite distressing but if it's OK, what kind of things were happening within you? What kind of things were you experiencing at that time and as a family?   |
| K   | [over speak] Devastation really, you know, we'd lost our son, as far as we were told. [yeah] He was, parts of his brain were dead or damaged to the point of not functioning. [mmm] We were devastated but there's a lot of fight in us [yeah] and we weren't prepared to give in and you know, on the news every day you hear or read of progress made in, in, in developments in brain neurology and so on, and we've never stopped looking for those little signs and still to this very day are looking [still going] for any erm, offers of, not offers, [mmm yeah] new developments in brain damage. |
| G   | Yeah, we are, but they're not.   |
| K   | But nobody else, absolutely, thank you, [right] we're the only ones we've had to be the protagonists the whole way through.  |
| Int | So not only are you fighting all the time, every day, but you're spearheading as well.   |
| G   | Yeah, The spearhead should come from the neurologists [yeah] or the people who used to look after him.   |
| K   | There's nobody   |
| G   | There's nobody   |
| B   | Nobody puts it to you?   |
|     | (Overspeak)  |
| K   | No not at all, never ever, we've had to fight  |
| G   | We initiate everything, we initiate everything   |
| K   | Even the GP has never come to us, Mr and Mrs C., there's a new development we'd like you to try. Nothing, nothing. We've always been the ones to write to the GP, 'Please could you refer us to a neurologist?' please could, AnGareth has been very forthright in that, a new wheelchair, 'Could we see a new physiotherapist?' through our complaining we went to a meeting at the National Hospital and we had sixteen people, didn't we? [yes] Sitting at a meeting at the National Hospital, through our own initiation.  |
| G   | They told us that his wheelchair positioning was all wrong, which was an NHS chair and he was in the wrong sitting position. So, we went out privately and I bought him a wheelchair, they said they couldn't, the NHS said they couldn't do anything for him regarding the wheelchair   |
| K   | For funding purposes   |
| G   | So we went out and we took him somewhere to buy him a new wheelchair and he's er, he's er his department has improved 100% since hasn't it, in this wheel chair,   |
| K   | Posture  |
| G   | his posture. Because he's sitting in the right way in a wheelchair. A simple thing like that they can't get right,   |

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| K   | Which he's sitting in for 12 hours a day, you've got to have comfortable posture.  |
| Int | Yes, So it feels like that's so incredibly important   |
| K   | To have 16 people at a meeting on one occasion and that's not exaggeration. [yeah no] We had physio, psychologist, nursing team, social workers, nurses, there was a lot of input, occupational therapists, erm, wheelchair people, specialists, what do they call them, people who checking your posture?   |
| Int | I couldn't say   |
| K   | Bio-Chemical Physics, something like that.   |
| Int | They're the experts in   |
| K   | They're the experts in seating posture. Splinting people to do splints   |
| G   | That's, you see, it's like selling Leonard, when you go there you've got five minutes or seven minutes with a neurosurgeon or a neurologist and you've got to sell your son within that seven minutes, otherwise you've lost.  |
| K   | And if you're not (overspeak) you can't do it.   |
| G   | If Leonard just has a bad day and we take him and he's asleep, you've lost it.   |
| Int | Wow  |
| G   | You know,  |
| Int | And that idea of selling and that if you can't get it in within that time that you've lost it, that feels like it's almost like a Dragon's Den type pitch.   |
| G   | Waste of time, Yeah, it's a waste of time  |
| K   | When you've waiting months for the appointment (overspeak) to get one  |
| G   | They've already pre-judged the situation before you get there, I think, really. But erm, nobody knows Leonard better than us two. And we might be over, you know about his abilities, and he's god, but they don't really wanna, they don't listen. They do not listen. You can see it in their faces.   |
| Int | They're just close down  |
| G   | So, we just erm  |
| Int | What, what, what I'm hearing, I think, is sort of that idea about fighting, constantly, constantly having to fight and I'm kind of wondering that when it gets to the point where you get to meet people when you actually see them how then does it feel when you're there that you've fought for months to get to that point to see the neurologist? |
| G   | It just wastes your time.  |
| Int | It feels like you just wasting your time   |
| K   | Try these pills, try those pills.  |
| Int | In that sort of a dismissive sort of a way   |
| K   | Well, we've found so, we've been through all that over the years, we've been through these pills those pills, something else, alter the times, and now we've, we've, we've, we're alright now, we've found a perfect balance of medication for him that works but I'm still always   |

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|     | on the lookout for improvements because we've tried to take him off medication because he was overloaded. [ok]  |
| G   | Three or four times   |
| K   | And erm, then we found that he'd built up a dependency on some of the drugs [right] and he went into a depression   |
| Int | Because of the, sort of withdrawal problems?  |
| K   | Yeah, yeah erm, so we've been through a lot of erm, traumas like that.  |
| T   | Trial and error   |
| Int | Trial and error. But we are the ones who have had to initiate everything, we've had to, we've had to obtain physiotherapy for him because the NHS   |
| G   | Won't pay for it  |
| K   | Wrote him off. That was really a heartbreaking experience.  |
| Int | What, what happened there?  |
| K   | Well, he was referred for physiotherapy, which, which we asked for, and on the very first interview, down at our local physiotherapists at the local hospital where they do the physio, that's St Michael's. Erm, she said, 'oh well we can't offer him regular physiotherapy, oh no no no, there isn't funding for that, we can give him six treatments and that's it'. But Leonard needs physio on a regular basis, preferably everyday. So, he can become [all tensed up] all tensed up. (Overspeak) |
| G   | He speaks afterwards, he speaks during and after the physio, [ok] the rare times that he does speak, he speaks after physio.  |
| K   | He's stretched and, you know, the muscle are relaxed and oxygenated his lungs and [overspeak]   |
| G   | No one's ever looked at, he speaks when he's on his back doesn't he, he speaks a lot and he speaks, and when he does speak there's non of it is rubbish, 'mumbo jumbo' it's what's going on around him. So we are aware that whatever Barry or whatever any of us say to him, he knows what we talk about. [overspeak]  |
| B   | He'll answer you yes or no by blinking or a 'yes no' card he'll point to, [ok] very slowly he'll point to yes or no   |
| G   | Or wind you up  |
| K   | Oh, he can wind you up as well.   |
| B   | He wound me up about a week ago, I asked him is he looking forward to his holiday, because he's going to America, he's flying for the first time since his accident.  |
| Int | Wow   |
| B   | And I asked him is he looking forward to going to America and he slowly pointed to 'no' and I said you're joking, and a big smile came on his face, I called his mother and told him what he'd said and the carer Agatha and there was, wasn't there, a big grin on his face.   |
| K   | Oh yeah, (overspeak)  |
| B   | Obviously winding me up, you know, which it shows he is   |
| K   | And another thing he does is he winds the carers up when he's having his physiotherapy, that being the time when he speaks more easily than at any other time. It's a standing joke now, they ask him how old   |

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|     | he is and he will insist that he's thirty eight. They ask him his date of birth and then he tries to calculate   |
| B   | He tries to work it out  |
| K   | A big grin from there to there. He just, he likes to have a laugh, [yeah it sounds] he's got a sense of humour [yeah] as well. And I speak to him in Italian sometimes, ahh, grin from there to there, big smile. So, little things like that, you know, which we know he can understand. The brain isn't completely written off, [mmm] you see, as we were told once upon a time.   |
| Int | That was the message you got   |
| K   | Yeah, definitely, yeah. That was Dr. Evans, I'll never forget that.  |
| G   | Well, if you wanted a copy of that letter we've got it   |
| Int | That might be really useful, yeah, thank you.  |
| G   | Well, his diagnosis was  |
| K   | Prognosis  |
| G   | Prognosis, yeah.   |
| K   | Diagnosis, yeah.   |
| Int | Can I just sort of comment on what happened, or what I saw happening. I think, erm, Barry, I think you said when he's having his physio he can speak more and then the whole room sort of livened and there were lots of smiles on faces, [yeah, yeah] talking about the things that Leonard is able to do when he's having physio.  |
| K   | We've got hope, [yeah] it gives us hope and we cling to that hope, because there's a lot of untapped energy out there and resources that we are always on the lookout for.   |
| Int | Out there in the world? Yeah   |
| K   | Erm, a recent erm, example was Eddie Kidd, do you, Eddie Kid?  |
| B   | Oh that's right, yeah I know   |
| K   | The, erm, stunt, stunt artist, motorcyclist. And, by coincidence, he happened to have been in the first home with Leonard because he was (overspeak)   |
| B   | Oh was he?   |
| K   | Yeah, in the Feldon Croft, and erm, he was fortunately dismissed from the home, don't record this, he was dismissed from the home because he was fraternising with the staff, OK. So we knew of him then, [laughter] as disabled as he was, because he'd had an accident. Many, many years later, some, what, 13 years later, we see in the press, in the national press, Eddie fit, taking part in the London Marathon. You must have read about it yourself just recently. [oh yeah] It took him about three weeks to complete the course but he had a walking frame [mmm] a walking frame so that if he fell he could, no not just something that he was incarcerated in [over speak] so that if he fell he could just lean on it. [mmm] He had a splint on his leg and a microchip inserted to stimulate the leg that was [oh ok] lame, if you like, paralysed. To stimulate it to go forward [yeah] and then the other foot could go forward. |
| Int | It sounds like it would sort of mimic an electrical impulse from that the brain would have   |

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| K   | And that is what my next goal is, to find somebody that can do that, so if you find anybody that can do that kind of thing. I've not been able to -  |
| B   | Leonard has already done the marathons a few times hasn't he   |
| K   | When he was fit, yeah. And if any  |
| B   | That's how fit he was, you know.   |
| Int | Ahh, yeah, Leonard was in the Parachute Regiment   |
| B   | Parachute Regiment, yeah.  |
| Int | Erm, so goals, goals are important   |
| K   | Oh yes, we never give up do we? You're always on the look out. I mean if it, I couldn't have coped with the strain of going to 'the brain injury association' meetings, because I've just had enough. I'd prefer to do my own things, research.  |
| G   | We work together in different ways   |
|     | (overspeak)  |
| K   | So, he got involved with 'the brain injury association', you see, and er, I've forgotten what I was going to say about it now. So you do your research in your way and I do my research in my way, [mmm] and we meet in the middle hopefully.  |
| Int | Yeah, yeah, so so, 'the brain injury association' perhaps might be, I think you used the word a strain?  |
| K   | Errr, I haven't got the time to go to meetings [right] and things like that, I've got other things that take up my time, from now in we're visiting Leonard, you know. That's important, go in everyday and stimulating him  |
| G   | One of us goes, tries to go in everyday  |
| Int | Yeah   |
| K   | That's very, very important, stimulation, stimulation, stimulation   |
| G   | And as we likes sport and if there's any football [mmm] on an evening I'll go along and watch, [go and watch it with him] sit down and watch it with him, enjoy, banter a little, you know and the staff do as well. The staff, they're very good like that, they...   |
| K   | And Barry goes along and stimulates him from another angle, you see. He's a friend, a military friend and he, [yeah] that's another source of input, isn't it? I go as a mother and I sing and he likes all sorts of songs, you know, Frank Sinatra, and Irish diddly-dee music and so on, and Italian music, so I do that side of it. [mmm] Do him nice little things to eat, you know, tasty food [yeah] and so between us we, |
| G   | He responds to pop, doesn't he, music, which he, before his accident in 1998 [yeah, yeah] he would sing The Who and all those groups of that age group [mmm] but he knows them, all the words, and he'll sing the words, [mmm] too them.   |
| B   | he'll mimic don't he.  |
| G   | Sing the words along, to all the old stuff.  |
| K   | Frank Sinatra  |
| B   | Frank Sinatra on Sunday, he was mimicking wasn't he?   |
| K   | Yes!   |
| K   | Yeah   |



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| K   | I did it my way (overspeak)  |
| G   | We concentrate things, music wise and also another thing we do, we go, if he goes on holiday or we go out for a day, I always take photographs of where we're going [ok] and when we come back I download them onto his PC so he can see   |
| Int | So he can see what's happening   |
| G   | Where he's been and what he's done   |
| Int | Could you just tell me a bit more, I've got a sense of why that happened but could you sort of explain why you do that?  |
| G   | Well, I mean, you know, why do I do it?  |
| Int | Yeah   |
| G   | Well, I'm interested in photography to start off with, and I think the stimulation I see in Leonard after he's been out and looking at himself and looking at where he's been and the people he's been with, erm, you know he seems to be interested. Especially his holiday he had erm the P&O cruise he went to. [oh yeah] I've got the pictures of that and put them on for him. And also another thing we do sometimes is we put videos of him skydiving [ok yeah] and we say 'would you like to watch yourself sky diving, Leonard?' He says 'Yes' and when he watches himself, 'would you do that again if you got the chance, Leonard?' 'yes yes yes yes'. [laughs] |
| T   | It's also because it's his short-term memory that's very poor, so that's why, that's why he needs the visual reinforcement of the memory.  |
| Int | Yeah, and I guess in a way we all do it, don't we? Just looking around the house here there's photos of things, so we like to remind ourselves, and there's cards on the fridge. But I guess with Leonard does it um   |
| G   | Well we've got all of, we've got a history, well a history of his life that I've tried to create haven't I, Barry?   |
| Int | Oh yeah  |
| G   | He was a policeman, a para, various things through his life, we've put pictures up for him so he can see his life. Well perhaps, he does remember that he was a para, he does remember that he was a policeman doesn't he? He does.  |
| T   | He remembers, well we know that he remembers everything pre-accident don't we? It's not clear what he  |
| G   | Yeah but then now and again, now and again he will remember what we've said to him, won't he?  |
| K   | Oh yes   |
| G   | He will remember   |
| K   | He remembers, he knows your name, you first name and your second name, so 'what's your brothers full name?' He knows that. [over speak]  |
| G   | There's things we've talked about as well, he sometimes picks up on and tells us later again, doesn't he? So you see now and again   |
| K   | If you prepare him for an event, like Terrence went and saw him in the week, [mmm] prior to our Golden Wedding [mmm yeah] celebrations and you primed him that you were going to both give a   |

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|     | little talk.  |
| Int | Yes   |
| K   | And Leonard was wheeled next to Terrence and Terrence had his arm on his brother's shoulder and you were talking and Leonard was alert. Normally at that time he'd be nodding off   |
| G   | Yeah, he'd be asleep [over speak]   |
| K   | And he was looking around at everybody in the room and smiling and that's it. Erm, priming, [yeah] you know, preparing, and it registered.  |
| Int | What was that, what was that like for you two, seeing   |
| K   | Wonderful, that was great   |
| G   | And em, I think, I think people are scared of brain damage [yeah]   |
| K   | Or anybody in a wheelchair  |
| G   | Or anybody in a wheelchair, aren't they, do you think that, Terrence?   |
| K   | Yeah, they're afraid of going up  |
| G   | You know, for example, I know a lot of people went and saw Leonard, there was about 120 people there. What and about 10 went and saw Leonard?   |
| B   | Must have been, yeah  |
| G   | At least, wouldn't be more than 10 would they? Wouldn't have been more than 10.   |
| B   | I went up several times [inaudible background noise]  |
| G   | The percentage of the people who were in the room   |
| B   | Probably wouldn't be more than 10, no.  |
| K   | And we got him dancing, in the wheelchair, pushing the wheelchair in and out up and down. And then they played quite coincidentally, they played a couple of Frank Sinatra pieces. One of them was 'I did it my Way'  |
| Int | And that went down well?  |
| K   | He enjoyed it, you know.  |
| G   | It was wonderful that it was our wedding anniversary, [short pause] some of my family have not been near Leonard since his accident, and they were there at   |
| K   | The party   |
| G   | At the party. [mmm] Now I think they were surprised at Leonard's abilities.   |
| Int | OK, yeah  |
| G   | You know what I mean? You know, a lot of the family are just 'well he's had his accident, best way of us coping with it is to stay away' and they do. Well that happens to a lot of people that Leonard knew, they stay away.   |
| Int | So sort of Leonard's social circle has  |
| G   | Diminished [diminished yeah]  |
| K   | And yet, well we say from the family, he's got an excellent friend and loyal friend in Barry and when we take him to Mass, he goes to Mass every Sunday, that's stimulation. I'm all for stimulation, I believe very firmly that the more you do, stimulates the brain, helping it to find new pathways. I'm not a neurologist, but that's the way I understand it. |

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| G   | But how, how many paras did Leonard know?  |
| K   | I know, I know   |
| G   | How many policemen did Leonard know?   |
| K   | But if they haven't got to go, they can't face it can they?  |
| Int | But what does that mean, what does that mean for you? Barry, what does that mean for you?  |
| B   | I've had experience anyway, I think this is what has made me able to cope with Leonard and I must say I'm glad because I had two cousins that, one side of the family was Irish and one side English and we had er, what we used to class as an invalid on both sides.   |
| Int | OK   |
| B   | So my, sadly, the Irish cousin, she died in her early 30s but my cousin Michael who's only just down the road here in a home has never ever said my name, never been able to say my name, he'll say, 'I want a biscuit' or 'I want a cake, I want a sweet' it's all food related. [yeah] But if I say to him, 'Say hello Michael' you know, 'Say hello, say hello Barry' he'll say 'Hello Michael' but even his mother, God rest her soul, she was a lovely lady, she used to say 'Come on, say hello to cousin Barry' and we often visited for as long as I can remember and he's also in his 60s now and he's never ever said my name, but. And I can talk to him and I know that I'm not going to get a response, so I think this is the big difficulty for other people that come along and for them it's like standing and talking to the wall, because someone doesn't speak back to you. [mmm] They probably feel |
| K   | They feel embarrassed, they feel embarrassed.  |
| B   | Embarrassed and uncomfortable, they don't know what to say next and I think that's why they drop off, because I know just the character Leonard was, you know, people loved being his friend, [yeah, yeah] absolutely. But mind you, there was a group of girls that he went to school with and ex-girlfriends that all got together recently, I'd would have loved to have gone along and been a fly on the wall. And they had a ball with him, they went to the Curry House here in [South East England] and I think it was about 7 (overspeak)  |
| K   | And the one above was when he was forty  |
| B   | I think, of course, it's, I think it's much easier for a group because they can  |
| Int | Feed off each other  |
| K   | He loves the girls   |
| B   | They can talk to each other  |
| K   | He loves the girls, though doesn't he, Barry? He's a-a ladies man and he's a handsome man.   |
| B   | It wasn't him that got thrown out with er, was it Eddie Kidd you said?   |
| K   | No, no, it's definitely Eddie Kidd, no unfortunately Leonard wasn't able to do that much, he was a prisoner in his little room there wasn't he.  |
| B   | Well you can see by the ladies there, you know, he had an eye for the ladies. All of those were ex-girlfriends, weren't they?  |
| Int | It makes me wonder, as we're talking about relationships. Something  |

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|     | that often happens, or that inevitably happens is that relationships change and often the roles people take change. Have you, how has that kind of effected you, I'm in fact, I'm making a massive assumption by saying that it has affected you, but is that something you've noticed or something that's affected you?  |
| G   | Well,   |
| K   | Do you mean with each other or with him?  |
| Int | With, with him and with each other, primarily with him  |
| K   | [short pause] Well he's become our baby hasn't he?  |
| G   | I probably have made his personality bigger than what it really was, I've given him more ego than he would, than he would have had, I think. When I start talking about it, I might say, you know, well not invent things, but we try to  |
| Int | Sort of a pre-injury personality or personality now?  |
| G   | Now, you know, like erm, all fathers when your sons get to eighteen or whatever age they go and do their own thing, so you don't really, after eighteen you've lost them in a way, they're in the big world. [yeah, yeah] You only find out from other people what they've been up to afterwards, you know what I mean? Perhaps I think I enlarged his ego more than it should be, you know (laughing)  |
| K   | But then we do that AnGareth because we try to encourage him all the time, [mmm] build up confidence again, repetition, repetition, boosting his confidence, 'Well done, Leonard'. I mean the odd occasion when he speaks to us, or says something that makes us laugh we applaud him, don't we? Well done Leonard or, and everything he does at home, erm, is repetition with the carers. Erm, they insist that he helps to prepare his tea. |
| Int | Ok, yeah  |
| K   | So they wheel him to the, to the, refrigerator and make him open the door, make him close the door, sometimes take a bottle of milk out, or whatever. If it's a bit awkward because he can't really reach it, he's sideways on [sure] , but, oh and another thing, they make him press his blender.   |
| G   | The food blender  |
| K   | Presses the blender to soften his food  |
| G   | And he helps with the shopping, he gets the things, they go to Tesco and he'll pick things up and tell him to pick things out.  |
| K   | And he'll put them in the big basket, the big trolley.  |
| G   | He'll put them in slowly, he'll put them in himself.  |
| Int | So it sounds like on one hand it's sort of trying to keep skills and develop new skills as much as possible, but on the other hand he's become your baby again.   |
| K   | Well in as far as, no perhaps that was a misinterpretation. In as far as we boost him for everything, we applaud him for everything he does, 'Well done, Leonard' for the slightest thing. We do building bricks and I say come on, put these bricks, put the red ones along that side, the blue ones along there. He's very slow to do it, but I make him stretch to go into the furthest point so that he can build them up.                |

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|     | 'Well done!' and then we alternate the colours perhaps of the bricks. 'Well done, Leonard!' You know, that's when I say he's like a baby   |
| Int | So it's only like kind of the way that you would with a baby, the way that you   |
| G   | He is vulnerable isn't he, he's vulnerable   |
| K   | But he needs all that encouragement, I do, right from day one when he was in the home, we used to take him out every day for stimulation. Limited in what we could stimulate him with, but 'What make of car is that, Leonard?' and we'd wheel him up so he could read the make of the car. So we established that he could read, you see. [mmm] And got him mouthing the words.   |
| G   | This has come from us, it hasn't come from the professionals [yeah]  |
| K   | Non of it has come from the professionals  |
| G   | No, non of it has come from the professionals  |
| Int | That's sort of the picture I'm getting, it's almost like we've come back to where we were talking about at the beginning as well, the fact that this is all you, that this is all your spearheading and all your stimulation and all your work.  |
| K   | And we've shown the carers how to do it  |
| B   | Oh, I was just going to ask you that, did you teach the carers to do all this?   |
| K   | Yeah, yeah (overspeak)   |
| B   | And recently they've had a horizontal  |
| K   | Handrail   |
| B   | A handrail, like a banister rail so he can pull himself along in the wheelchair, you know when he comes home.  |
| G   | That instigated from 'the brain injury association' because they've got a long rail in 'the brain injury association' where he goes and he pulls himself along there and Elizabeth said, 'We should have a handrail here' I said I'll arrange for a handrail to be put up so he can pull himself along, he's doing something himself, pulling himself along in his wheelchair.   |
| B   | Is that Elizabeth from the, one of the carers?   |
| K   | Yeah   |
| G   | Yeah, oh yeah.   |
| Int | So what do you think that means for him, to be able to   |
| G   | Oh   |
| K   | Achievement, he's done something [mmm]   |
| B   | It's not easy either [overspeak] because the wheelchair, remember it has to be guided, [yeah of course yeah] you know so he's not in control of steering it, but he pulls him along and  |
| K   | That's because the wheels in the front osculate like a shopping trolley, so, [yes] and he can only use the one hand so he's got to and another thing we've done, thanks to Gareth, he's had one of those extra wheels that you can push on a wheelchair to push yourself [ok yeah] but with only one hand he's going to go round in circles, you see, so, we help him from the back but he doesn't realise it, just to keep the wheel going straight. But it's something he's doing, we make him go from |

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|     | one end of the room right through his lounge into the kitchen, [mmm] it's something he's done, 'Well done, Leonard' and we applaud him [slaps] , you know   |
| Int | And again that sort of, as you described it, I was thinking in my head, of you know, the picture of erm, the father holding the back of the bike when the child is cycling along erm, in that phase between stabilizers and, it sounds like a very similar kind of story, that kind of nudging and [yes]  |
| K   | And another thing you did was, he had his lounge carpet removed to facilitate the wheelchair [mmm] moving along more easily we had the floor laminated [mmm].   |
| G   | You know, you get this, you get these ideas and you wonder why you never thought of them before.  |
| K   | Well no one else is going to think of them, no one else   |
| G   | No they don't do they? You just think, you know. But we don't get, we don't get any visits from anybody to come and see him. The only time he ever gets a visit is if he's ill. But the GPs are very supportive of him, they are very ,very good and without our GP he wouldn't be at home, because he had to say he would take him on with the, you know, supporting needs, so we're lucky that the GP took him on. Other than the GP coming to see him now and again when he's not well, there's no support at all from anybody. You know, fortunately, fortunately because of his disability it's, he gets a reasonable military pension   |
| Int | Yeah, I'm just sort of thinking, as we were talking about, about, just kind of bringing the conversation back a bit, back in time, um, back to the accident. So, thinking about the time when the accident happened, would you, would someone just be able to describe what happened and what your sort of, how you heard and what was going on, again, sort of difficult questions.  |
| T   | Shall I do it? Erm, [short pause] Well the initial, because it happened in France, the initial information was vague, wasn't it? And it was Leonard had been involved in an accident and I think we got the news on a Thursday didn't we, [mmhh] I think it was a Thursday. And er, [short pause] I remember, I think [short pause], Sarah was round here or had been round here or, my ex-wife, and I got a message from her I think, initially, or it may have been mum, I'm not sure. That there'd been an accident and, you know, we were waiting on further information. And then I think by the end of the afternoon it was clear that it was serious and that you were going to be going, you were going to be going to Toulouse, but you didn't quite know how, how serious and er, that was the first, that was the first and then when, when, when I knew how serious it was I kind of left, left work and came here I think and you know, you were in the throws of getting ready to leave, you know, for the next morning get a flight. I think I can't remember whether I came then or I joined you. |
| K   | No, actually  |
| T   | I joined you didn't I? I came later   |

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| K   | Erm, there was some, some confusion, we were told that there was an aeroplane leaving from Gatwick at about 8 o'clock that evening.  |
| G   | The army booked us a flight on (overspeak)   |
| K   | For us you see, but they didn't tell us at that time that they were going to pick us up with an escorted car to take us to Gatwick, so it was 6 o'clock and we thought, we've got to get to Gatwick, you know, so we went to, by train, we knew there was a train going from [South East England] Town to wherever to pick up the Gatwick Express, so we went that night. Anyway, we got there and um, we only had just some hand luggage, you know, and we were looking and we were told we picked the tickets up, well we asked for the tickets didn't we and they said, 'Oh, no no no, we don't know where'. Anyway, turns out we were back to back with the team from the army who were looking for us and we were looking for them. Anyway, there were minutes, literally minutes for us to get on the aeroplane and it was like something out of a James Bond film, we were running down this very, very long corridor [yeah] and there they were with their caps, the whoever they were, the crew, with their caps standing there with the door open, 'Come on, we're waiting to shut the door.' You know. And they sat us in the front and oh, 'What would you like to eat?' and because it was club class, you know, it was all, 'Would you like Champagne?' 'Just a brandy please!' You know. [laughter]   |
| Int | That in itself sounds like a very conflicted experience, so going into a class is one thing and you don't know what you're going to find. [Overspeak]  |
| K   | Before we, before that, we arrived, I'd say it was kind of nearly midnight by the time we got to Toulouse and erm, it's only a small airport [mmm] and the few other passengers that were with us, they had gone through the check out, they've got their, retrieved their baggage, we waited on the merry-go-round for hours, nothing. Where was our little case? Our overnight case? It wasn't there. And then we were enclosed in this, with a glass partition in this er, area and we could see members of the military on the other side of this glass enclosure [mmm yeah] waiting for us to meet us to take us to the hospital, but where was our luggage? Nobody in there to talk to, to speak to, [mmm] it was late at night, all we had was a telephone. So I've got pigeon French, if that. Minimal. [yeah] and I picked up the phone and I said, 'mon valise, blah blah blah is missing' (laughing) and non arrive as best I could. And, anyway, we were told that the case would be delivered to where we were staying the following morning, it had been left behind at Gatwick. And so then they opened the barrier and we were driven by a couple of men from the military. Ahh, it was a horrendous night, wasn't it? Oh, well you weren't there with us at that time. The wind was, the trees were going like that, storms, it was stormy. Pitch black. And they drove us to the hospital and as we arrived they were just wheeling Leonard out of the operating theatre, all bandaged up, quite distressing. [yeah] He was being taken to intensive care, and then I don't know, did you arrive - and we stayed overnight [mmm] in a hostel attached to the hospital, |

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|     | [mmm] which was quite traumatic, because there was a helicopter pad just by where we were. [yeah yeah] It was a teaching hospital and fortunately a neurological training hospital. So all night long there were people being brought in from all the regions of France because it was a neuro-hospital, university.  |
| G   | At the base of the Pyrenees   |
| K   | So we didn't sleep a wink that night, and then I think you arrived a couple of days later or  |
| T   | Yeah, I think so.   |
| G   | The funny thing, you were sleeping in these rooms and if they wanted you during the night they would come and call you. [mmm] And, you would lie awake and here these footsteps going along the corridor and you're going, 'Are they going to knock on your door?' It was frightening. Remember that? I'll always remember that. Well people were dying and coming in and all the time you heard these clatter of feet up and down the corridors and you think is this, are they going to knock on our door? They tell us that you can't go to intensive care straight away because Leonard was going |
| K   | Because he was in intensive care, we had to gown up, only two visits a day. One was at 2 o'clock in the afternoon and one at 7 o'clock at night. So what do you do with yourself during the daytime? We didn't have transport, erm, we were in the middle of nowhere really   |
| Int | You can't speak French, didn't want to be too far away  |
| K   | Exactly   |
| G   | We had somebody in the army, a captain, what was he, I forget his name now. He stayed with us, what was his name? I can't remember now  |
| T   | And of course, you know, Leonard's girlfriend at the time came out straight away didn't she?  |
| G   | Laura   |
| K   | Yeah  |
| G   | She came out with us  |
| T   | Did she?  |
| G   | Came out with us, didn't she? Laura came with us.   |
| K   | I don't remember that   |
| G   | Laura came with us  |
| T   | She was out there when I got there  |
| K   | She came with her mother  |
| G   | No, she came with us, because the original, the first phone call we got, now it's coming back to me, that Leonard had broken his leg, so I went down the building society and drew some money out for Laura to fly to Toulouse to see you know oh the idiot, he'd broken his leg, you know.   |
| Int | Ok, so jus-jus-just er, so that was the first thought, that Leonard had broken his leg, so that was the level of severity. [over speak] So yeah, it's a biggy but it's not  |
| G   | Now I remember I went to the building society and drew some money out and gave it to Laura to go to France to be with him as they were  |



|     |  |
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|     | living together at the time, you know. So erm, she came with us to France.   |
| K   | I don't remember that.   |
| G   | She was with us, yeah  |
| B   | Sorry, you said that Leonard was being wheeled from the operating theatre when you arrived   |
| K   | Just as we arrived   |
| B   | Was that to do with his leg or   |
| K   | No nothing to do with his leg, he hadn't broken his leg, that was what we were told by the army.   |
| B   | But they had operated on him   |
| G   | He'd had two operations [over speak]   |
| K   | They had removed a portion of his skeleton, or his skull to allow for the swelling [over speak]  |
| G   | And stored it in his stomach   |
| Int | To keep it alive?  |
| K   | On his rib, yeah to keep it alive.   |
| G   | They stored it in his stomach.   |
| Int | That whole time period feels like it's the most apprehensive.  |
| G   | Well, it was because it was the time, what do you do with yourself during that time when you couldn't see him and he was not well  |
| K   | Well we spent a lot of time in the chapel  |
| G   | In the church, yeah.   |
| K   | And there was a little Chapel attached   |
| G   | There was a French priest and he used to see him   |
| K   | Yeah, he came and he anointed Leonard straight away, [mmm] the following morning because I said, you know, that night I said he was quite on the danger list really. And I said, is there a Chaplain here, and being a Catholic country, 'Yeah, no problem' and he came and he anointed Leonard and we were there around the bed able to be with him doing that and thank goodness for the Latin because we could understand, we could communicate, you know. [oh yes] |
| Int | Were you thinking about last rights at the time?   |
| K   | Yeah, the anointing of the sick yeah and the ???   |
| Int | Mmm, so I guess a couple of times you've mentioned that you, you didn't know whether Leonard was going to be alive and that you were expecting a knock on the door to say that, so that was very much the kind of narrative at the time. Is he gonna die?  |
| T   | Yeah, it (overspeak) very, very serious from my limited French, yeah [yeah] it was that pressure, the pressure on they were measuring the level of pressure or on his you know on his brain  |
| B   | His brain had swollen  |
| T   | Yeah, it was, it was er, even though they had taken a piece of skull away, the brain was still swelling, [still swelling] even though, it was at a very concerning level.  |
| Int | Was it the swelling that did most of the damage, or?   |
| T   | Well, he had a double fracture of his pelvis, that was the, a ruptured spleen or something   |

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| K   | They removed the spleen altogether   |
| T   | And, you know, but I mean, the most significant injury was the   |
| K   | The brain damage   |
| T   | He didn't break his back or anything like that, but he kind of hit the ground, well we learned later that he kind of hit the ground sideways, so horizontally.   |
| Int | OK   |
| T   | And he kind of bounced off the ground and then, you know, because of the speed at which he, he, he, you know he hit the ground and then, you know, yeah but there was, the guys that, the guys that were erm, jumping with him, erm, spent quite a bit of time er with us and they became increasingly wary about what they said to us. Um, after they'd been advised, coz yeah yeah, they was |
| K   | Did you get that Barry? Did you hear that?   |
| B   | Not all of it, no, no. Is it   |
| T   | Barry, I said, you know, the guys that he'd been jumping with on the exercise, they came to the hospital and, you know, at first they were quite forthcoming to talk about the circumstances of the accident, and that's how we  |
| B   | Found out something  |
| T   | Yeah, but then they stopped and they became much more wary about saying anything about what happened, and we assume that was because they'd been told  |
| B   | Told not to say anything (Coughing)  |
| G   | Yeah, but we were so traumatized about what had happened to Leonard, we weren't in any state to take in anything (inaudible coughing) well you were but I wasn't, certainly wasn't. I couldn't. And you think after the event (inaudible coughing) you know, you weren't in a, after the event, if I'd have been   |
| K   | Compos Mentis enough?  |
| G   | Enough, I would have gone to those soldiers and asked for their name, their number, could I contact you and press you to tell me exactly what happened? But I wasn't emotionally able to do it, [no] because of what had happened to him.  |
| K   | But we did try later, didn't we? Much, much, much later, when Leonard was home, we did try and they were all very tight lipped because they were still in the TA and erm, it could have cost them their bounty, yeah.  |
| G   | Their bounty or whatever it is.  |
| Int | So how, so right from the very off then, you were fighting a bureaucracy.  |
| K   | Yes, yes   |
| Int | So it was the army first of all and the tight lipped German soldier and then it became the NHS.  |
| T   | And there was a whole army inquiry process   |
| Int | There was?   |
| T   | Yeah, which is all, you know they always have after incidents called a board of inquiry which is opaque to say at best, you know. It's, you  |

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|     | just don't know what goes on there.  |
| K   | Because the weather, the weather conditions at the time were not conducive   |
| Int | To jumping   |
| K   | To jumping, and the guys that had been standing around for a couple of days, they'd gone over to France for this, specifically.  |
| G   | I've still got the original accident report  |
| K   | And they were all disappointed, most of all the, what was he the Colonel or somebody in charge, because he wanted to get this exercise over and done with and get back to Britain. And he'd had a delay already [yeah], and I think, he'd cut some corners.  |
| G   | There were six or seven other accidents on the same exercise, [really] but Leonard was the most serious.   |
| Int | Did Leonard's chute not open? Is that  |
| G   | Oh, it did   |
| K   | It tangled up, didn't it   |
| G   | We don't, we never ever found out why it happened [yeah]   |
| K   | And yet he packed his own parachute, he wasn't a learner parachutist, he'd done  |
| T   | About 100 jumps  |
| K   | 100 jumps  |
| B   | It was a freefall jump, wasn't it?   |
| G   | Yeah, yeah yeah. But we've never been able to get, well you see you've got Leonard as he is, you've got this board of inquiry into Leonard's accident, [mmm] you've got, your fighting on so many fronts, [yeah] you know where do you give your energy? To you son? [yeah] To get him the best quality of life you possibly can. You know you look back and you think, we should have done more and stood up to them more than we did |
| Int | Is that the resonating feeling there, that we should have done more?   |
| G   | Yeah, well I   |
| K   | I don't, I think we did as much as we could, AnGareth. To the point that in the end we even paid, what was it? £2000, no how much was it?  |
| T   | ... an investigation of the er   |
| K   | For a barrister.   |
| T   | We had someone independent to look at the, er parachute didn't we?   |
| G   | Yeah yeah  |
| K   | That's right, that cost a lot of money   |
| G   | We wouldn't, we would not allow the military to look at Leonard's parachute [ok] on their own, so  |
| Int | For fear of?   |
| G   | For fear of, [laughs] you know   |
| K   | Cover up   |
| G   | Cover up   |
| Int | That is what it is isn't it, it's er.  |
| G   | So we had an independent person to look at Leonard's parachute.  |
| B   | I'd like to say something about, you said the guys out on the accident,  |

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|          | they wouldn't have been in fear of losing their bounty, not at all. I'm sure finances wouldn't have come into it at all. They would have been under strict orders, 'You don't talk about this'. It's like you can't talk to the press, if something goes wrong you're not allowed to talk to the press, you know, you'll be court marshalled. So their more likely under threat of court marshall if they speak when they're not supposed to, you know, under orders not to speak. They wouldn't be, wouldn't be anything to do with finance. I'm pretty sure |
| G        | Well it did get to court, a no win no fee, then we got to a, we went to a barrister and he looked at the case and he wanted £1000 an hour.  |
| K        | Which we did pay  |
| G        | No we didn't  |
| K        | Didn't we do that, go that way then?  |
| G        | Well £1000 an hour for his services [wow] and if we lost we get the cost, the MOD costs as well.  |
| T        | His advice was not to proceed wasn't it?  |
| G        | Yep, yeah   |
| Int      | Was this sort of erm, was it sort of legal proceedings against the Army?  |
| G        | Yeah  |
| Int      | Like to get compensation (overspeak) and the legal advice was not to proceed?   |
| K        | It was us against the system, as it was us against the system at the NHS  |
| G        | We had enough   |
| Int      | That's a really recurring theme isn't it?   |
| G        | We had enough problems anyway, to cope with. You know what I mean? With Leonard as he was.  |
| Int      | Yes, Hence the fighting and   |
| K        | Plus the fact, I mean not blowing our own trumpet, but we're both quite literate people. We are computer literate, [yeah, yeah] a lot of correspondence, volumes, we've got them upstairs in files, volumes of correspondence, [mmm] as you can imagine [yeah]. You know, with dealing with all these things, you know, from day one right through to the current time. So erm, other, a lot of people who perhaps are not able to write, keep records as well.   |
| Int      | Yeah and so there's the literacy but there's also the drive as well from the whole family that constant need to fight.  |
| G        | And also the constant need to provide health care, once he'd been discharged from the military hospital, where the care was excellent, the one to one care, you were in a culture shock when you come into the NHS [mmm] because we have to go to everyday to see Leonard [mmm]. We would not leave him on his own [yeah]. Basically, we had to be there by 12 and we didn't come back until he went to bed at 10 o'clock, everyday. Seven days a week.   |
| K        | What were you going to say Terrence?  |
| Terrence | I was going to say obviously you did a lot of travelling as well because he was, coz when he came back to   |

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| K        | England  |
| Terrence | England, he was in a military hospital in  |
| K        | Gosport  |
| Terrence | Gosport [overspeak] south coast  |
| Int      | It's a long way to Gosport isn't it  |
| G        | Yeah   |
| Terrence | And then when he got transferred to Hedley, Hedley Court which is near Epsom[mmm] you were travelling there.   |
| G        | Yeah   |
| Terrence | Frequently as well   |
| K        | Three or four times a week   |
| Int      | Did, did you receive any compensation for  |
| G        | No   |
| Int      | So this is all   |
| G        | Yeah   |
| K        | Nothing  |
| G        | Nothing  |
| T        | And he got, he got um I mean he got a war pension as it were didn't he   |
| K        | Yes  |
| G        | He got two war pensions, he has two war pensions.  |
| B        | No compensation  |
| G        | No   |
| K        | No, Nothing  |
| G        | They came up - he had what, a basic war pension and then a year later they came up with another severe disability pension as well [short pause]  |
| Int      | Yeah   |
| K        | So once he came home, em, we were told, from the military rehab hospital in Hedley Court, Leatherhead, we had to find a suitable home where they could give him all he needed to help him rehabilitate including speech therapy, and physiotherapy and so um a suitable, so called suitable place was found in Hemel Hempstead [mmm] and it was Kippers and Lace if you know what I mean.  |
| Int      | Errrr  |
| K        | Beautiful chandeliers and the [right] lounge and very nice when you went in, the food was good but the care was appalling, absolutely appalling [yeah] there were a few elderly ladies who had gone there to spend the rest of their days and they sat around the wall like flies and one dear lady controlled the remote control from morning till night and other than that being in the day room, Leonard was confined to his little room [mmm] which consisted of bed, space for his wheelchair, and a wall mounted television which we took in. That was all there was in his little room. And um, he was neglected, [mmm] he wasn't hydrated at all, his teeth weren't brushed, we knew because we used to place the toothbrush in a certain position [ahh] and it was still there |
| G        | Still there, still there,  |
| K        | Still there,   |

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| G   | Same position   |
| K   | His urine was like the strongest shade of tea [mmm] because he wasn't getting enough fluids   |
| G   | Was he losing weight  |
| K   | And he was losing weight, pressure sores  |
| B   | I was just going to ask you were they turning him or moving him   |
| G   | No,   |
| K   | No, they weren't even looking, pressure sores, he had an air flow mattress [yeah] you know but one of the cells had collapsed and he was lying, laying on, on, on, em a metal rod [mmm]. No one had noticed that and his wheelchair, the back support behind the cushion  |
| G   | Came through  |
| K   | Had been put on back to front so the bolts were sticking into his back  |
| Int | Oh dear   |
| K   | Instead of the round bit of the [yeah] the bolt was sticking into his back.   |
| G   | Going into his back.  |
| K   | Nobody noticed. Nobody noticed. The sheets were like muslin, so thin [yeah] and the pillows because they used to put them in the laundry with all the other things, they'd come out looking mangled up [yeah] you were sort of sleeping like that on the edge of a rock, all these things, and to get another pillow my goodness me there would be an inquest. Little things like that [yeah] |
| Int | Is, is this the house that  |
| G   | Closed down   |
| Int | The, one that closed down   |
| G   | The one you got the transcript  |
| Int | Yeah, that's right.   |
| K   | The one what?   |
| G   | I gave Andrew a transcript of, of the, of the documentary.  |
| K   | Oh right, yeah. Em, we were afraid to leave him [yeah] we were afraid to leave him  |
| G   | Yeah we were  |
| K   | And we weren't allowed to speak to any of the other residents, or, I mean   |
| B   | You weren't allowed to speak to them?   |
| K   | Oh no, no, no   |
| G   | No, no, no that's why, in case we talked too much.  |
| K   | In case we found out too much. And you know sometimes if the door was open as you went past and the other residents -   |
| G   | You'd go in and chat to them coz they were lonely   |
| K   | And they'd say, they'd call out Hello, you know [overspeak]   |
| B   | They probably wanted someone to chat to   |
| G   | They do, we used to go in there [Overspeak] but because they didn't want us to find out what was going on, we use to help try, we had a little, a little community that wing, we all were together weren't we because we'd sit with each other's if   |
| K   | Yeah, that was only in the winter time [overspeak]  |

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| G   | If they had no visitors we would go, one of us would go in and see see that other person because he, wondered what do they want or whatever didn't we.  |
| K   | Yeah, but the only time we really could get together as relatives was in the summer time when we would take   |
| G   | Yeah that's right   |
| K   | Our loved ones into the grounds   |
| G   | Outside   |
| K   | So they couldn't stop us from talking to each other and that's how we found out that the standard of care was the same for everyone   |
| G   | Same [overspeak]  |
| Int | It wasn't just Leonard that was neglected   |
| K   | And em, there was one commode for upstairs and downstairs one commode, so if you needed, if one of the patients needed the commode, tough if it was upstairs [yeah] you know, tough you had to wait, for all the clients, and oh it was disGarethting, covered in splashes of faeces  |
| G   | We brought his own one  |
| K   | And you know the padded [sound of two knocks] of the arm [mmm] of the commode, it was all broken away and it was all sponge, harbinger for germs [yeah] and that so we bought his own commode anyway that was another thing and em well I think that we've got a video because we complained so many times [yeah]   |
| Int | Kristina, sorry, just, just, just to interrupt the story slightly at this point, what was, at the time it sounds like this home particularly and everything that had led up to this point just kind of talking about the physical health stuff, as well so was there physical health and the physic - Leonard's physicality in the difference physically how would that parr with his brain injury, what kind of -  |
| K   | Well it was, it was, alleged to be a rehabilitation home and nursing home   |
| G   | The military went in there and inspected it and said oh yes they thought it was a suitable place near us [yeah] for Leonard to go to where he'd get cared for   |
| K   | And they would have physiotherapy on tap, [mmm] and em available, availability of speech therapy as well. [yeah] we thought wonderful you know but that was another thing, he was booked down for physiotherapy but the owner of the home used to use the physio department as her little em er social er goodwill thing for al the members of her golf club if they got injuries they were 'oh come along I'll get my physio to sort you out' so the clients, the residents who were booked [yeah] that afternoon for physio, well you'll have it tomorrow, tomorrow never came. |
| G   | Where in the military place where we would go in with Leonard when he had his physio to encourage him [yeah] we were never allowed to go into this place to see how Leonard got on in his physio to encourage him to do so. We were never, wasn't allowed, because he never got any that's why [yeah, yeah] [laughter]  |

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| Int | Yeah and like you say with hindsight you feel like you would have done and shouted more   |
| G   | Yeah  |
| Int | And scream  |
| G   | But we couldn't have done, we couldn't, well we couldn't have done any more than we did   |
| Int | It, it, it doesn't sound like it.   |
| G   | And she knew, she knew that we were reporting them  |
| Int | She die   |
| G   | Yeah, oh she said if you don't like the place   |
| K   | You can bugger off  |
| G   | Bugger off  |
| B   | Her words   |
| G   | Yeah, yeah, so what do you do with someone in Leonard's condition   |
| Int | She's put you in that position that   |
| G   | Where do you go, where do you go.   |
| K   | But the problem was, we were complaining to the em Hertfordshire County Council, the care people who do the care, who em  |
| G   | Was it Social Services inspection unit [overspeak]  |
| K   | An inspection unit at Hertfordshire County Council which was done on a local basis at that time and who was head of the Social Services committee but the lady who owned the home,  |
| Int | Oh dear   |
| B   | Oh dear [laughter] [overspeak]  |
| K   | You've been reporting me, if you don't like it you know what you can do. And in very crude terms she told us we could bugger off.   |
| Int | So [gasp] the, the, the tail is a constant er a constant set of circumstances that you are butting, butting [overspeak]   |
| G   | yeah  |
| K   | And the system then was that there were two, two announced visits from the inspection unit and one unannounced.   |
| Int | Unannounced   |
| K   | Well when the announced inspection were taking place  |
| G   | They used to know it was coming   |
| K   | You knew it was happening [yeah] there was hibby scrub in the rooms, you know, the washy thing  |
| G   | [Laughter]  |
| K   | All the paper towel things were filled up [yeah], all the laundry in the laundry room was clear. Normally, it would literally be covered up like that, oh it was horrible, that was right opposite Leonard's room and em flowers in the hall everything smelt sweet you know, lovely [yeah] but the unannounced one, well that was different. But she was so charming that [yeah] there would be a silver salve with the sandwiches and a silver coffee pot you know and er just to |
| G   | Even, even our Social Worker didn't back us up who was with us, the Social Worker was absolutely useless. [short pause] and the representative from the PCT she was as bad as well. [yeah] So we were the only, we were fighting [laughter] we were fighting the lot  |



|     |  |
|-----|--|
| Int | Yeah completely  |
| K   | And do you know what we hijacked him out of there because [ Gareth laughs]   |
| B   | You hijacked him   |
| K   | [overspeak] found another home [yeah] that was supposed to cater for younger [ok] brain damaged people.  |
| Int | Because it sounds like maybe with people who could have had strokes and things all mixed up in that.   |
| K   | Yeah, yeah it wasn't suitable at all. [overspeak]  |
| G   | ...in general, well they didn't specialise in people with brain damage did they.   |
| Int | So Leonard has got a traumatic brain injury compared to  |
| G   | Yeah   |
| K   | But there was nothing, there were no activities or anything taking place there at all.   |
| G   | We used to take him out  |
| K   | We used to take him out every day for that purpose again because we believe [overspeak] stimulation, stimulation [yeah] so then we found a place in Sawbridgeworth em which was like a breath of fresh air wasn't it by comparison [mmm] and er they said yes ok we can take him em in a month's time. [overspeak] wait a month  |
| G   | Is that how long   |
| K   | We can't wait a month's time, it's desperate there now, you know the situation, the woman knows that we've reported her and we fear for Leonard's safety [yeah] [mmm] so she said well ok then bring him next week [aahh] we wanted to redecorate the room but its' good enough [yeah, yeah] bring him next week. And so that afternoon as we, was our general practice we took him out for a walk in the wheelchair and we had his invalid van parked down the road |
| G   | And didn't take him back   |
| K   | And didn't take him back and we wrote a letter [yes] to the effect that we wouldn't be returning but we asked that that letter would be presented in the evening, we asked one of the nurses who we were friendly with [mmm] we said you know if you say you found this letter in Leonard's room you know and handed it in. she was hopping mad but we don't care you know and   |
| G   | We escaped   |
| K   | We escaped, it was quite a , quite exciting [laughter] really.   |
| G   | Straight from colditz. [laughtter]   |
| B   | And how long before it was closed down afterwards?   |
| K   | Ohhh, a couple of years I suppose... negotiation   |
| G   | No it wasn't as long as that   |
| K   | No?  |
| B   | Did you say TV station got involved?   |
| G   | The station got involved, ey   |
| B   | Did the TV get involved  |
| K   | Yes, yes   |
| G   | Yes  |

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| K   | Yes, yeah. Fortunately we em   |
| G   | We, Leonard had gone by then   |
| K   | Yeah, fortunately we kept in touch with some of the other relatives you see [mmm] and we'd share all our problems and our misgivings about the place and anxieties and one of the ladies had a friend who was a freelance reporter [mmm] and she worked for ITV wasn't it?   |
| G   | Freelance so it was Channel 4  |
| K   | For channel 4 and she managed to get a, a carer to go in, get a job, I mean they were so desperate for staff that they'd take anybody [yeah] anybody in off the road that was looking [mm] for a job, it was as bad as that and they got this young black girl to go in and said she was a carer, they gave her a job straight away and she had a, a camera  |
| G   | A hidden camera  |
| K   | A hidden camera, and some, that's what clinched it because she had the written proof [yeaah] em just if you're interested they – she took you into the laundry room and they were showing her what to do and they had a pair of tongs that they were picking up all the dirty laundry and putting them into the washing machine and they were picking up people's face flannels that had been used to wipe bottoms with, full of faeces, [mmm]they were going into the washing machine together with everybody's clothes, disGarethting. That was one thing  |
| G   | It wasn't even washed at the right temperature was it?   |
| K   | Not even washed – to kill of germs yeah. Then there were two carers that were upstairs, a young fellow and a girl and she filmed them that they put an old lady on a commode, stark naked and left her there,[mmm] how undignified to be stark naked like that, disgraceful with her you know poor little toes hanging off the end of the commode, and once they'd sorted her out they made the beds, got rid of the patients, brought them all down to the dayroom and the young lad carer was laying on her bed, 'oh I'm shattered' and the girl, the other carer laying on another bed 'oh, we're worn out, we've done our day's work' and this was all filmed, laying on the patient's beds. So that's what clinched it in the end             |
| Int | Yeah that's the thing that did it. So, so again it, it, it sounds like the things that you are, that you're fighting and fighting for  |
| G   | Yeah, the impact of that film was that we were talking to Social Services about Leonard coming home, a consultant recommended that the best place for Leonard and as he had good family support would be at home [mmm] and there were argy bargy about who's going to pay, well money, money, it's going to cost them money for Leonard to come home, no hoo harring about it so when I knew this film was going out on the particular night on Channel 4 TV I emailed everybody in Social Services, everybody, councillor, every body I knew that had a connection with Leonard's case, Watch Channel 4 television tonight, the programme about Leonard, because Leonard being a policeman and an ex-para it was news, it was [yeah] a news thing |
| Int | It was a yeah  |

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| G        | Neglecting home that sort of stuff, I had, we had sixteen people to a meeting a fortnight later to get Leonard home.  |
| Int      | Yeah [laughter] yeah.   |
| G        | Didn't we   |
| K        | Yeah  |
| G        | See, that shows, they wouldn't have done it, they wouldn't have put Leonard   |
| B        | Publicity you see   |
| G        | Or and I haven't used it very much to my advantage since then, I haven't any great problems with anybody, I am tolerant, I'll wait so if people say they are going to do something [mmm] I give them time to do it but if they don't do it, ok, I'll get a journalist from Channel 4 to ring you perhaps you'd like to tell them why you won't do it. [overspeak] [yeah] oh I don't think that's necessary Mr Carroll. It's there the next day and I'm lucky [yeah] what about other people who can't who haven't got those connections, I know we've had to work hard to get them but that is, you know [stutter] conservatives or labour it doesn't matter who's in, you're not going to get care for people with acquired brain damage [yeah] [laughter] |
| Int      | Well thank you [laughter] thank you all of you that's been, it's been really, really helpful, em just sort of as an ending to this how is everyone sort of feeling now about having had these conversations and [short pause]   |
| Terrence | Oh, it's brought back, it's brought back um memories of the detail, some of the detail you lose over time   |
| G        | Yeah you feed off each other don't you [over speak]   |
| Int      | Sort of sparking memories off   |
| G        | Difficult memories some of them   |
| Int      | Yeah I'm sure.  |
| G        | Yeah, yeah, I suppose us being retired and not having a job to distract us from [mmm] what's being going on I suppose it's perhaps, perhaps I've been well thank god I wasn't younger than I, than I was, I don't think I would have been able to manage it all really, if I'd been working   |
| T        | Leonard has been...   |
| G        | Ay?   |
| T        | Leonard has been a full time job at times hasn't he   |
| G        | Yeah, yeah he has, we wouldn't have been, you know we wouldn't, we'd never have managed it if I'd, if I'd been in full time employment  |
| Int      | Yeah of course.   |
| G        | A lot of people are in full time employment when this happens to one of their children or aren't they and they have to carry on with their job and cope with, are you, do you look at other cases where this sort of stuff has happened or  |
| Int      | For this research it will just be this  |
| G        | This family   |
| Int      | This family yeah. So it's your own er based on the case study, em case study, using a single family it means that we can get more into the  |

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|     | detail so it's kind of a smaller area of interest but much deeper so that's one way of doing it. The other way of doing it is looking at lots and lots of families but not being able to get as deep. So for me this is the better way of of doing this, doing this work yeah.  |
| G   | Because, because of the skill of the, of the medic modern ways now a lot more people are being saved from   |
| Int | Exactly right yeah, so it'll become more and more of an issue   |
| G   | Yeah but have all those families got to go through the same thing? Mmm?   |
| Int | I know it's, it's a horrible situation. Ok, well thank you, thank you all of you. Em just sort of reflecting on this meeting that we've had, how, how are things feeling now, now that we've  |
| K   | Following - I don't think we can take, we're pretty strong now really because we've been through so much [yeah]   |
| G   | We've been through  |
| K   | This is just [overspeak]  |
| G   | Terrence, probably we bore people [laughs] the pants of people or I have once I get going I never stop but you know   |
| Int | [over speak] full time job  |
| G   | Em what's it mean, that em [slight pause] what's the right word for it, [short pause] anger [mmm] anger which I should have I'm still angry, still angry. Anger, anger,   |
| B   | I didn't tell you this when the camera was on but I've seen him take his anger out on Leonard [overspeak and laughter]  |
| G   | They do it to have a bit of sport [over speak]  |
| B   | Leonard defends himself [over speak] and then he goes like this and Leonard on the nose isn't it, on the nose he gives him a little touch on the nose with his fist so it's good really though have a little sport like that  |
| Int | Still able to yeah  |
| B   | We have an arm wrestle  |
| G   | And he has an arm wrestle,  |
| B   | I have an arm wrestle with him as well since [over speak]   |
| G   | ... his right arm, you cannot move him can you [overspeak] it's strong god, if he hadn't been, well that's it if he hadn't been as fit as he was he wouldn't be with us [yeah] I'm sure of it.  |
| K   | We never really finished the story em I don't know if it's relevant now but then when he did eventually come home [mmm] we had to set him up with appropriate, an appropriate care package, [mmm] and the first agency that we were given by Social Services that we were recommended too were an absolute waste of space, they were hopeless, they were sending people in who weren't trained, didn't have a clue, didn't have a clue and we had lots of friction. That was frustrating because they were getting paid to do the work, they were charging two thousand a week was it |
| G   | I don't know what it was a week   |
| K   | For Leonard's care  |
| G   | But we were doing all the work  |

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| K   | And we were doing all the work [mmm] I was doing all the shopping, the cooking   |
| G   | Medication   |
| K   | Ordering his meds  |
| G   | Taking him to places   |
| K   | Collecting and getting them dispensed, I was doing it all and saying trying to persuade the carers 'oh let's take Leonard out for a walk this afternoon' because I do believe very firm - erm very positively about the impact of fresh air and integration [mmm] not like poor Michael who has been, what's the word, institutionalised, hasn't he  |
| G   | Yeah he has  |
| K   | And if you took him out now he'd probably feel quite em what's the word, lost wouldn't he  |
| G   | Yes  |
| K   | I think so he's been in, institutionalised for so - I don't want Leonard to do that and I believe fresh air [mmm] is a tonic, it toughens them up otherwise when he goes out to somewhere like 'the brain injury association' he's going to pick everything up.  |
| Int | Ok, of course yeah, there's that yeah  |
| K   | So, em but you know I had to sort of persuade them, oh let's take him out you know, ah in the end we, we em, we, we departed from that company didn't we.  |
| G   | While we talking about him it reminds me of something else that happened. When he came home he had to pay, he had to pay a contribution towards his care [mmm] through Social Services. We found out that we were you know he was so delighted that Leonard was coming home to live in his own house [mmm] you know they tell you about these things and you don't really take them in but we had to pay a - Leonard had to pay a contribution towards his care which we discovered was illegal because if they were paying for everything in a care home and his needs hadn't changed [mmm] when he came home |
| K   | The NHS were paying for his care   |
| G   | His needs hadn't changed. They were paying for everything in a home  |
| K   | Physio, speech therapy, as well as everything else   |
| G   | So his needs hadn't changed so it was, what they were doing was illegal. We had to fight in the court for three years to get, to get continuing care for Leonard   |
| K   | And we received very, very -   |
| G   | We went to the court in St Albans  |
| K   | Yeah   |
| G   | To get [laugh] didn't we   |
| K   | Yeah   |
| G   | To get it  |
| K   | But we got excellent advise and support from [South East England] Disability Action in Four Street   |
| G   | Community Care - fantastic   |
| K   | They were fantastic they guided us and they had a lot of legal   |

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| G   | So that's another, another  |
| G   | Another struggle [over speak and laughter] spanner in the works you know  |
| K   | And I thank god and that is an answer to prayer we've got an excellent team of carers who have been, who have been specifically appointed and trained to look after Leonard [mmm] and well the worlds his oyster now [yeah] they are fantastic.   |
| G   | The whole team has been with Leonard since this company has took over haven't they  |
| K   | Same, same staff all the time.  |
| G   | Same staff  |
| Int | How long has that been  |
| K   | Well this new agency, about three years   |
| Int | Oh wow, so, so the most settled kind of   |
| G   | Four years really   |
| Int | Kind of period  |
| K   | Oh, they love him to bits, they're excellent and we, we can confidently stay home,  |
| G   | And relax   |
| K   | And relax, and just leave them to do their job knowing that they will give him fluids to drink, the right food, and very healthy food, again I'm not blowing my own trumpet but they, they were learners when they started [yeah] and they said well you know what food do you want us to give him? This, this, this, this, this, healthy food. Write us how to cook it, write the recipe and we will do it [mmm] and they do it. So he has a lovely, you see what he eats, it's good isn't it, |
| G   | Yeah good, very good  |
| K   | Good balanced meals   |
| G   | It has to be pureed though [yeah, yeah]   |
| K   | But, and what they do, they have a big cook in once a month [mmm] Leonard goes out and they buy loads of meat, veg and other things and, and em then the night staff do the cooking and they follow the recipes [ok, yes] and em and they put it in the freezer, little boxes in the freezer and it leaves the staff free to do other things with Leonard during the day time.  |
| Int | Yeah so they're not having to cook.   |
| K   | And they take him out twice a day most days. [mmm] they're very good, thank god for that. They're lovely.   |
| G   | But all his physio, hydrotherapy and other activities he joins in he pays for himself.  |
| Int | Out of his pensions   |
| K   | Yeah that was the biggest em [short pause] biggest hurt, apart from being told that Leonard had brain damage and there was no, no hope of improvement [mmm] the next biggest hurt was when he did come home and he went for em physiotherapy on the NHS [inaudible background noise] and they'd written him off there was nothing we could do [overspeak and background talking while Terrence leaves] oh bye bye Terrence, bye love. Take care see you.  |

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| T   | Sorry I was late Andrew but I couldn't leave work in time  |
| Int | No that's no problem at all, em can I - I'll be in touch about   |
| T   | Yeah my details are on there.  |
| Int | Lovely   |
| T   | Ok, cheers   |
| K   | Yeah so to be told that no we can't give him physiotherapy so that made us even more determined and positive. We would buy his physiotherapy and blow the NHS [yeah] which we managed to find a physiotherapist who was semi trained in neuro, there's [yeah] a slight difference between a neurophysio and an ordinary physio, not a lot but anyway she's excellent and she comes to the house [does she].  |
| G   | Twice a week [yeah]  |
| K   | Oh and another thing while we're at it going on about physio, when we had Leonard's home converted [mmm] again no thanks to anybody but us, we were told we had to get advice on em a hoist, he's got a hoist [mmm a hoist] over his bath and over his bed, excuse me I'm bunged up, em and so we got a beautiful nice bath you know with a shower attachment as well as a shower unit on another side of the room, special floor, wet floor   |
| G   | He paid for it all himself   |
| K   | And he paid for it all himself. Then the carers came in the first agency that we had, oh we're not allowed to bend over, we might hurt our backs, it's against the company rules. So immediately the bath became obsolete, [yeah] a brand spanking new bath with all the fittings which cost a fortune, obsolete. And then came the time when we wanted a physiotherapist for Leonard. He was going out to em the Bow Bath Centre,   |
| G   | Bow Bath Centre  |
| K   | in Finchley, which was, every time we went every few weeks they were putting the price up and up and up and up and up and I think it got to about £85 for one session, it was getting ridiculous you know, he needed physio, anyway we found this physio who gives him two sessions a week, for the same price that we were paying [oh] for one [yeah] so what we did, we had the brainwave to remove the bath which was obsolete [Yeah] and we bought a massage table, physiotherapy table, [oh wow] and had it installed because we had the overhead tracking for the hoist [yeah] anyway [yeah] and its, and we've never looked back since because he gets two sessions of physio [mmm] and the carers give him his, excuse me I've got a lot of catarrh and bunged up with a cold, and they give him his stretching exercises every morning in bed, they stretch him [wow] so em he's as well as |
| Int | Yeah as well as can  |
| K   | We can get him. But if I can find anybody that can put a   |
| G   | ???  |
| K   | An implant into stimulate even his swallow [yeah] and his speech that would help, so keep your ears and eyes open won't you.   |
| Int | Ok, ok. Well thank you, thank you very much for letting me come in and intrude on your.  |

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| K   | Don't forget that will you. |
| Int | Oh thank you.               |

Appendix I: Notes on the family interview

First Family Interview Notes

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|---|---|---|
| 1 | 2 | When Gareth is asked to introduce himself, he offers lots of factual information about L<br>What does this mean?<br><b>The very first point that G makes, is that authority figures do not care about L or the family</b>   |
| 2 | 2 | <b>My initial question – this might be useful for the method section</b><br>T G its been a ten year struggle, nobody will ever tell you anything, military environment to an NHS environment, perhaps we would have known more, perhaps we would have done things differently.<br><b>This is a theme that recurs trough out the work with Gareth</b>  |
| 3 |   | T G Because of what happened to L I have changed – intolerant, change in character – lessons learned from the struggle.<br>You have to be rude and aggressive to get anything done<br><b>Gareth puts words and intentions into other peoples mouths, and</b><br>In the monologue, he says that he is alone against the injustice of the system involved in L's care<br><b>T The way he tells in in this monologue, he says that this happened to L, therefore I had to become this person, there was no choice</b><br>T “Nobody listens, no body cares” – we had to get the TV into shut down the home that L was in however, for other people in the same situation, what options do they have?  |
| 4 |   | Terrence – very carefully speaking, no emotional words, simply that there was a steep leaning curve for m and d to negotiate (NOT ME)<br>G We got blamed for being trouble makers in our quest for L to get what he deserved and needed<br>T G “They couldn't be bothered” – <b>this is a really important theme for G all the way through the work</b><br>“Nobody wants to rock the boat, like in Bristol” – <b>linking the recent BBC TV programme in Bristol with L's case in the home</b><br><b>my summary: they are butting heads against a faceless bureaucracy, who don't act in order to have an easy life and want to slot L in to place rather than see him as an individual with individual needs who needs to be treating accordingly</b> |
| 5 |   | Terrence towing the party line, lack of provisions for L, rather than saying what he actually feels – <b>15 second pause, what is happening here?</b><br><b>K her first foray into the conversation is all about facts – neurosurgeons, Headley court, brain scans (she uses the phrase “all very disheartening” when this is likely to be the absolute tip of the iceberg</b><br><b>K Kristina's themes emerge here very strongly, so she usually uses the plural “we” when talking for her family....being</b>  |



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|   | <p><b>fighters....we...repetition, repetition, repetition....clinging to hope,....</b><br/> <b>It feels very much during this monologue that she is saying ‘don’t argue or disagree with me on this, or is she saying it to her audience here, whoever that might be?’</b><br/> Kristina and the others go into the first person voice when recounting stories – <b>does that mean anything?</b></p>   |
| 6 | <p>“Devastation, wed lost our son”..... BUT there’s a lot of fight in us<br/> Were still looking every day for new developments - <b>she is so tenacious, is this so as not to feel the emotion which would just be overwhelming?</b><br/> <b>T Their role is not use to be the fighters for L but it is also to spearhead his care, they feel that the spear heading should be coming from the neurologists and the people who are designated to care for him, rather than the family – however, is this a story that stays consistent throughout the interview? I wonder if they would be happy letting that go?</b><br/> T G “we initiate everything, everything.”<br/> K in a pleading and begging voice mimics talking to the GP and asking for help with L to be referred to a neurologist – <b>she seems to be demonstrating to me the depth of her need at this point in the story – her voice then changes as she continues the story along with the story of complaining to the authorities and getting what was needed for Lin a meeting with 16 people – so she has the needy pleading voice, but also has the gutsy angry complaining voice in her repertoire.</b><br/> Kristina- we're looking for new developments/fighting etc., Gareth then interacts with his major narrative theme which is about other authority figures not caring.</p> |
| 7 | <p>T G The authorities don’t care, they said that L was in the wrong position, but then wouldn’t do anything about it,<br/> <b>Gareth-how could we leave his care to anyone doubts when they can't do the simple things right?</b><br/> <b>Just seems to give people's intentions and reasons for doing things: "couldn't be bothered" "they don't want to rock the boat" "authorities don't care" "selling Leonard" "they have already prejudged the situation".</b><br/> T G You have to sell L, you have 5 or 7 minutes and if he isn’t on form, then you’ve lost it, and wasted months of work, <b>is G saying ‘how can you treat me so neglectfully’, the idea of ‘lost it’ – that feels like he must be on edge all the time whenever L has to interact with the authorities.</b></p>  |
| 8 | <p><b>G and K really own the “family story’</b><br/> <b>T G interpreting for the authorities – “they don’t listen, you can see it in their faces”</b><br/> <b>K dismissive of doctors as pill pushers who don’t care about L BUT where is L in this story, when K talks it is possible to lose him within the dialogue a bit – i.e. “we’ve got the perfect balance of medications for him now” etc.</b></p>  |

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|    |    | <p>K we have to initiate everything for him<br/> It was heart-breaking to be written off by the authorities regarding physiotherapy for L. <b>this is the first time that physio is mentioned, but it becomes a very important theme for the relationship with L and the family</b></p>   |
| 9  |    | <p><b>When talking about L's strengths, the family are all so much happier in their speech and demeanour</b><br/> <b>He speaks more when he's had the physio</b><br/> <b>Standing joke about his age and he insists that he is 38 and tries to work out his dob</b><br/> <b>He doesn't talk mumbo jumbo, it is all proper sentences</b></p>   |
| 10 | 10 | <p><b>My words – look – the Drs were wrong, look at what he can do, and look at how happy we all are regarding this small progress and you doctors would deny us this?</b><br/> My summary on line 10 is important here and needs to be noted.<br/> T K there are a lot of untapped resources out there and energy <b>for when we're not here?</b></p>  |
| 11 | 2  | <p><b>K my goal, where is Leonard within that statement?</b><br/> <b>T when K says that “we never give up do we” does she actually mean that “I” never give up?</b><br/> <b>Kristina says that she and G do their research differently and meet in the middle, and that she doesn't have the time or the energy for ‘the brain injury association’ – I wonder if that is because it is too emotional?</b><br/> <b>Kristina seems very business like here really</b></p>   |
| 12 |    | <p><b>K look at how well we are doing here – we have got everything covered from all the angles</b><br/> <b>K doesn't mention Terrence in here monologue about L's care being covered from all different angles</b><br/> G takes pictures for him for his short term memory and for stimulating him in when they are not around, <b>he didn't really understand the question when I asked why he did it – to get his sense of why he does it</b></p>  |
| 13 |    | <p>G creating memory bank for L<br/> He knows who everyone is<br/> Printing</p>   |
| 14 |    | <p>G other people are scared of brain injuries<br/> They are let down by other people and family regarding L's brain injury<br/> <b>Kristina doesn't go along with the theme of other people's intentions which G is progressing along here, instead she sticks to her line about things being great – getting him dancing and playing Frank Sinatra etc.</b><br/> G T sticking to his theme – lots of people stay away after brain injury – like they have the thought process ‘its the best way to cope with the injury’ <b>he is hurt by this, and it becomes a familiar story regarding L and his friends – how many people did he know from the paras? – He is cross here when he is saying this</b></p> |

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|    |           | Again Kristina goes back to her theme, they are talking at cross-purposes here a bit, so that each person is talking about their own special interest.  |
| 15 |           | B he is able to see L because he has had experience of this before with his cousins,<br>Barry feels that it is embarrassing for other people who must experience it like talking to the wall when they are with L – it is easier for him though given his previous experiences.<br>B “it is easier for people in a group with him”  |
| 16 |           | <b>how have your relationships changed with Leonard since the accident?</b><br>Kristina-he's become our baby hasn't he – <b>this is the most important statement from K so far</b><br>Gareth-we've made his personality bigger than it was, going up his ability<br><b>This is the fundamental difference between K and G in their attitude towards L.</b><br>Kristina talks about L and his abilities in the present tense<br>She justifies her action a lot, this happens in relation to Gareth on this page but continues all the way through too  |
| 17 |           | <b>Kristina often does the voice of the person that she's imitating and mimics Leonard actions</b><br>T K telling the story of how well L is doing and stimulating L right from day one<br>G then interjects with his main theme which is that they have done all this together rather than the professionals doing it – this is how their stories interact with each other.  |
| 18 | K1<br>K15 | <b>Haven't we done well at this?.....It feels here's a Kristina is looking for acknowledgement about how well she's done, all reminding herself of how well she has done, or is she simply answering the question in the way that she understands it?</b><br>T He has a sense of achievement when he does things like pull himself along in his wheelchair. <b>They push him from behind too to straighten out the wheelchair, my metaphor was of a father pushing a child's bike from behind when learning to cycle.</b>   |
| 19 |           | They make material changes to L's world i.e. removing carpet etc.<br>T G “no one else will think of these things” <b>this is his relentless theme</b><br>We don't ever get anybody to meet him, <b>this is so unfair and hurts G</b><br><br><b>Terrence started to tell the story of Leonard's accident, but Kristina took over and went with it. P 20 Included lots of details such as club class, caps on, champagne, long corridor etc. with no emotional words in her speech. She started to talk about the luggage, I wondered whether this was in order to delay getting to the point or delaying a for suspense.</b> |
| 20 |           | Kristina tells a very detailed story of the parts in time which lead up the accident, and takes ages to actually get there. <b>What is she doing</b>  |

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|    |              | <b>with the details in the story – what are they being used for? It is about staying away from the difficult parts of the story, or does she think that this is what is required of her to give her ‘accurate’ and ‘objective’ account of what has happened?</b>   |
| 21 |              | K This is a very rich description about how it was, with lots of speaking about the storms and blowing trees, pitch black, helicopter pad. All very factual from Kristina, very few words which display an emotional reaction to events and very little actually about L and putting self into his shoes.<br>Footsteps on the corridor, worrying what they might mean<br>Helicopter pad outside as it is a brain injury specialist hospital  |
| 22 |              | K this is the first time that Laura gets a mention.<br><b>T K doesn’t like her which seems very obvious by the way that she talks about her as much as what she is actually saying</b>   |
| 23 |              | Church, thinking about L dying, getting last rights – this might be quite important in the wider context as many people talk about thinking their children will die, only for them to have a brain injury down the line.   |
| 24 |              | T-Terrence saying that his pals were increasingly wary of talking to the family after they had been warned off by the Army.<br>‘I wasn’t emotionally able to do it’ I would have asked for name, number, ‘ then his voice becomes stronger and more forceful – performative – ‘perhaps you would care to tell me exactly what happened at the time?’ first person retelling of a possible alternative scenario.<br><b>Could this feeling of being kept in the dark with the initial stages have infiltrated their latest thinking about authority figures related to the case?</b>   |
| 25 |              | Terrence understated the family feeling towards the army ‘opaque at best’<br>Kristina putting intentions into other peoples minds, saying that the colonel wanted to get back to Britain and get the jump over with.<br><b>This is something that Gareth usually does more than Kristina. This seems like a story which has been established, whether through the actual board of enquiry or a combination of that and the family story its self – but it was given without any friction from the others in the group.</b>   |
| 26 | G5<br><br>16 | T G Fighting on different fronts looking back and wishing you'd done things differently/done more – <b>this is a theme for Gareth, that they are continually fighting and unable to do enough, but that they should be doing more</b><br><b>Kristina then cuts in with her positive spin and says that actually they had done all they could and maintained her positive spin on events.</b><br>Counter Narrative – Here Barry gave the point of view which is different to that of the family, it wasn't picked up on and the story moved on, it wasn't mentioned again.<br><b>It is interesting about how they deal with counter narratives as a</b> |

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|    |   | <b>family and how Barry's words were not quashed, but were definitely not integrated into the family story.</b>  |
| 27 |   | <p>K T It was us against the system<br/>We have literacy, drive and fight, and there are volumes of correspondence to get through, <b>so if people didn't have those qualities, then how would they cope, is the implication in this statement.</b></p> <p>T G there was a big culture shock in the NHS , we had to be with L for 10 hours per day as after coming out of the army place where he had everything that he needed.<br/><b>This is a theme which has never been resolved.</b></p>   |
| 28 |   |  |
| 29 |   | <p>T Headley Court.<br/>Bad care: all the things that led up to it to including evidence for their bad opinion of Headley Court.<br/>Here Kristina has embraced that theme that "nobody cares"</p> <p><b>P 29 onwards personal reflections:</b><br/><i>I'm bored of this story and my mind is wandering. At the actual interview and also in subsequent listenings. Is it something to do with the lethargy of those care homes with really hot central heating and tired staff, or due to the emotionless delivery: fact/fact/fact? This is hard to tell only to reflect on this.</i></p> |
| 30 |   | K and G give a list of how they were affected by Headley court and justifying their positions regarding L's care – that other families were also experiencing it in that way too.  |
| 31 |   | <p>I had to pause her story at this point as my mind was wandering – and bring her back to ask whether it was the brain injury or the physical difficulties which were most important.<br/>Physiotherapy occurs in this story of Headley court as the owner used the physio there to treat her golf buddies, rather than for the use of the patients. This was particularly poignant for the family given their relationship with physio which comes up later.</p>   |
| 32 |   | <p>T Gareth has said at different points in the story that he would have done more and now, that he couldn't have done any more (in a resigned sort of voice).<br/>T G they were being put into impossible positions by the authorities – if you don't like it then bugger off!<br/>This is in relation to headily court – however, it seems to resonate with their relationship with many different authority figures and positions too.</p>  |
| 33 | 8 | <p>generally the Headley Court story and G8<br/><b>in developing their new identity, could the family be learning their role through the rough and tumble of working with public services? In being let down and having to fight for everything, not trusting other people and not relying on anyone.</b><br/>T G being let down by the people who were there to represent you</p>   |
| 34 |   | We escaped, we hijacked him, straight from Colditz   |

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|    |  | Overall this story is one of being let down and of not being served by those people who ought to be looking out for you   |
| 35 |  | <b>What is this story for on page 35??</b>  |
| 36 |  | <b>Classical conditioning</b><br>Impaired associations-"we make a fuss and things happen; look at the proof" therefore not making a fuss means that you get forgotten about by the faceless authorities who don't care anyway.<br><b>As if to say 'look - this is a result of all of our hard work and our fighting, see it pays off'</b><br><b>Performance stuff:</b><br>Gareth does the performative voice of someone threatening to get the channel 4 journalist to come and intervene on his behalf.  |
| 37 |  | Ending –<br>T G L has been a full time job<br>TG have all those people got to go through the same things? - <b>Gareth has a surge of emotion at this point, and I recognised the angry person that I first met at the cares day with Amy.</b>   |
| 38 |  | P 38K 13 for Kristina was it important to tell the story as a factual account of Leonard's life?<br>"Anger" is mentioned for the first time by Gareth, although it has been present all the way through.<br>K comes back in after leaving to make tea, and possibly to avoid some of the emotions that were stirring in her.<br>She goes straight back to her story – this seems important for her, it that the point of the interview for her?<br>Her story in this case is that the carers who were provided by social services were useless and that she was doing all the work. |
| 39 |  | T K I had to do it all, the lazy and lethargic carers would never do anything from their own initiative.<br>I had to make all the suggestions so that L didn't end up like "poor Michael".<br>T We had to discover that they were being illegal in their funding towards L - nobody told us, nobody helped us out   |
| 40 |  | <b>3 year settled period so even though this has been going on for 13 years, things have only been settled for three years.</b><br><b>We had to set this all up, no one else helped up, we had to train the carers, and show them how to do things – now at last we have a decent team around us, however that hasn't always been the case and it is an answer to prayer.</b>   |
| 41 |  | P 41 physiotherapy-a big theme which needs to have a lot made of it.<br>T K described the lack of physiotherapy as the second biggest hurt after being told that L had no hope of improvement.<br>T exacerbation with the NHS "blow the NHS" we'll do it ourselves  |
| 42 |  | Gets good physical and physio care but the price keeps going up   |