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Trajectories of Care & Changing Relationships: The Experiences of Adults with Acquired Brain Injuries and their Families

By

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A Doctoral Thesis

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Abstract

This PhD thesis explores issues around acquired brain injury, focusing particularly on changing relationships between patients and carers and the trajectories they follow from the point of injury or diagnosis as a reconstructed life unfolds. Patients are identified as having strategies of adaptation and carers as taking on levels of agency, both of which shift according to time, context and other complex interactions. Each impacts on the other to produce an internal dynamic, the functionality of which is explored. Issues of care delivery are also raised, including the effects of mismatched expectations and of sharing or restricting information. This research is qualitative and based on the principles of grounded theory. 62 interviews were conducted involving 82 people (52 patients and 30 carers) and additional evidence was gathered from professional records, media reports and personal diaries. Themes were developed that can be linked together to form a trajectory of care, inside of which there is a finely balanced ecology. It is proposed that this trajectory although developed around data from people with brain injury is also applicable to other chronic conditions.

Keywords:

'Trajectory', 'Care', 'Brain Injury', 'Agency', 'Adaptation', 'Grounded Theory', 'Qualitative'

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Chapter 1 - Introduction

1.1 Brain Injury in a Historical Context

Over the past two decades there has been a massive increase in the number of people who have experienced and survived head injury, leading some commentators to describe the increased incidence of such trauma as a 'silent epidemic' (Powell, 1998). This may be primarily attributed to medical advances which increasingly keep people alive following what would have once been fatal incidents. In the late 1970's, 90% of patients with severe head injuries died, whereas nowadays the majority will likely pull through and will in all probability have a near normal life expectancy (Department of Health, 1997). The largest group of 'survivors' are in fact adolescents and young adults who have many years ahead of them, coping with the residual after-effects of head injury. These resulting deficits are as varied as the functions that the brain supports (McKinlay and Pentland, 1987).

Many head injuries are the result of trauma (such as road accidents, falls or assaults), but there are also many acquired brain injuries (ABIs) that are non-traumatic. The causes include infections tumours and haemorrhages. They may produce similar deficits to traumatic injuries, but the treatment patterns and personal experiences are very different. A major traumatic brain injury is a sudden event, where the patient will usually be rushed to hospital for treatment, which in the case of many severe head injuries, is life-saving. A non-traumatic injury may develop over time and diagnosis can be a lengthy, and sometimes inaccurate, process. These differing experiences may affect the way in which people adapt to their injuries and their views of the services available to support them. For example, a person with a brain tumour, who was consistently misdiagnosed, may express mistrust of doctors and therefore discount important later advice. Instead of seeking professional support, they may rely on their family who, by contrast, they believe, have not let them down. Instead of working towards recovery they may therefore accept dependence.

Taking brain injury as one distinct condition, there is a tremendous variability in its effects and the way in which they are researched. The earliest scientific reports took the form of case studies, such as the famous accounts of Phineas Gage, who survived

a penetrating head wound that destroyed a large section of his frontal lobes (Harlow, 1848; Bigelow, 1850; Harlow, 1868). However, most other work of this time was based on post-mortem evidence, correlating damage to deficits (Broca, 1861; Jackson, 1869), but 'hard evidence' required a living patient and so the focus moved towards experimentation on animals, using the systematic stimulation and destruction of different parts of the brain to ascertain areas of functional specialisation and the effects of damage (Flourens, 1824, 1842; Fritsch & Hitzig, 1870). These lesion studies continue (see, for instance, Kendall, David, Rayment, Torres, Annett & Dunnett, 2000), but their value is a controversial issue. The ethics of animal experimentation, particularly in the case of primates, are the source of widespread discomfort both inside academic circles and more broadly in society at large. There are also claims that lesion studies of a specific animal group will only tell us about that species and that generalization from animals to humans is misleading and potentially dangerous (Greek, 2002).

The first non-invasive technique to be used was the monitoring of electrical activity (Caton, 1875), but details of electroencephalograms (EEG) were not published for over fifty years (Berger, 1929). Electroencephalography has many applications, but in the field of brain injury research, its use is very limited. In 1917, x-rays were used to take the first pictures of the living brain; these showed the basic structure but were unable to capture much of the soft tissue that makes up the nervous system (Greenfield, 1996). Around fifty years later, technology had advanced to computerized axial tomography, better known as CAT scans; these produced the first detailed images of the brain, allowing damage to be assessed without the need for surgery.

In the 21st century, we now have the capability to scan the brain in action using positron emission tomography (PET scans) and functional magnetic resonance imaging (fMRI). These scans actually show which areas of the brain are working while the patient is engaged in a particular task. This kind of technology, with its promise of being able to map hypothesised cognitive architecture onto patterns of neural activity, holds a powerful sway over much neurological research, with the result that much research into brain injury remains focused around neuropathology.

Beyond the world of hi-tech scanning procedures there is the low-tech field of psychological testing and medical assessments, which formed the checklist revolution of the mid 20th century. Performance on these tests is frequently correlated to different outcomes, allowing for population estimates and the creation of aggregate recovery patterns. But this is done at the obvious cost of downgrading the specific and idiosyncratic qualities of the individual. Crudely put, but patients are turned into statistics. If patients are treated as instances of a generic category – that is 'put into boxes' - the temptation for the professional is clearly to attend to the category at the expense of the person, or simply put, to read the label, accept it and move on, never looking inside. The danger is that outcomes may be assumed on the basis of what can often be quite superficial predictors. Can we really judge whether a person with a 'moderate' injury will be affected less than a person with a 'severe' injury without taking account of their wider life experiences and expectations?

Although the types of research highlighted so far have their place in a broad understanding of the effects of brain injury, more recently there has been a return to qualitative research with calls for more in depth studies of the problems faced by the ever growing number of 'survivors' (Hubert, 1995). This means, in effect, returning to the depth of analysis present in the early case studies, such as those of Phineus Gage (Harlow, 1848; Bigelow, 1850; Harlow, 1868). These studies utilised multiple streams of information, from the patient, from those that knew the individual prior to their injury, and from the professionals who later participated in their life story. In contrast to checklist and neurological studies, using rich and variegated qualitative data taken from multiple sources provides for more comprehensive and well rounded accounts of individual patterns of recovery (or decline). It is to this call for a more complex account of the lives of individual survivors of ABI that this thesis responds.

1.2 Personal Experiences Across Individual Trajectories of Care

Brain injury is a long-term condition, where patients are often returned home following an acute incident, but have many years of slow recovery ahead of them. For most there will be a ceiling on this recovery, which is below their pre-injury status. Disability may be mild such as a reduction in sensation on one side of the body, or it may be severe, such as loss of the ability to form new memories. Often, however, service providers must make rapid assessments of the needs of patients

without understanding the nature of the process. This is because there are huge demands on the system and limited staff, particularly in specialisms such as neurology. With priorities on deadlines and waiting lists, a 'checklist culture' has been created where people are 'processed' quickly so that responsibility may be handed over and more urgent 'cases' may be dealt with. This is reflected in the fact that despite a growing population, the number of NHS staffed hospital beds (in acute, general and maternity sectors) has fallen from 250,000 in the 1960's to 147,000 in the year 2000 (Department of Health, 2000).

Patients may be subject to a multitude of checklists and brief interviews, the earliest assessment usually being the Glasgow Coma Scale (Teasdale & Jennett, 1974). These are important tools, but do not enable the professional to adequately understand how the specific character of a particular brain injury will impact on the vicissitudes of a given individual's life. Assessments are used to give feedback about the patient's current state, but also as predictive tools. By classifying an injury as mild, moderate or severe, the level of future disability is implied. Assumptions are made in advance of outcomes so that services can be planned and where deemed appropriate, people can be prepared. These predictions however, are made on a snapshot of information, often with little or no understanding of the person behind the injury.

What I hope to do in this thesis is something very different. I intend to provide a genuine, systematic and detailed insight into the process of dealing with and recovering from brain injury, rather than just a snapshot. This lengthy process can be thought of as a 'trajectory', involving shifting social relations, changes in people's sense of personal identity, changes in capabilities & personal boundaries and along the way, input from many different agencies. The idea of a trajectory of illness was developed by Strauss and Glaser (1975) and has been used repeatedly as a basis for research relating to chronic conditions (Strauss, Corbin, Fagerhaugh, Glaser, Maines, Suczek, & Wiener 1984; Corbin & Strauss, 1988; Strauss & Corbin, 1988).

The concept of a trajectory of illness was developed from the earlier concept of a dying trajectory (Strauss & Glaser, 1970). In both presentations of the trajectory concept, Strauss and colleagues focus on not only the physiological unfolding of a disease, but also the organisation of work done around that unfolding. Work – here broadly defined as active efforts directed at the management of the condition – is done

by all involved parties, but may not be recognised at such (that is some forms of work may be rendered 'invisible' – see Star & Strauss, 1999). For patients it can include actions such as cooperation with carers or professionals and self-monitoring of health. Family may be expected to provide practical and emotional support, but may also do informal work such as monitoring medical equipment. Professionals, such as medical staff, do work to aid recovery and maintain safety and comfort. The trajectory is also an expression of the impact on those involved in this work and its organisation, including the effects on their social world and their perceptions of self-identity.

This thesis will demonstrate the value of adapting and applying this concept to the experience of acquired brain injury. It will use the concept of a trajectory as a means of expressing the unique experiences of individuals, as well as highlighting the common phases that involve changes in 'health' status and intervention need. Trajectories will be considered as singular patterns of activities and events, unique for each individual that shift internally according to unfolding circumstances and specific situations. In this way trajectories are not of the patients own making, since they are partly defined by the network of carers and professionals who contribute to the management of the individual's condition. The intention in bringing together these often highly varied elements into a single analytic framework, is to display how highly interconnected all aspects of the patient's life are. For example, it is possible to separate out assessments of the patient's level of physical independence from their ability to return to work. These might be conceived as entirely separate trajectories. But for the patient, the relationship between what they are physically able to do, and expectations of a return to working life (which often involve a significant downward career shift) is highly complex and fraught. Preserving elements such as these as aspects of a singular trajectory allows us to shed light on something of that complexity.

1.3 Re-Establishing Identity – An Inductive Viewpoint

My intention in this work is not to support or refute existing theories of brain injury, but to consider issues important to the everyday lives of survivors and their families. The focus is on the broader personal and social context of injury and recovery rather than the specifics of the biological mechanisms involved in the brain injury itself. In this sense, there are parallels with the work of Ole Dreier and his notion of

'trajectories of participation' within family counselling (Dreier, 1999). Dreier argues that the course of therapy is best conceived as a series of engagements (and disengagements) between the therapist and clients in which the nature of the business at hand may be radically reframed as the therapy sessions unfold. For example, for a parent the therapy may shift from being 'about' managing family conflict to being about restoring a form of individual autonomy. The point Dreier makes is that the very nature of the trajectory shifts according to the various activities and events that it passes through. For example, in ABI the trajectory may initially be about 'getting better', but once a patient has been discharged from hospital and entered into home care, the predominant concern may be with managing dramatically altered family relationships. This may alter again if the patient's health declines (a common experience being that of declining cognitive capacities, particularly around memory), when the primary concern may be one of managing routine activities such as mealtimes and taking medication, along with difficulties of negotiating casual social interaction.

Dreier's work draws on his own established theoretical model of activity and participation. Whilst this provides for a clear account of family counselling, the danger is that simply applying this model in a different context might end up specifying in advance what the issues around ABI are likely to be. To this end, I have chosen to take a broadly inductive approach, drawing on principles of grounded theory. I developed a semi-structured interview framework where people were asked about the injury, its effects and the support they received. The loose structure of the interview gave people a starting point to tell their stories and they would often diverge and expand as they discussed key issues. These issues were then transformed into analytic categories. This process necessarily involves interpretative work on the part of the analyst. Although I have striven to fit these categories as closely as I can to participants concerns, inevitably, I have used my own knowledge (including knowledge gained from my long term participation with Headway) as an analyst to elaborate and rework issues which have emerged from the data. These categories were then subsequently mapped out onto comparable trajectories towards the end of the analysis. In this way although trajectories do not directly emerge from the data itself, every effort has been made to preserve the richness and diversity of participants' accounts, and to avoid unwarranted simplification.

The data for this research consists of 62 in depth interviews, involving 52 patients and 30 "carers". Alongside this, many additional materials were collected, including health & social care assessments, medical letters, newspaper reports and personal records. This additional data stands usefully alongside that provided by the interviews and also allows for claims to be made about how a trajectory is shaped by the participation of a variety of people. Indeed the very definition of the trajectory — what it is 'about' — is often a highly contested matter. The most effective way to explain this is by example of a brief case study. Note that, as with all data in this thesis, participants have been given pseudonyms.

1.4 Case Study

Tom was out cycling in the summer of 1997 when he was involved in a collision with a lorry. He sustained a subdural haematoma, requiring neurosurgery, and he stayed in hospital for 8 months. He is now living with the effects of acquired brain injury, supported by Susan, his wife of 30 years. A brief synopsis of the data collected on his case will be presented. This will provide an initial insight into the research that has been conducted, and the issues that have been raised through analysis of the data. It has been selected as a fairly representative case. There are some issues specific to this couple, but many are applicable to other families dealing with acquired brain injury. Links into sections of the thesis where the broader implications are explored, will be highlighted throughout.

1.4.1 The Media Representation

In 2002, a local newspaper printed Tom & Susan's story. This was a full page spread with a large colour photo. It gave a narrative of Tom's accident, interspersed with quotes from his wife. The article was titled, "Repairing the Damage" and was part of a regular feature called, "Focus on Health". Within it was a message on safety:

Eight months in hospital, a lifesaving operation to remove part of his damaged brain and months of rehabilitation lay ahead. All this might have been prevented if he had worn a cycling helmet on that fateful day.

By focusing on safety, this article was in effect built around a case of 'blaming the victim'. This is a common pattern in the reporting of such cases. Hence one of the problems patients have right from the beginning is negotiating their own personal

accountability for their injury. This can take many forms, including systematic description and re-description of the injury episode, claims about the adequate management of the injury by critical-care staff, or even claims not to recall any details whatsoever of what happened. This will be explored further in Section 4.2.

Returning to the article, packed within this paragraph, leading up to the virtues of cycling helmets, it is stated that Tom had part of his brain removed. The fact that this is included becomes interesting when considered alongside Susan's conduct during and following the research interview. She used mime to intimate that surgery had taken place, and only explained when Tom was out of the room that she did not want him to know that the tissue had been removed during surgery.

WHAT SORT OF THINGS DO YOU THINK THE QUEENS MED COULD HAVE PREPARED YOU FOR THEN?

Susan: Well they've told us, you know, that he had the (mimes brain tissue removal), you know, because it was that or death, but then after that, they didn't give us any more information.

Interview responses from Tom suggest however that he already knows about the neurosurgery. This data will be presented and discussed in section 4.1.2 – Dealing With Sensitive Information. In particular, this raises questions as to how Tom knows and the often fraught way in which information is communicated to patients and carers both at the time of the injury and during the immediate recovery period. It also brings forth the issue of concealment and why carers and professionals may choose to withhold certain information. Why does Susan apparently feel the need to restrict this information, and what is her role, as she sees it, in providing Tom with 'insight' into his own condition?

Returning to the newspaper article, one might ask why someone would put into print, a fact that they wish to remain secret. One possible interpretation is that Susan believed that this article would be beyond Tom's reach – although it would be reasonable to expect that someone will read it to him, either at home or at the Headway day centre he attends. It seems that he was not involved in the newspaper interview as no comments from him are included. This implies that more value is placed on Susan's recollections, even though many of the experiences are, of course, Tom's. His recollections are then being systematically discounted and it is easy to see how Susan would usually be treated as the 'reliable witness', in a professional culture that views the carer as the only person equipped to give an accurate testimony.

Two paragraphs on, the neurosurgery is highlighted again, but this time it is flagged up as a direct quotation from Susan. In it, she uses the phrase, "We were told". This implies that Tom knows about the surgery unless the, "We", is a euphemism or refers to someone else:

Susan: Eventually, to save his life, it was decided to remove the damaged part of the brain. We were told that this would result in some form of disability, but no one could predict how much.

In the context of this newspaper article, it seems that references to Tom's neurosurgery are being used for dramatic effect whereas during the research interview, Susan felt it was something to be concealed. There are two issues here. Firstly, that the emphasis in the accounts offered by people of significant life events may change subtly according to the context in which they are told. Second, that in brain injury, the patient's viewpoint may be overlooked. This notion that account giving is context dependent is a well established social scientific principle (see Garfinkel, 1967; Goffman, 1971b for classic statements). Simply put, context dependency manifests as people behaving differently depending on where they are, whom they are with and what is at stake. This can be as minor as putting on a 'telephone voice' but can extend to an apparently complete change in personality (e.g. a patient may be confident, outgoing and talkative in the company of friends, but shy, subdued and unwilling to ask questions in the presence of their doctor).

Context dependency then results in variability in accounts. As Potter & Wetherell (1987) noted, it is remarkable that this commonsensical notion has not always been attended to by psychologists. In the case of ABI this can lead to a very partial and skewed picture of the patient and their recovery process. In order then to interpret the accounts that people give, we must understand the intrinsic relationship between the account and the setting. We cannot assume that we are accessing a direct and unchangeable truth; instead what we are hearing are representations of situations which are fitted to perceived demands of the current audience, environment and time. These constitute what Goffman (1975) terms the 'frames' in which accounts are delivered.

Returning to the issue of the patient's viewpoint, it is important to be aware of the way a neurological disability can make a person seemingly invisible in certain

contexts. Discussions about patients are often directed towards carers, in both formal and informal situations. Despite this tendency to overlook the patient as a potential contributor, when they are present, conversations may be structured to avoid sensitive topics. Where patients are aware of this, there are obvious esteem implications, but this reduced input also means that we may miss key information. Repeated incidents where the patient is overlooked, reinforce their silence and the opinion of others that they do not understand or have nothing to say. This research will try to address this issue in patient-carer and patient-carer-professional relationships.

1.4.2 The Professional Viewpoint

Following his accident, Tom was assessed by Social Services and a care plan was produced. To give this its context, a care plan is a summary of needs, often matched into existing services available to the client. These needs are split into seven sections: 1) Social/Occupational, 2) Additional Needs, 3) Any Other Specific Tasks to be Undertaken, 4) Personal Care, 5) Health Care, 6) Access, 7) Mobility. The professional responsible for completing the form must write about the client's personal requirements in each section. Within the segment on additional needs, it is written that:

Tom has problems with comprehension of verbal communication. He responds well to instruction or rephrasing of questions into statements. He has been agitated in hospital, but now has insight into, and understanding of his accident and injury. His agitation has now diminished.

There are two points worth making here. The first is that the social worker has said, "He responds well to instruction". We must ask how this evaluation - which was presumably made in a matter of minutes - was arrived at. Using data from the interview, Susan seems to disagree:

Susan: No, he doesn't understand. If I was in here and I told him to go and put his trousers on, he wouldn't know what his trousers were. When he's helping me sons, they tell him to go and fetch something, he doesn't know what they are.

It is interesting how Susan constructs Tom's failure to follow instructions as proof that he does not understand. It is possible that Tom sometimes chooses not to comply or lacks the motivation to do so. In other words, behaviour that would be routinely expected on the part of others - such as not complying with a request because it is offensive, disagreeable, troublesome or that the recipient of the request simply cannot

be bothered to do so at that moment (such are the mundane features of everyday life!)
- is apparently discounted by Susan when dealing with Tom, thereby compounding
her reliance on his injury as a generic explanation for all aspects of his behaviour.

The second point to address, links in with the issue of concealing the past, including the neurosurgery that took place. It is written in the care plan that Tom, "Now has insight into, and understanding of his accident and injury". Susan claims that Tom's insight is based not on concrete memories of the past, but on a cartoon version of events, presented to him by the rehabilitation unit.

Susan: He doesn't remember the accident, the only way he knows the accident is when he was in erm, now then where was it? He was up the YDU, up the General, and they drew him pictures, they drew him pictures of what happened and that's what, that's how he knows he had his accident, he didn't know nothing.

In other words, his own recollection is one that has been systematically shaped by the crude information he was provided in the immediate recovery period. It is therefore inaccurate. The way in which memory is affected by brain injury is complex and fascinating. Many traditional studies focus on neurological aspects of impairment but this thesis will look beyond neurology. Memory will be the focus of Section 4.3 and of particular relevance to this case study, the issue of reconstructed memory will be explored further in Section 4.3.2.

Once Tom was absent, Susan claimed that much of the damage to his brain was not caused directly by the accident, but was a result of the neurosurgery, necessary to save his life. She claims that Tom does not have insight into this, but right at the beginning of the interview, he explained:

Tom: Well I think I had summat knocked out of here (points to head)

YEAH, HOW DID THAT HAPPEN?

Tom: It must be hit on something

YEAH

Tom: You know and er, summat were wrong on there, so they take it out

This suggests that he does have the insight, which Social Services recognise but his wife denies. We must also enquire into the nature of the social practice through which Tom has acquired a simplified version of his injury, and the dilemmas involved in the communication of information to patients in a highly vulnerable state. A crucial issue to be flagged up is the right to know and the way in which the informational burden is placed upon the family. As they become the keepers of knowledge, they have the

power to control what information the patient has access to. This can affect the dynamic of relationships and sets up tensions if the patient feels that important details are being withheld.

Turning now to the section on health care, we find the following statement:

Tom sustained a subdural haematoma following a RTA. He also damaged his pelvis. He is improving greatly and no upper limit on the level of function he may achieve has been stated.

It is the final sentence which is striking as Susan describes the neurosurgery as having limited Tom and it would seem likely that a substantial loss of brain tissue would affect the level of function that is achievable. It is possible that this suggestion of potential recovery is designed to entice or 'enrol' services that will challenge Tom and enable him to learn, rather than services that will simply meet his basic comfort needs. It is worth bearing in mind that the care plan is designed as a generic document, and as such is written for a range of possible readers (including a host of specific care and service providers and assessors).

Following the statements of need, the care plan has a section on the day service to be commissioned. Within this, the purpose of the service is outlined, alongside the views of the 'user' and the 'carer':

THE PURPOSE OF THE DAY SERVICE IS: to stimulate Tom who enjoys working with his hands, in a supported environment.

USER'S VIEWS: Tom enjoys the heavy workshop at LGH and, if introduced to day care sensitively will enjoy this resource.

CARER'S VIEWS: Mrs Brown is requesting the provision of appropriate day care for Tom to give her some relief and enable her to continue to care for her husband.

Looking particularly at the views ascribed to Tom and Susan it seems quite probable that both actually came from Susan as her husband would have struggled to articulate the need to be introduced sensitively to any new service. He may also have had difficulty conceptualising what any new service might be like if it was only explained verbally. We must then ask who it is who is really 'speaking' through the care plan. Is the plan really an 'accurate' record of the patient's needs and wishes, or rather some amalgam put together through negotiation between patient, carer and social services? If it is the latter, to what extent is that negotiation fair? That is, what is left out from the process?

1.4.3 The Patient/Carer Interview

I initially interviewed Tom & Susan together, primarily in order to ensure informed consent as Tom has been diagnosed with (global) aphasia. In formal terms, this meant that it was a possibility that Tom might have been seen as being unable to understand any formal agreement he made, and hence in terms of local ethical clearance would be seen as a 'vulnerable person'.

Through the interview, it became apparent to me that Susan has particular conversational strategies for managing interactions with her husband; for example, she tends to speak on his behalf and to instruct rather than negotiate. Strategies such as this might have evolved on the basis of Susan's experience of Tom's earlier cognitive status and in conjunction with her own particular understanding of his actual deficits. For instance, Susan talks through experiences in slow steps that require closed responses, but sometimes she uses this strategy in what might be seen as an inappropriate way so that it narrows Tom's ability to participate in conversation. We may speculate that her strategy may sometimes increase Tom's difficulties by affecting his confidence in his own understanding, and by breaking the flow of his thoughts, as we see in the following:

DO YOU REMEMBER THE YDU TOM? DO YOU REMEMBER GOING TO

THE YDU UP NEAR THE GENERAL?

Tom: Up the General?

UP NEAR THE GENERAL, YEAH, THE YDU

Tom: You mean Leics down Leicester. Do you mean that one or?

Susan: No, no Tom, you know where you go now?

Tom: Where I go?

Susan: And you walk up sometimes

Tom: Up there

Susan: And you see people

Tom: Yeah

Susan: Yes, you remember being in there don't you?

Tom: Yeah

Susan: You used to go and stop in there

Tom: Yeah, stop in there I do

Susan: Yes, yes

Tom was being asked whether he remembers the Young Disabled Unit, which is situated in Leicester next to the General Hospital. His response suggests that he knows what is being referred to as he spontaneously mentions its location. However, his wife's uptake suggests that she believes that he has not understood ('No, no, you know where you go now?') and uses her step-by-step strategy to elicit answers that

she finds satisfactory. Later in the interview, Susan makes her strategy explicit. She works back through items slowly and attempts to link into what she takes to be tangible knowledge and or memories:

Susan: See when you're in a, in a group like I say, for instance we go to his mum's er and we have a drink on Friday evenings, and we're talking obviously, but Tom can't, we have to sort of slow down and then we have to sort of work back and tell him what, what's been going on and he doesn't always understand then

Susan: But if I can sort of, say if I've seen somebody and I can sort of pick on something that will jog Tom's memory, you know, give him a, then I can sort of tell him who I've seen like, but it's hard probably to explain to you I KNOW WHAT YOU MEAN

Susan: You know what I mean? Give him a clue SOMETHING THAT HE CAN LATCH ONTO

Susan: Latch onto, and he'll go, "Ah yes, I know" and we communicate that way, you know

One effect then of the rhetorical strategy adopted by Susan is that it establishes her as a vital mediator between Tom and others. Tom's social inclusion must then necessary include Susan as a key component. Now whether Susan is deliberately adopting this role, and the extent to which it might be viewed as creating a further dependency is a controversial issue. This relates into Section 5.3: Encouraging (In)Dependence

It is also of note that she flags this up as a strategy that is personal, and perhaps exclusive, "We communicate that way". In this way Susan presents this technique as something that has evolved between them as a part of the recovery process. However, as we have seen, there is evidence to suggest that this technique is not altogether helpful in promoting Tom's recovery. This tension between what carers, for a variety of reasons, take to be the 'best approach', and the way in which patients adapt to these approaches, will be a major issue throughout the thesis.

Staying with this idea of a private world which they both inhabit, Susan makes claims over Tom's past, sometimes assuming that she has more knowledge of his experience than he does. As this next extract demonstrates, she is not always correct in this assumption:

DO YOU REMEMBER, HAVE YOU EVER BEEN TO SEE DIANE (NEUROPSYCHOLOGIST'), BIG WOMAN, OVER AT THE HOSPITAL

Susan: No, I can't remember him going to see, can't remember going to see that lady

no NO

> Susan: No Tom: No

Susan: Went to see Dr Smith (Neurologist)

DR SMITH YEAH

Susan: Yeah, yeah, he was under him. We had to go, when he was discharged from

the hospital, we went every six months

Tom: Were it 'im that told bits and bobs, and shows you how to do it, is she one like

that? (Enacting OT task)

Susan: No

SHE'S NOT LIKE AN OCCUPATIONAL THERAPIST OR, WHAT SHE DOES, IS SHE LOOKS AT PROBLEMS YOU MIGHT HAVE WITH YOUR WORDS AND THINGS AND SHE SORT OF, MIGHT SHOW YOU PICTURES AND ASK

YOU ABOUT PICTURES, THINGS LIKE THAT

Susan: Oh well that would be speech, he did all that

Tom: I think I know one of that, one of them

Susan: Julie (Speech therapist) used to bring pictures as well as...

Tom: Was she quite a big lady with glasses on YES AND DARK HAIR, BROWN HAIR

Tom: Yeah, I think I've seen her somewhere, don't know where, can't remember

YOU MIGHT HAVE SEEN HER AT HEADWAY

Tom: Perhaps

SHE MIGHT HAVE SPOKEN TO YOU AT HEADWAY

Tom: Perhaps she were up, up there, top 'o there SHE DOES COME TO THE YDU AS WELL

Tom: She'd got one up there, took me in a thing and erm, done that

Susan: Oh I see

YEAH, DID SHE GET YOU TO DO SOME LITTLE TESTS?

Tom: Yeah, I think so, you know, say if you want to put bits and bob into it (miming

task), you know

WHAT PUTTING SHAPES TOGETHER AND THINGS?

Tom: Yeah

YEAH

Tom: Think there's some woman up there, think

YEAH

Tom: You know, just once I think it was

YEAH

Tom: And I think she comes back, she come downstairs one day with it

MMM

Tom: Come in there with a, it's a thing down here (Pointing to my bag)

DID SHE COME WITH A BAG

Tom: Yeah, a bag

A BAG OF STUFF TO HEADWAY

Tom: Yeah [...] was on that YEAH, YEAH THAT'S HER

Tom: Ah, perhaps I seen that one that you're on about, I don't know

YEAH

Tom: I know I remember something like that there was. Woman used to tell me how to, you know, put the bits together and, she'd tell you how to do. Can't remember now what, it's going back a long while that is.

We can see the lengthy process through which Tom formulates his ideas and responses. His wife is convinced that he has not seen a Psychologist and at first he automatically agrees with her. However it becomes apparent that he does possibly remember seeing a Psychologist. As he tries to explore this possibility, his wife contradicts and disagrees, constructing her inability to recall as veridical. It is easy to imagine how this situation could arise in different contexts, and how in a range of interactional settings assumptions about Tom, based on his obvious deficits, might be made which result in authority being automatically accorded to his wife. However in this case, Tom is correct.

Returning to the beginning of the extract, we can start to unravel what is going on:

DO YOU REMEMBER, HAVE YOU EVER BEEN TO SEE DIANE, BIG WOMAN, OVER AT THE HOSPITAL

Susan: No, I can't remember him going to see, can't remember going to see that lady

no NO

Susan: No

Tom: No

Tom is asked whether he has been to see a particular Neuropsychologist, his wife however, responds for him. She says, "No", and clarifies that she cannot remember him going, with another, "No", for emphasis. Her response is repeated back to her and she confirms, at which point Tom agrees with the majority (indicated on the tape by the intonation of his, "No"). Susan continues, now steering the direction of conversation, by introducing visits to a neurologist; it appears though, that Tom is still contemplating the initial question:

Susan: Went to see Dr Smith

DR SMITH YEAH

Susan: Yeah, yeah, he was under him. We had to go, when he was discharged from

the hospital, we went every six months

Tom: Were it 'im that told bits and bobs, and shows you how to do it, is she one like

that? (Enacting OT task)

Susan: No

At this point he re-enacts the tasks he completed with an occupational therapist, asking if she is one like that. The neurologist is male, so Tom's reference to 'she', clearly marks that he is not talking about the newly mentioned professional.

As the role of the psychologist is explained, Susan responds again to say that the tasks mentioned were performed by a speech therapist. Meanwhile, Tom continues to pursue the previous conversational thread, seemingly unnoticed by Susan:

SHE'S NOT LIKE AN OCCUPATIONAL THERAPIST OR, WHAT SHE DOES, IS SHE LOOKS AT PROBLEMS YOU MIGHT HAVE WITH YOUR WORDS AND THINGS AND SHE SORT OF, MIGHT SHOW YOU PICTURES AND ASK YOU ABOUT PICTURES, THINGS LIKE THAT

Susan: Oh well that would be speech, he did all that

Tom: I think I know one of that, one of them

Susan: Julie used to bring pictures as well as...

Tom: Was she quite a big lady with glasses on

YES AND DARK HAIR, BROWN HAIR

Tom: Yeah, I think I've seen her somewhere, don't know where, can't remember

As Susan continues to talk about speech therapy, Tom begins to describe the Neuropsychologist, about whom he was initially asked. As his description is

confirmed, Susan pulls back from the conversation, displaying, perhaps, a recognition that Tom may have some unshared memories. Tom appears to be having difficulty progressing further with his recollection until Headway is mentioned:

YOU MIGHT HAVE SEEN HER AT HEADWAY

Tom: Perhaps

SHE MIGHT HAVE SPOKEN TO YOU AT HEADWAY

Tom: Perhaps she were up, up there, top 'o there SHE DOES COME TO THE YDU AS WELL

Tom: She'd got one up there, took me in a thing and erm, done that

Susan: Oh I see

Headway is suggested to him as the Neuropsychologist has close links with this day centre, which Tom attends. He starts referring to her being 'up' somewhere; the offices at Headway are all upstairs and the rehabilitation unit, at which she also has appointments, is uphill from Headway, so Tom could be referring to either of these.

YEAH, DID SHE GET YOU TO DO SOME LITTLE TESTS?

Tom: Yeah, I think so, you know, say if you want to put bits and bob into it (miming

task), you know

WHAT PUTTING SHAPES TOGETHER AND THINGS?

Tom: Yeah YEAH

Tom: Think there's some woman up there, think

YEAH

Tom: You know, just once I think it was

YEAH

It seems that Tom is now referring to a single event, as he states, "Just once I think it was". He continues with an account of this event, describing a large bag which the Neuropsychologist carried:

Tom: And I think she comes back, she come downstairs one day with it MMM

Tom: Come in there with a, it's a thing down here (Pointing to my bag)

DID SHE COME WITH A BAG

Tom: Yeah, a bag

A BAG OF STUFF TO HEADWAY

Tom: Yeah [...] was on that YEAH, YEAH THAT'S HER

Tom appears to remember the Neuropsychologist, but the original question was whether he had been to see her. As his contributions to the conversation develop, his claims continue to be tentative, as if he feels unable to rely on his memory:

Tom: Ah, perhaps I seen that one that you're on about, I don't know

Tom: I know I remember something like that there was. Woman used to tell me how to, you know, put the bits together and, she'd tell you how to do. Can't remember now what, it's going back a long while that is.

Tom finishes his monologue with a culturally accepted explanation for his vagueness, "It's going back a long while". So although assumptions may be made about Tom's cognitive deficits or the need for collaboration with his wife in retelling events, it could simply be that the passage of time has made this memory distant and hazy.

It seems however, that Susan attempts to fit all of Tom's deficit behaviours into issues of memory and understanding. She constructs his communication problem as feeding directly from understanding rather than being a deficit in itself. There are also more subtle deficits such as motivation, which may be relevant. Expanding on an extract which has already been presented:

DO YOU UNDERSTAND WHAT OTHER PEOPLE SAY?

Tom: Yeah THAT...

Tom: Yeah, yeah it's harder, harder to think what I'm doing, coming out YOU THINK IT'S HARDER TO GET IT OUT THAN TO UNDERSTAND?

Tom: Yeah, I can't get it out

Susan: No, he doesn't understand. If I was in here and I told him to go and put his trousers on, he wouldn't know what his trousers were. When he's helping me sons, they tell him to go and fetch something, he doesn't know what they are.

Tom is explaining his perceived difficulties with communication. As far as he is concerned, he understands most of what is said to him, but struggles to give appropriate responses. However his wife steps in to contradict his explanation, saying that he doesn't understand what people say to him. She gives examples of him failing to follow instructions and presents these as understanding issues. Perhaps though he does not wish to follow the instructions or he is simply lacking in motivation — a common brain injury deficit, which the patient identifies in himself in this next excerpt.

Tom: Oooh it's the thing, that it, the thing I used to be the, it sounds like I were with something, you know, somebody said, you know, you're going to do so and so later on, I can remember it in 'ere (points to head)

YEAH

Tom: And I know he'd told me to go and do it, but that thing is, is not now, know what I mean? I don't seem if I can...

Susan: He can't remember like he used to

Tom: ...get with it

Susan: I think that's what he means

Tom: Its sounds funny it does, you know

IT SOUNDS LIKE, WHAT YOU'RE SAYING TO ME IS YOU CAN KIND OF REMEMBER THINGS BUT YOU DON'T ALWAYS ACT ON THEM

Tom: Yeah, something like, something like that

SORT OF, YOU KNOW SOMEONE'S TOLD YOU TO DO SOMETHING, BUT YOU DON'T ALWAYS DO IT

Tom: Yeah, don't understand it, yeah

IS THAT CAUSE YOU DON'T UNDERSTAND WHAT THEY'VE SAID OR...?

Tom: No

Tom claims that he can remember things he is told to do, but that he does not always act on them. His wife flags this discussion up as concerning a memory issue but is seems clear that Tom is talking about difficulties in taking action, which is most likely a motivation issue. In his Social Services care plan, it is stated that Tom, "May require some prompting". Prompting may have the dual effect of reminding Tom of the task in hand and encouraging him to continue, but Susan judges his level of understanding to be fairly low. Her comments to this effect include:

Susan: His brain only, he's probably saying yes to you but he's not getting what you're saying

And:

Susan: He can't hold a conversation

Susan appears to underestimate her husband's degree of comprehension, perhaps not accounting for his recovery over time. I would question the adequacy of both of these statements as global judgements of Tom's abilities, based on the evidence of the interview and my experience of working with Tom over the past four years. In which case we must ask what these statements represent. They may well be a reflection of Susan's understanding of Tom's condition, but they are also part of a wider interactional strategy that Susan appears to adopt in relation to Tom, The implication of this is that in interviews with service providers, she might dismiss her husband's input and seek to mediate the responses given. Tom's trajectory of care is then shaped to a significant degree by the manner in which Susan interprets her husband's needs and abilities as she describes them to others.

1.4.4 The Importance of Context

Through the presentation of this case study, numerous issues have been raised which will be treated at length throughout this thesis. There is the way in which carers deal with sensitive information and issues of concealment. There are concerns of how the balance of power may change in relationships and how the patient's viewpoint may be undervalued and overlooked. There are the strategies which people use to deal with the effects of brain injury and how these may conflict with needs. Perhaps most importantly though, there is the issue of context and how the same person's experiences may be subject to presentation and interpretation in many different ways.

The stories and accounts, which will be told through the course of this thesis, are brought together to highlight common themes such as, "The Use and Loss of Memory" (4.3), "Re-Establishing Roles" (5.2) and, "The Manipulation and Restriction of Information" (6.3). These will be further developed to illustrate how trajectories of care unfold and are shaped by the interaction of the patients with his or her carers and a range of other care and service providers. Clearly an understanding of how these themes are negotiated by patients and their carers is of vital concern if future services are to meet the actual needs of people with acquired brain injuries.

The next chapter will present an overview of the causes and consequences of brain injury, measurements of severity and issues around recovery. This will discuss current theories and point to areas that would benefit from further exploration. Chapter 3 will address methodological concerns, again referring to current research into brain injury and related subjects. Chapters 4 to 6 focus on interview data, addressing in turn, issues raised by patients, by carers and about professionals. Chapter 7 will bring these themes together with a single case study, developed mainly from interview data and personal diaries. Finally, Chapter 8 will explore connections between emerging themes and will make suggestions for future development.

The case study presented in Chapter 7 is of a man who died, due to a brain tumour, during the writing of this thesis. His and his wife's lives since the first symptoms appeared, are documented through five years of personal diaries. This information will be presented alongside interview data and additional personal and official records. Their story will demonstrate how many of the issues raised fit together to form patterns of existence which are not immediately clear in the snapshot assessments of many service providers. This thesis is dedicated to them and to all those who are living with the effects of brain injury.

Chapter 2 - Setting the Scene

2.1 Introduction

This thesis will explore issues that are of direct concern to participants involved in the management and care of brain injury. Rather than attempt to directly validate existing theoretical models, the present research will analyse participant's concerns and will seek to place these at the heart of a subsequent formal model, rather than attempting to validate existing bodies of research. This way of organising research, which is intrinsic to the grounded theory approach, attempts to avoid forcing the data into a pre-existing framework. As we have seen already, second guessing the nature and sequencing of the issues which patients and their carers confront may impair rather than assist our understanding. That said, clearly it is important to set the present research within what is currently known about the causes of brain injury, its effects and the established professional approaches to this condition. This chapter will present a range of accepted concepts and will raise critical questions to be addressed. It will also determine the place of this thesis within the complex framework of current brain injury research.

2.2 Causes of Brain Injury

Acquired brain injury (ABI) is an injury to the brain that has occurred since birth. ABI has many causes, both traumatic (such as a blow to the head) and non-traumatic (such as a tumour). Patients with different types of injury may share common problems such as memory loss, but are also likely to have symptoms specific to the damage incurred. It is likely that they will experience the injury in different ways depending on whether it has a sudden or slow onset, and what treatment path they follow. This section is an outline of the main causes of brain injury and will be referred to as individual patients are discussed later in the thesis.

2.2.1 Traumatic Brain Injury (TBI/Head Injury)

"'Head injury' is the foremost cause of death and disability in young people. In an age of increased motorisation and violence, head injury is a health care problem which is not going to go away."

Head Injury: Rehabilitation Third Report 2000 - 2001 Session Health Select Committee, House of Commons

TBI is a brain injury caused by trauma to the head or by any complications that follow (e.g. intracerebral haematoma). So initially there is some form of impact and this causes the first injury, but a chain of events is then set in place and further injury may occur depending on the medical intervention that follows. The initial damage may be exacerbated by a lack of oxygen, rising pressure or swelling in the brain (Medical Disability Society, 1988)

There are three types of initial head injury, closed, open and crush. Closed injuries (also known as blunt trauma) are the most common (Richardson, 2000). They are called 'closed' as there is no open wound and they are typically the result of rapid movement of the brain within the skull. In a road accident the head may be thrown back and forth and the brain follows this pattern of movement, rapidly accelerating and decelerating against the bony ridges of the skull, causing multiple contusions. This rapid movement can also cause diffuse axonal injury as the nerve fibres get stretched, twisted and even torn. This can result in loss of consciousness and is an important determinant of the quality of recovery (Ponsford, Sloan & Snow, 1995).

Open (also known as penetrating) wounds are not so common. In this sort of injury, the skull is damaged and the brain exposed. This can occur if the head impacts with a sharp object, or if a person is attacked with a weapon (i.e. causing a bullet-wound or a stab-wound). This type of damage is often confined to one area of the brain, in which case predicted outcomes may be quite good.

The final and often forgotten type of closed injury is crush damage, where the head is caught between two hard objects e.g. trapped under a vehicle. It is the least common traumatic injury and it does not always cause a loss of consciousness. Damage is most likely to occur at the base of the skull and the brain stem rather than to the brain itself.

The initial injury however, may not be the end to brain damage. There are often secondary or even tertiary injuries. Secondary injuries can happen when the brain is starved of oxygen (hypoxia), which makes damage from the first injury worse. This can happen when the airway is obstructed, most commonly if the patient starts to choke on blood or vomit after an accident. Further damage can also be caused if other injuries are present, (which is often the case in traumatic injuries), as serious blood loss can affect blood flow to the brain, again causing hypoxia.

Tertiary injuries can occur at any time after the initial and secondary injuries; it may be days or even weeks afterwards. They can result from bleeding, bruising or swelling in the brain or because blood clots have developed. To reduce the risks, patients should be kept under close observation and may be put on a ventilator to ensure an adequate supply of oxygen. If carers are not prepared for the possibility of tertiary injuries then it can be very traumatic to see the patient's condition go downhill when they are expecting ongoing improvement. It is often assumed that living through the initial incident is the greatest hurdle overcome. When complications such as blood clots arise, this may be the first indication that carers have of the unsettled trajectory ahead.

It should be noted that people who suffer traumatic brain injuries do not form a representative sample of the general population. For example, traumatic injuries are twice as common in men as in women (Currie, 2000); they are also more common in people who indulge in risk taking behaviour (Ponsford, Sloan & Snow, 1995). It should also not be forgotten that in the case of traumatic injury there may be issues of blame and culpability.

2.2.1.1 Road Traffic Accident (RTA)

Mitchell (1997) describes with irony, how the first of this country's 430,000 road accident fatalities occurred in the year that the first motorized vehicle appeared on British streets. It was 1896 and the car was travelling at only 4 miles per hour. Today, road accidents are the most common cause of traumatic brain injury and they account for approximately half of all fatal head injuries (Wilson, 1997). Many survive their head injuries but are left with permanent damage to the brain. A large proportion of these survivors are young people with a near normal life expectancy,

however many of them will never work again and some will remain permanently dependent upon others for daily care. Those who do make an apparently good recovery may still have residual cognitive impairment or emotional disturbance (Ponsford, Sloan & Snow, 1995; Wilson, 1997)

2.2.1.2 Accident (Non RTA)

Traumatic brain injuries are also caused by falls, domestic accidents (most common in elderly people) and industrial injuries (more likely to involve younger men), (Currie, 2000). Many also occur through sport, in particular the combination of assault and sport, commonly known as boxing. The principal aim of this activity is to render an opponent unconscious. This is done through repeated blows to the head causing the brain to accelerate against the bony ridges of the skull, damaging cerebral tissue throughout. Boxers suffer cumulative head injuries as most are knocked out many times through their career. This leads to 'punch-drunk' syndrome, which is characterised by dysarthria, slowness of movement, tremor, unsteadiness and intellectual impairment (Hopkins, 1993). Other high-risk sports include rugby, skiing, rock climbing and horse racing.

2.2.1.3 Assault

Assault related acquired brain injury appears to be on the increase as the head is more frequently targeted when people are attacked (Kraus, Black, Hessol, Ley, Rokaw, Sullivan, Bowers Knowlton & Marshall, 1984; Richardson, 2000). Ten percent of patients interviewed for this thesis were assaulted; one of these sustained an open head injury as a screwdriver was forced into his skull. This type of injury produces more focal damage and the resulting deficits may therefore be more predictable than those caused by the diffuse damage associated with closed (non-penetrating) head injuries. In the USA open head injuries are far more prevalent, with gun shot wounds accounting for 13% of traumatic brain injuries and another 8% being caused by general assault (Novack, 1999).

With assault cases, it is particularly important to think beyond neurology as there are potentially huge emotional implications. To be attacked can affect the way a person feels about his- or herself. They may ask questions like, "Why did it happen to me?"

and, "Why couldn't I stop it happening?" There may be attempts to seek justice with lengthy court cases and compensation claims making it very difficult to move on.

Assault can leave people feeling particularly vulnerable and this may be part of a permanent change in self-image. Differences in the way people who have been assaulted talk about and deal with their injury will be discussed in this thesis.

2.2.2 Non-Traumatic Injuries

Many studies of brain injury focus only on traumatic incidents (Ponsford, Sloane & Snow, 1995; Richardson, 2000), but there are also many forms of non-traumatic injury, with causes including infections, tumours and haemorrhages. People with these injuries may share many of the same symptoms as those who have had a blow to the head, but there are subtle differences in the trajectories they follow. There may not be an immediate crisis situation, but instead a slow build up of symptoms that require diagnosis. There are potential issues around this process of diagnosis (which may not always be immediately accurate), and also the different ways in which people deal with the consequences when they have time to plan and prepare.

2.2.2.1 Metabolic

A small proportion of brain injuries are caused by anoxia/hypoxia, a lack of oxygen to the brain. If the body lacks oxygen for just a few minutes, the cerebral cortex will suffer irreversible damage, as the brain is unable to metabolise anaerobically (Holmes, 1993). Typically this is the result of cardiac arrest but it can also occur following drowning, hanging or suffocation, any of which may be suicidal. It is reasonable to surmise that there are complex emotional issues to be faced by any person who attempts to end their life but survives with permanent brain damage. Brain metabolism can also be compromised by hypoglycaemia (lack of glucose); this can be caused by insulin overdose. More often, metabolic damage is secondary to an initial traumatic injury.

2.2.2.2 Toxic

Alcohol is a major factor in brain injury as many accidents are the result of intoxication (Currie, 2000; Hopkins, 1993; Reilly, Kelley & Faillace, 1986). Brain

injury can also be caused directly by the toxic effects of alcohol misuse. Perhaps the most well known expression of cerebral alcohol damage is Korsakoff's syndrome, a profound amnesic state with characteristic confabulation (Sacks, 1985). People with this syndrome can lose access to years of past memories forgetting all that is recent including homes, families and careers. It is a condition for which services may argue about liability of care, as unlike most brain injuries, it is often degenerative.

Damage to the brain can also be caused by a variety of toxic substances such as solvents, mercury, lead and other heavy metals (Hopkins, 1993). Those at risk include miners, dentists, gilders and various manufacturers, all of whom have reported occupational exposure to mercury Hua, Huang & Yang (1995). The neurotoxic effects of chronic exposure to mercury include neuropathological changes to the frontal and occipital cortices.

2.2.2.3 Infection

The most common infections to cause brain injury are encephalitis and meningitis. Encephalitis is basically an inflammation of the brain and is usually caused by viral infections such as Herpes Simplex and HIV. Bacterial infections can cause meningitis, an inflammation of the tissue surrounding the brain (the meninges), which can lead to abscess formation. Less commonly, fungal/other infections can affect the brain tissue; these are usually only present in immunosuppressed people (those with HIV or on immunosuppressant medication). The degree of brain damage caused is directly related to how long the patient has an untreated infection. If there are delays in diagnosis and treatment, then patients and carers may well respond by losing confidence or developing animosity toward medical professionals that affect future interactions and support.

2.2.2.4 Tumours

Brain injury can also be the result of tumours or their removal. Brain tumours arise from the substance of the brain (gliomas), the membranes lining the brain (meningiomas) or nerves coming from the brain (neuromas). Like any tumour they can be either benign (non-cancerous) or malignant (cancerous). They occur mainly in childhood or old age and are fortunately quite rare. The location of a brain tumour is

often indicated by the range of symptoms demonstrated; gliomas however may spread widely throughout the brain tissue (PatientWise, 1997). Tumours can develop over many years and as with infections, there are often issues of delayed diagnosis and reactions to this. Tumours can also re-grow after treatment, so the patient's recovery may be difficult to predict and a long-term plateau may never be reached.

2.2.2.5 Haemorrhage, Subdural Haematoma & Aneurysm

Haemorrhages, haematomas and aneurysms are a collective group of blood related incidents. They involve veins or arteries stretching and leaking often causing quite diffuse damage. Each class of incident will be considered in turn although they are interrelated and a person may suffer any combination of these events.

Sub-arachnoid haemorrhage tends to occur in much younger people than other types of haemorrhage and it is less easy to predict, as it is not associated with high blood pressure (Smith, 1991). It occurs when blood vessels in the arachnoid (a membrane surrounding the brain) leak or burst and the escaping blood puts pressure on the brain. This damages the delicate cerebral tissues and causes the individual to have a stroke. As with all head injuries, the after-effects depend upon which areas of the brain are damaged and to what extent (British Brain and Spine Foundation, 1998). A person who has suffered one haemorrhage is also at risk of further incidents, making a return to 'normal' life more difficult even if recovery appears to be complete.

A subdural haematoma is best described as a small clot that forms between the brain and the dura following a venous haemorrhage. This is often undetectable at first, but can grow significantly over time when signs and symptoms will become apparent, such as headache, hemiparesis and deteriorating consciousness (Currie, 2000). Chronic subdural haematoma is most often seen in older people (Gronwall, Wrightson & Waddell, 1998), but it can also develop following trauma and is often identified as the cause of symptoms collectively referred to as shaken-baby syndrome (Parker, 2001). Subacute subdural haematoma tends to be seen more in younger people who have had a 'mild' head injury and it is indicated by nausea, vomiting and drowsiness (Currie, 2000). In this case it would be classed as a tertiary injury.

An aneurysm is caused by the weakening and dilation of an arterial wall. This may then press on other structures such as the cranial nerves, producing signs and symptoms such as pain or disorientation (Snell, 1980). The risk is that the aneurysm will burst causing a possibly fatal haemorrhage, and many people die due to the difficulty of making an early diagnosis. When an aneurysm is identified, it is important to treat it as soon as possible, but surgery to 'clip' the aneurysm is invasive and therefore a further cause of brain injury. For the patient and their family this requires an orientation to the possibility that they may be relatively well when they enter the hospital, but that the lifesaving surgery they need may leave them permanently impaired.

2.2.3 Causes in Context

Figure 1 shows the primary cause of injury for all of the patients interviewed. On the left, there are non-traumatic injuries (accounting for 46% of those interviewed) and on the right, there are traumatic injuries (the remaining 54%). The only cause not represented by any of the patients is metabolic, although many will have had problems of this nature that were secondary to the initial injury.

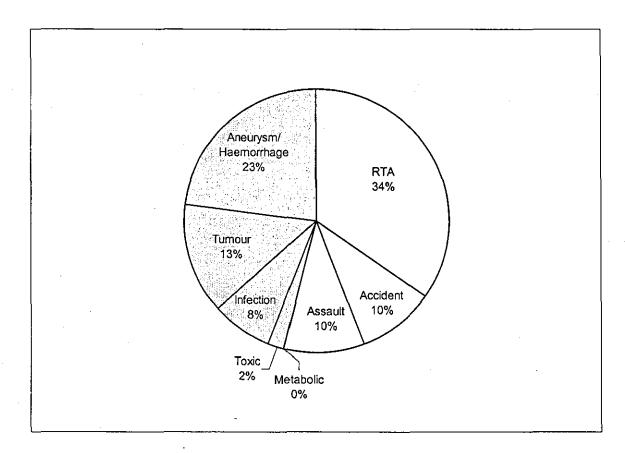


Figure 1. Main Cause of Acquired Brain Injury in People Interviewed

It will be argued through this research that although the symptoms of these two types of injury may be almost identical, the personal trajectories are different. A non-traumatic injury requires diagnosis and there may be many months or years of waiting to find out what is wrong. If it involves a lengthy decline, then many changes may be imperceptible and the patient has time to adjust and find strategies to compensate. A traumatic injury is immediate in its effect and will be treated quickly, so the experiences of early intervention are often represented in positive terms. The decline in function is clear and often shocking as a person may find that after an accident, they suddenly lose the ability to communicate their thoughts effectively, or to remember their past and the people around them. Section 2.4 will explore some of these effects, but first it is important to return to the injury itself; the next section will consider traditional methods of measuring severity.

2.3 Measurements of Severity

When a person first receives medical treatment and brain injury is suspected, various tests will be performed so that severity can be determined. The most commonly used is the Glasgow Coma Scale (GCS), with tests for post-traumatic amnesia (PTA) being introduced if and when the patient is conscious and responsive.

2.3.1 The Glasgow Coma Scale (GCS)

The most commonly used and widely recognized measure of severity is the Glasgow Coma Scale (GCS) designed by Teasdale & Jennett (1974) as shown in Figure 2. Patients are given a score of between 3 and 15, based on their ability to open their eyes, move and speak. An initial score of between 3 and 5 indicates a very severe injury from which full recovery is unlikely. GCS scores are monitored regularly and when they reach 14, the patient is considered to be out of the coma.

Glasgow coma scale ratings have been shown to be related to recovery after brain injury (Jennett, Teasdale, Braakman, Minderhoud, & Knill-Jones, 1976). Very severe brain injury carries a high risk of death. According to Jennett et al. (1976), those who survive this level of brain injury are expected to have permanent and significant disabilities. Most patients whose brain injuries are rated as severe are expected to

survive, but there is a high probability that they too will have permanent and significant problems. People with moderate brain injuries should make a more complete recovery but this may take a long time and certain residual deficits may continue. Finally, those with a minor brain injury are predicted to make a full and rapid recovery, however a small number will have significant and prolonged problems.

		٦
Eye Opening (E)		
Spontaneous	4	1
To Speech	3	[
To Pain	2	
Nil	1	
Best Motor Response (M)		
Obeys	6	
Localizes	5	
Withdraws	4	GCS score = $E + M + V$
Abnormal Flexion	3	GCB Scole E : Wi - V
Extensor Response	2	
Nil	1	3-5 = Very Severe
		6-8 = Severe
Verbal Response (V)		9-12 = Moderate
Oriented	5	13-15 = Minor
Confused Conversation	4	15-15 - WIRIOI
Inappropriate Words	3	
Incomprehensible Sounds	2	
Nil	1	

Figure 2. The Glasgow Coma Scale (Teasdale & Jennett, 1974)

Although the Glasgow Coma Scale can be used as a predictor of outcome, it does have limitations and based on the GCS score alone, clinicians may give inaccurate prognoses. In particular, they may miss small lesions, which if they continue to grow may cause rapid deterioration. On these grounds, Stein, Spettell, Young, & Ross (1993) suggest that all patients who have suffered a loss of consciousness or amnesia following head injury, should also have an urgent cranial CT scan. The key point being that tools such as the GCS should not be used in isolation.

The Head Injury Severity Scale (HISS) was developed by Stein & Spettell (1995) as an alternative practical classification system for closed-head injury. The HISS categories are minimal, mild, moderate, severe and critical. These categories are based on the GCS intervals combined with a complication dimension e.g. seizures, anticoagulation therapy/haemophilia, non-neurological injuries, age <2 or >65. This

scale provides a more in depth survey than the GCS but takes longer to complete and is therefore not so widely used.

These scales are ordinal as they place people in order of the severity of their injury but the individual numbers are not mathematically derived. It cannot be legitimately stated that a person with a GCS score of 10 is twice as recovered as a person with a GCS score of 5, or half as likely to have long-term disabilities. There is no sense of what the differences are between each point on the scale and there is a danger that when we focus on numbers, we may lose the association they have with actual people and events. We may use statistical manipulation to relate points on a scale to future outcomes, also measured in some superficial way, but our results rely on the faith we have in the relationship between these numbers and their underlying source (Howell, 1995). The value of these scales is that they are easily applied, they allow us to generalise and they give straightforward indicators of progress. They should not however be used as a substitute for the knowledge that can be gained through building a relationship with the patient and their family.

2.3.2 Post-Traumatic Amnesia (PTA)

Post-traumatic amnesia (PTA) describes the period of disorientation and disturbed memory function that is apparent after brain trauma. The duration of PTA is often used to indicate the severity of brain injury and to predict patient outcomes (Forrester, Encel & Geffen, 1994).

Symonds & Russell (1943) state that the end of PTA can be determined when the patient can give a clear and consecutive account of what is happening around them. Clinicians often attempt to measure this rather than relying on variable patient reports, especially as research suggests that patients will overestimate the duration of PTA (Ponsford, 1995).

PTA	Severity	Expected Outcome
Up to 1 hr	Minor	Full recovery although a small number of patients
	· <u> </u>	have prolonged and significant problems
1hr – 1 day	Moderate	Full recovery, but there may be problems (e.g.
		memorising and memory loss, irritability,
		emotional lability) for some months.
2-7 days	Severe	Eventually most patients will make a full recovery,
		although this could take many weeks or months.
1-2 weeks	Very Severe	The chances of full recovery diminish with this
		severity of PTA. Recovery is likely to be slow
		(over many months), and often incomplete.
2-4 weeks	Extremely Severe	Greatly diminishing chances of full recovery.
> 4 weeks	Extremely Severe	Chances of complete recovery are extremely small.
		Most patients will have permanent and significant
		disabilities.

Figure 3. Expected Outcomes in Relation to Length of Post-Traumatic Amnesia. Taken from NHS Health Advisory Service, (1997). *Mental health services: Heading for better care*. London: HMSO p.145.

A popular standardized measure is the Galveston Orientation and Amnesia Test (GOAT), which can be administered repeatedly to determine the emergence from PTA (Levin, O'Donnel & Grossman, 1979). In this, patients are asked 16 questions including their name, the date, and their memories immediately before and after the injury. There is also an adapted version for children and adolescents (Ewing-Cobbs, Levin & Fletcher, 1991), known as the Children's Orientation and Amnesia Test (COAT). This test uses reference points familiar to children, such as school and television. Both the GOAT and the COAT are designed to assess general orientation, temporal orientation and memory. The results are used as predictors of long-term outcome (Iverson, Iverson & Barton, 1994) but of course a simple test cannot provide an accurate picture of how a brain injury will impact on a person's life or how their future trajectory will be shaped and experienced.

The key measures of severity look to identify the extent of neurological damage but to the patient and their family, severity is about more than the injury. It might be a measure of the extent to which identity has to be reconsidered, or perhaps it is affected by the patient's ability and willingness to adapt. As an example, the extent to which a person represents their injury as severe is likely to be conditioned by their understanding of their dependence on others. Persons who feel that their own personal independence has been severely compromised are likely to directly frame this in terms of their injury. Thus a person with an injury that is classified as mild may feel more

'disabled' than a person whose injury is rated as severe. A guiding principle for this thesis will be that neurological measures such as these provide, at best, uncertain evidence as to the likely pattern of recovery, since they give no insight into how the patient themselves negotiates their condition with carers and with service providers.

2.4 Effects of Brain Injury

Acquired brain injury can have a range of far reaching consequences. This section will explore some of the most commonly perceived effects, falling into the brackets of physical, cognitive, communication, social/emotional and psychiatric. Each deficit will then be explored more broadly to consider the often overlooked effects on everyday life.

2.4.1 Physical

The NHS Health Advisory Service (1997) describes limb weakness or paralysis and impaired balance and coordination as being among the main physical disabilities following head injury. Fine motor skills are also often affected and Freeman (1998) explains that without the use of the hand, the arm also loses a lot of its usefulness; this can be a cause of great frustration. However a fairly large area of the brain controls the hands and Freeman suggests that this provides them with a great capacity to have their function restored. Long term physical disability can have emotional and lifestyle implications, for instance if a person needs a wheelchair for mobility, they may find that access problems make following previously established patterns more difficult. There may also be interactional difficulties, such as the unwillingness of some interlocutors to directly engage with a person who is visibly disabled, thereby avoiding direct conversation and choosing to address others in their company with questions such as, "How is she?" To be overlooked can be extremely damaging to self-esteem and as such can hinder emotional recovery.

Five percent of people with brain injuries develop post-traumatic epilepsy and will have one or more seizures (Rosen & Gerring, 1986). These post-traumatic seizures can be classified based on the time of occurrence, if they happen within a week of injury then they are classed as early seizures, after that they are known as late seizures. Early seizures are the most common (frequently within the first 24 hours)

and often do not develop into recurrent epilepsy. Seizures are an important sign of brain contusion and intracranial haematomas; as such they can aid the diagnosis of neurological damage (Dalmady-Israel & Zasler, 1993).

Looking beyond neurology though, epilepsy can have many social implications (Wilde & Haslam, 1996). Suffering from fits can lead to a sense of being 'marked' socially; notably if there is the possibility of convulsions occurring unpredictably in public settings, then social contact may be restricted to a trusted few. There may be a heightened anxiety of being alone, especially outside, in case a seizure might occur. Lifestyle may be further diminished by the inability to regain a driving licence within two years of having a fit. Some patients may resent taking anti-convulsant medication as this itself brings restrictions such as warnings not to drink alcohol. If their epilepsy is under control then patients may have to judge the risks of discontinuing medication, against the possibility of further seizures. When these are severe (grand mal), patients are at risk of falling and hitting their head, which can of course damage the already injured brain.

Brain injury can also cause sensory impairment affecting vision, smell, touch, taste, hearing and vestibular function (e.g. balance). The visual system is particularly vulnerable as it can be affected by damage in a number of different areas across the brain (Schlageter, Gray, Hall, Shaw & Sammet, 1993). The most common deficits include reduced visual acuity, impaired depth perception, oculomotor dysfunction, convergence insufficiency and accommodative dysfunction. Visual deficits have many practical implications, for example as with epilepsy; they may make it impossible to regain a driving licence. This can affect independence and employment prospects as although alternative transport is available, it often lacks the convenience of driving, and for some jobs, driving is considered essential. Visual damage can also leave a person more vulnerable to further injury, particularly during the early period of adjustment. Finally, there can be issues of visibility and misunderstanding as many visual deficits are quite complex in nature e.g. a person may be registered as partially sighted who can actually see, if their brain is unable to interpret the visual information, leaving them unable to tell what they are looking at (agnosia). Such a person can walk around obstacles and play sports that rely on visual feedback, but may struggle in any new environment without someone to provide navigational support and to explain what objects lay around them. These disabilities are complex

and are often difficult to communicate to others. Such a disability is difficult to comprehend and misunderstanding can breed animosity. The person whose disability does not meet with classic definitions and cultural representations may feel that they are obliged to continuously 'educate' others as to their condition simply to prove that are worthy of support.

So the research tells us that many people will have physical problems after brain injury and that this is often the focus of treatment. What is not so clear are the effects of physical problems on identity and everyday life, especially when combined with the other complications of ABI. To illustrate, a brain injured wheelchair user may also have communication problems and therefore struggle to ask for appropriate assistance. If the same person had epilepsy, they may forget their medication due to a memory deficit. If they also had balance problems, then they may be unable to regain independent mobility, even after any physical recovery. This complex network of deficits will be addressed in Chapter 4.

2.4.2 Cognitive

Walsh (1991) reports that memory disorders are amongst the most consistent findings following head trauma. Memory can be lost of events prior to the injury (retrograde amnesia) or subsequent to the injury (anteriograde amnesia). Patients may have problems with their immediate short term/working memory e.g. remembering phone numbers, shopping lists etc. They may also have difficulties in remembering future events (prospective memory) such as taking medication and attending appointments. This is often referred to as everyday memory; it is a fundamental aspect of cognition, necessary for day-to-day functioning. As such, damage to this system can have devastating effects (Kinsella, Murtagh, Landry, Homfray, Hammond, O'Beirne, Dwyer, Lamont & Ponsford, 1996). Many patients will also experience a loss of drive or initiative, making self-starting and self-directing behaviour difficult to exercise (Miller, 1984; Vogenthaler, 1987b).

Neurologically produced cognitive problems such as memory loss and decreased motivation are often treated as interesting windows on the functions of the brain.

Great efforts have been made towards 'mapping the mind' in this way (Carter, 1998), with the promise of ultimately understanding the way in which things go wrong

(Miller, 1972) and on how we can measure this (Cohen, Swerdick & Phillips, 1996). What is often forgotten is the 'real world' effect that such deficits create in everyday life. It is, for example, difficult for many people to believe that a person can forget what has been said or done in less than five minutes. This disbelief can affect a relationship as much if not more than the memory problem itself. With initiative and motivation problems, imagine trying to live an autonomous and independent life if you even lack the self-starting behaviour or 'will' to eat when you are hungry. It is important to think of deficits not as isolated, but as belonging to people who must cope with them (and possibly a range of other problems) in real situations. This is an issue that this thesis will aim to address; for example, one of the patients interviewed has visual agnosia (caused by neurological damage behind the central sulcus) i.e. she has forgotton how to see and therefore cannot recognise objects around her (Gregory, 1998; Sacks, 1985). She also has memory problems, motivational difficulties and a tendency towards depression. She wears dark glasses and carries a white stick and these symbols help to make her disability more visible, but she finds herself repeatedly challenged by people who see her responding to the visual environment. She is accused of faking her disability to avoid employment and other responsibilities, and these accusations even come from within her own family. As a result she lives alone in a hostel and has little contact with her father or her brother. Her brain injury has caused physical and emotional damage, but the impact on her life is just as great. Her losses include her independence, her family relationships and many friendships. The reality of her disability extends far beyond neurology and therefore beyond the demographic, quantitative data collected in many studies into the effects of brain injury. These wider social issues will be at the core of this thesis.

2.4.3 Communication

Many people with brain injuries are given a tracheotomy, where a tube is surgically inserted in the neck to bypass constricted areas higher up in the throat. This procedure is used to assist breathing, but it can however cause damage to the vocal cords. Such treatment is often necessary though in order to avoid secondary brain damage (through hypoxia). Vocal cord damage is just one example of how brain injury can affect communication. Some of the other common disorders are presented in Figure 4:

Terminology	Description	
Dysarthria	Slurred speech (muscle weakness)	
Dysphasia	Receptive and/or expressive language loss	
-	(language centre brain damage)	
Dyspraxia	Difficulty making voluntary purposeful movements	
	for articulation (coordination)	
Dysphagia	Swallowing problems	
Dysphonia	Voice disorder (muscle weakness)	

Figure 4. Communication Disorders Following Brain Injury

There are also a wide range of associated speech behaviours and anomalies such as echolalia (mimicking) neologism (making up new words) and confabulation (reporting fictitious experiences) (Linscott, Knight & Godfrey, 1996). Such behaviours conflict with social expectations and can be interpreted by others as either a wilful attempt to exasperate them or as symptoms of an underlying mental health problem.

However adults who have sustained a severe head injury typically exhibit a more generalized language deficit that is associated with global cognitive impairment (Ehrlich & Barry, 1989). This type of communication problem can affect many other aspects of a person's life as the ability to hold conversations is key to maintaining social contact, at work, in leisure and in the case of patients, in treatment/therapy. Santos, Farrajota, Castro-Caldas, & De Sousa, (1999) found that carers can misjudge the communication problems of people with aphasia (also known as dysphasia). They may only recognise language production deficits, not realising that oral comprehension may also be affected. This may affect their relationship if the carer believes that their words are being ignored rather than misunderstood.

Perceptions of people with communication difficulties obviously go beyond immediate family. An example would be when a person has dysarthria and therefore slurs all their words; this can be mistaken for intoxication and means that the patient may receive quite negative reactions in public settings. A person with dyspraxia may take longer to express what they want, frustrating others who do not understand this difficulty. A person with dysphonia may struggle to be understood and so choose to remain silent rather than draw attention to the deficit. As social beings, communication problems are much more than a physiological loss of function. By

losing the tools of conversation, people may also lose confidence and ultimately access to a wider social world.

2.4.4 Social/Emotional

Head injury is in many cases a hidden disability as the effects may not be immediately obvious and those who are unaware of a head injured person's circumstances may misinterpret their behaviour. Deb, Lyons & Koutzoukis (1999) explain that despite the emphasis placed on physical disability following a head injury, it is actually the underlying cognitive and neurobehavioural problems which leave many people unable to return to work and maintain social activities. Wright & Telford (1996) showed that even after a predominantly minor head injury, psychological changes can still be identified 3 years later. Key features of these changes include the impairment of social functioning and interpersonal relationships.

Brain dysfunction can not only influence the affected individuals present relationships, but it can also impair the development of new ones (Lees, 1988). Friendships and contacts outside the family are often lost, and this may coincide with the absence of leisure activities (which enabled these contacts). As a result, individuals often experience a sense of isolation and loss. Spence, Godfrey, Knight & Bishara (1993) investigated social skills following closed head injury (trauma without skull penetration). They found quite marked impairments especially in relation to the initial stages of social interaction. This was suggested to be a cause of failure in establishing and maintaining friendships following brain injury. Spence et al. (1993) also noted that closed head injury patients lose confidence in their ability to relate to others socially.

As time goes on, it is the cognitive and personality changes associated with head injury that have more impact than any physical disabilities (Armstrong, 1991). Many head-injured people stay at home doing nothing once rehabilitation has ended and they can often find the resulting social isolation and lack of productive work distressing. Burton and Volpe (1993) emphasize the long lasting social and emotional impact of head injury; they suggest that these areas should be monitored for a considerable time after patients are discharged.

Long-term psychosocial difficulties are linked particularly to those who are unemployed, have few leisure activities and lack social contact outside of their immediate family (Crisp, 1992). Those who adjust better, tend to be the people who seek social support. Kosciulek, McCubbin & McCubbin (1993) found that social support is not only beneficial to the individual, but it is of vital importance for successful family adaptation to head injury. As Kosciulek (1996) points out, head injury does not just affect the individual, but their entire family system, changing roles within established relationships.

The National Stroke Association (1995) describes socializing and making new friends as a vital part of the recovery process. They highlight the value of spending time with people who have only known the recovering person after their stroke, as there are no preconceptions or expectations involved. It is also noted that spending time with others who are going through the same difficulties can be a very supportive and reassuring experience.

Much of the research on social relationships focuses on the individual, but it is an issue that affects the people involved in providing care and support. The work of Kosciulek, McCubbin & McCubbin (1993) is quite rare in that it considers how the social network of the patient has a wider resonance. It is important to remember the impact of a decreasing social circle on family relations as the situation can develop where the only people the patient and 'carers' see are each other. This may create tensions and could also affect the patient's ability to live independently.

2.4.5 Psychiatric

People with acquired brain injuries (and their carers) are at greater risk of developing mental health problems and disorders than the general population (NHS Health Advisory Service, 1997). Van Reekum, Bolago, Finlayson, Garner & Links (1996) identify traumatic brain injury as a risk factor for a range of psychiatric symptomatology including major depression, bipolar affective disorder, generalized anxiety disorder, borderline and avoidant personality disorders. Co-morbidity is also prevalent.

Douglas & Spellacy (2000) researched depression amongst 35 adults with severe traumatic brain injury and their primary carers. They found that 57% of their patient sample and 60% of their carers showed significant symptoms of depression 3.5-10 years post-injury. It should however be noted that it is difficult to establish a temporal sequence through retrospective assessment (Van Reekum et al., 1996). Some people with brain injuries may have had undiagnosed psychiatric disorders prior to any neurological damage. However, it is to be expected that some psychiatric symptoms will follow ABI. A typical example would be depression, as it might be expected that someone who has suffered a severe brain injury would initially be depressed about their altered situation. Perhaps if depression is expected, then it may be perceived and treated differently, possibly even disregarded.

2.5 Childhood Brain Injury

There is a popular belief that children suffer less than adults from the effects of brain injuries. This is often attributed to greater brain plasticity and the ability to compensate more easily in youth. One of the most widely cited studies used to support this theory is Kennard (1936), the findings of which were based on animal experiments. However, it has since been established that children can in fact suffer far more devastating consequences as brain injury can interrupt the early process of development and stop certain milestones from ever being reached.

Webb, Rose, Johnson & Attree (1996) investigated the unwillingness of clinicians to discard the Kennard Principle and found that of their sample of 156 health care professionals, all predicted better recovery in children (under 10's) when compared to adults. These findings have serious implications as clinicians who assume that children will make a good recovery from brain injury, without serious long-term impairment, may not make suitable provision for rehabilitation and after-care.

Although adult and childhood diseases/injuries may have a similar cause, diagnosis and treatment, there are a wide range of developmental issues which distinguish the rehabilitation needs of each group. Or put more simply - "children are not miniature adults" (Chorazy,1985, p.xix). Furlonger & Johnson (1989) explain that the postinjury level of personal and social skills will depend upon the pre-morbid stage of personality development.

Head injured children and adolescents often exhibit noticeable difficulties with later-developing functions, such as social judgement (Ewing-Cobbs, Fletcher & Levin, 1985) and a primary residual deficit in severely head injured children is impaired social interaction, which is one of the most devastating effects for not only the patient, but for family and friends (Haarbauer-Kruper, Henry, Szekeres & Ylvisaker, 1985).

It should be noted that age continues to be a factor in recovery beyond childhood. Thomsen (1989) investigated late outcomes of head trauma patients from two age groups, 15-21 and 22-44. It was found that the younger patients had problems with immaturity and lack of insight, which it is suggested have a negative impact on late outcome, making young people more prone to later emotional and behavioural problems. Six of the patients interviewed for this thesis (four of whose parents were also interviewed), were injured as children but now access adult brain injury services.

Issues around the age at injury and how this affects the trajectory of care, will be explored. These go beyond recovery of function to areas such as social dynamics, as a person who is injured as a child will never have been fully independent prior to the injury. Instead of relationships changing, they may stagnate, with a child never leaving home. This dependency can be problematic for parents - who may themselves be aware that they 'will not be there forever' - but sometimes it may be encouraged in very subtle interactional ways by carers who are unwilling to confer the full status of 'adulthood' on their now grown child. The experience of loss on the part of young patients can also be very different, as they may not fully realise their limitations until they reach adulthood.

Looking beyond the patient, wider family dynamics can be irreparably damaged as parents are likely to devote much of their time to the care and well-being of the injured child, to the exclusion of any siblings. They may struggle to hold the family together as relationships are neglected at a time when love and reassurance is greatly needed (Currie, 2000).

2.6 Recovery from Brain Injury

Recovery is one of the key issues in brain injury research. It allows professionals to measure the success of interventions, from life-saving surgery to the provision of aids for daily living. However, it is a complex issue with a mere disguise of simplicity.

2.6.1 The Glasgow Outcome Scale (GOS)

Recovery from brain injury is often measured using the Glasgow Outcome Scale (GOS) designed by Jennett & Bond (1975):

GOS	Description	
5	Normal or deficit not impairing work or leisure	
4	Independent but unable to work or follow leisure pursuits	
3	Dependent but conscious	
2 :	Vegetative	
1	Dead	

Figure 5. The Glasgow Outcome Scale (Jennett & Bond, 1975)

This is a fairly crude, functionally based assessment tool used to categorize patients in terms of their post-acute outcomes. It appears to be fairly straightforward and should therefore be a reliable measure, however Anderson, Housley, Jones, Slattery & Miller (1993), found that although psychologists are able to assess patients according to this scale, general practitioners find it much more difficult. The results show that there is a tendency amongst GPs to make over-optimistic assessments of good recovery as they do not always consider psychological and behavioural problems. In some cases, GPs will assess recovery as being good when psychologists still consider the patient to be severely disabled.

As indicated in the GOS, return to work is often used as a measure of recovery. What is not made clear is that the specific occupation is often disregarded. A person may work in a highly skilled job prior to brain injury and find that post-injury they can only cope with repetitive low skilled work. In this example, the person may feel frustrated at their impairments and not consider themselves to be recovered. The professional, using a checklist type assessment, might claim that the person has made a very good recovery.

In a further scenario, a person may <u>choose</u> not to work following brain injury if they can live a fulfilling life, financed by benefits and possibly compensation. This person may be happy with their adjusted life, but the professional may again disagree, seeing the lack of employment as a failure to recover.

So what is recovery and is it even possible to have a generic definition? Can we know in advance what constitutes recovery without adequate knowledge of the subsequent illness trajectory? This thesis will address issues around recovery, adjustment and adaptation, looking beyond the checklist and towards real experiences, as individuals who are living with the effects of brain injury perceive them.

2.6.2 Theories of Recovery

If for the moment, we crudely define "recovery" as the "return of function", then we can start to think about how recovery takes place. Traditionally this is an issue dealt with using the tools of neurology and neuropsychology, and it seems appropriate to outline some of the most accepted ideas.

There are two main theories described by Miller (1984) as to how recovery following brain injury takes place. To some extent the brain may go through physiological changes, creating new pathways or using different areas to achieve goals once dealt with by the damaged areas; this is known as 'anatomical reorganization'. However Miller (1984) reports that although this process is an established fact in young children it is not necessarily so effective in older people whose brains' are more developed and have less plasticity. The other theory is that of 'functional adaptation' where the affected person compensates for their difficulties in practical ways so that they can meet the same goals using different strategies. To illustrate, a person may find that they have memory difficulties so they can adapt by making lists of what needs to be done and when. Visual deficits can be overcome in many situations by using other senses such as hearing and touch. Daily living aids are also available for aiding physical activities from walking to simply opening a jar.

Functional adaptation can be broken down into three further categories; compensation, substitution and direct retraining (Prigatano, 1986a). Compensation is

the way in which patients get around a deficit through the reorganization of psychological function. It can involve practice and repetition and also the use of tactics e.g. if they are slow to process thoughts and someone asks a question then they can state that they are considering the question but will take a while to respond. This is mainly spontaneous but can be built upon by therapists.

Substitution is the way in which people attempt to solve a problem that the brain is capable of dealing with, but using different methods of approach. They are not avoiding solving the problem but finding new ways to do it, i.e. they are using intact brain functions to get around deficits. An example of this is the use of Braille when vision is damaged. The brain itself can physiologically use substitution, in this way language function can sometimes be restored following left hemisphere damage as it is possible for the right hemisphere to take over this function.

Finally, direct retraining is an attempt to retrain specifically impaired functions directly by working repeatedly to improve memory and/or thinking etc. In this way it is possible to recuperate some of the lost function. Neuropsychologists may implement training such as this, but it is a lengthy process made available only to a minority of patients.

The anatomical and adaptation theories should not be seen as exclusive of one another, as most people will probably rely on both to regain their independence. In order for anatomical reorganization to take place people must practice completing tasks and attempt things over and over. Functional adaptation often requires insight into how a problem may be approached from a different angle. Both of these pathways to recovery may be aided by day care that provides stimulating activities and has staff on hand to give advice and provide support where necessary.

The theories of recovery that have been presented focus on the individual patient and place responsibility on her or him to work towards a return of function. In reality though, this is often not a socially isolated enterprise. A huge impact may be made by the level of family support and the expectations of loved ones. Goal setting may be affected by how much independence a patient is allowed, or chooses to take when they return home. These goals may also change, as the patient takes on different roles, in different contexts (Strauss, Corbin, Fagerhaugh, Glaser, Maines, Suczek &

Wiener, 1984). So a patient may tell their girlfriend that they are aiming to regain full mobility, they may agree with the physiotherapist to aim for walking with support and they may tell their employer that they are unlikely to walk again.

2.7 The Way Forward

There is a need for more detailed qualitative material focused on head injury, in order to help professionals to plan and provide effective services for those whose lives are affected by this trauma (Hubert, 1995). This thesis will present a wealth of qualitative material that identifies the care pathways followed not only by people who have had head injuries but also by people with non-traumatic acquired brain injuries. Key issues will be explored and related back to common trajectories, the understanding of which would greatly benefit professionals responsible for planning services that meet actual, rather than assumed, needs.

Through this chapter I have presented a base of information about brain injury taken from a selection of established research. I have shown that there are areas beyond this research in which further investigation would clearly be of value. An overview has been given of the causes of brain injury and how these may be split into traumatic and non-traumatic cases (a difference which can impact on the trajectory of care). The key measurements of severity have been identified and questions have been raised about their use to predict future outcomes. The main effects of brain injury have been discussed including ways that they may impact on a person's life. Particular mention has been made of childhood brain injury, as there are separate developmental issues in these cases that may be overlooked. Theories and issues around recovery from brain injury have been considered, including the question of how recovery is defined. Finally, issues of professional support have been identified and the potential utility of the trajectory concept has been explained.

The presentation of this research is not intended to answer questions before they have been asked and the aim of this thesis is not to simply confirm existing theories. The value of understanding the background of brain injury research is that we become sensitised to a range of issues. It gives a starting point for planning interviews and considering responses, but the data will be treated holistically and will not be forced to fit pre-existing ideas. The themes that will be explored are not pre-determined but

are analytic attempts to impose order on the range of concerns expressed by participants. In line with the procedures of grounded theory, the process of imposing this order goes through numerous iterations with the aim of trying as far as possible to avoid making immediate theoretical re-descriptions of way participants represent their concerns. Once these themes are established and formalised, they will be related back to other areas of health research. It is hoped that the data collected will allow an insight into common trajectories of illness and care, enabling us to consider the implications of such trajectories and how knowledge of them may be a useful tool for those who provide support to this client group.

Chapter 3 - Methodology

3.1 Interview Development

The key aim of this thesis is to explore the personal impact of brain injury on patients and their families. It was decided from the outset that this would be a piece of qualitative research, which would allow participants concerns to be explored in depth and with some degree of flexibility. In-depth semi-structured interviews were chosen as a methodological strategy that that would provide a basis for discussion but that would not constrain data collection to pre-determined themes.

3.1.1 Deciding on a Method

Much of the existing research into acquired brain injury is quantitative, typically based around measures such as checklists and rating scale assessment. This obviously places many constraints on both the depth and the nature of the kind of information which can be conveyed. By contrast, a rich and detailed kind of information regarding the actual experience of ABI was precisely that which I wished to make central to my enquiries. To this end, a qualitative methodology that was sensitive to complexity in participants' accounts and interpretive in character appeared to be the most appropriate choice.

I also wanted to consider the restrictiveness of the accepted language of brain injury. Stainton Rogers (1996) suggests that the ideological nature of 'traditional' health psychology is such that the tendency is to assign superiority to biomedical concepts over lay beliefs. She maintains that people develop and negotiate a rich pattern of beliefs around health and illness that cannot be accessed through a purely biomedical framework, where medical knowledge is treated as fact. To subject people to questionnaires and scales built around the assertion that there is a single truth and only limited predictable variables is to impose a, "Conceptual strait-jacket upon people's explanations of heath and illness" (p75). Stainton Rogers argues that more critical, post-modern approaches such as discourse analysis offer us ways to explore new possibilities that are beyond the scope of traditional methodologies. My response is to

take a broadly interpretative approach where analytic claims are, as far as possible, made with clear reference to participants' accounts and dilemmas (see Section 3.3).

Although I have for a number of years maintained an interest in issues around brain injury, informed by my experience as a volunteer worker at the local branch of the charity Headway, I sought to avoid an analytic 'rush to judgement' by adopting an inductive approach, thus bracketing out to some degree my knowledge of the way in which recovery from ABI is typically understood and theorised in a clinical framework. In particular, I have sought to avoid positing hypotheses derived from existent research or otherwise forcing the data into pre-existing analytic categories. The overarching rationale here is that much of the understanding of brain injury to date is based on a medical model that is to some degree insensitive to the dynamics of what it is to be a person with ABI existing in a particular way. I wanted to talk to people who had experienced brain injury and to gather and present their own stories. And then subsequently to try to make sense of commonalities and shared experiences which would not otherwise be visible to the participants. Buchanan sums up this position well in the following way:

The quality of qualitative work cannot be determined by following prescribed formulas. Rather its quality lies in the power of its language to display a picture of the world in which we discover something about ourselves and our common humanity. Buchanan (1992: 133)

Which is to say that what is being attempted in qualitative work is gaining access to the world of the participant (as it shared with the researcher) in order to understand rather than explain.

The value of qualitative data in psychological research has been established through lengthy debates that can be found throughout existing literature (Burt & Oaksford, 1999; Giles, 2002; Gillett, 1995; Marks, Murray, Evans & Willig, 1999; Willig, 2001; Woolgar, 1996) and its use should no longer require justification. The decision of quantitative versus qualitative can be seen at its most basic level as an issue of what will best 'fit' the phenomenon being studied (Guba & Lincoln, 1982). In this thesis, the aim is to explore the concerns of people with acquired brain injuries and their families. The phenomenon I want to study is their representation of experiences and ensuing relationships – areas so diverse that I could not hope to capture them in quantitative terms – I am not looking to measure isolated variables but to provide

detailed, multilayered interpretations of different situations (Yardley 1997) and in this sense my investigation would not fit a quantitative approach. I want to add to existing research without being constrained by previous findings. The nature of quantitative research is to collect facts that can be statistically analysed and compared but I want to research issues that cannot be summarised in a bar chart or a table. I want to get some sense of the rich experiences of people affected by brain injury, and I would not be so bold as to try and predict their responses so that I can condense my data into an easily analysed questionnaire. I believe that there is far more value in trying to answer my research questions through a series of in-depth interviews that will be shaped by each person that contributes.

The qualitative data presented in this thesis is a mixture of interview data (involving single and joint interviews with patients and carers), secondary materials (such as care plans, newspaper reports) and diary materials. As such a broad and mixed corpus of materials is available from which to draw inferences and make interpretations about the common experiences of living with ABI.

3.1.2 Formulating the Questions

I became a volunteer at Leicestershire, Leicester & Rutland Headway, a local branch of the national brain injuries organisation, in 1998. I worked with many people who were coping with the effects of acquired brain injury and found it incredibly interesting and rewarding. I negotiated with the manager to do my undergraduate dissertation research looking at the positive benefits of specialist support. I conducted 30 short interviews and completed needs checklists with the clients. During the interviews and through ongoing informal discussions with the clients, I became aware that there were many critical issues which remained unexplored. Part of the motivation for the current research was to address some of these questions and to highlight the gap between existing knowledge of ABI and the experiences of the clients.

My lengthy and continued involvement with this group gives an added dimension to the research. Although in formal terms the research does not constitute an ethnographic study, it has an ethnographic dimension that is reflected in my long-term experience of brain injury support, with regular access to participants in the local culture. I cannot take myself out of that context; therefore, where appropriate, I will seek to reflexively consider how my involvement informs the analytic process. Previous studies of this type of client group have been unable to produce substantial findings because of the researchers' clinical and distant approach. To encourage open conversation where people with ABI and their carers feel able to discuss sensitive areas of their lives you need to build up a trust and a rapport. Perhaps more importantly, to understand not only what is said, but what is being accomplished in the saying, it is important to have some knowledge of individual lives. I cannot then, and refuse to be, purist in my approach. My experiences and personal knowledge are not an obstacle which introduces bias into the claims I will be making, but are rather a key resource which allow me to introduce finer grained interpretations than would otherwise be possible (for example, in the joint interviews with patients and carers, my knowledge of the patient's abilities as displayed at Headway allow me to reflect upon the various social functions being enacted by carer's claims in some depth).

In designing the semi-structured interviews I had support from the Head of Neuropsychology at the Leicester General Hospital. This was to ensure that questions (See Appendix I) were appropriate and pitched at the right level for this client group. I was careful to ensure flexibility within the interviews to allow restructuring of the questions so that I could follow interesting trains of thought (within and between interviews) – and more importantly – so I could respond at a level appropriate to each individual (bearing in mind the potential presence of cognitive or communication impairment).

Each of the interviews conducted will be viewed as social interactions that produce actively constructed narratives (Holstein & Gubrium, 1995). This premise, drawn from the ethnomethodological notion that social action is collectively accomplished (Garfinkel. 1967), requires that interviews be treated as a two-way process, and the knowledge obtained is recognised as having been created from the action that takes place within that context built up during the interview.

The focus of the analysis will be on the manner in which people construct their stories, but with the added dimension of considering how neurological damage affects this construction. It is feasible that some of those with frontal lobe damage will only answer direct questions and without substantial elaboration; this in itself is an issue of

importance when we consider the verbal assessments that they will have been subject to. I will also be analysing written 'storytelling' data, as discussed in the next section.

3.2 Personal Diaries

The 60th interview conducted was with a husband and wife. The husband, Rod, was living with a terminal brain tumour, the first symptom of which was a fit in the summer of 1997. It was revealed during the interview that from the initial fit, he had kept a diary. This began as an independent project but was later assisted and then completed by his wife. I was offered open access to these diaries, which span 5½ years, concluding with Rod's funeral in January 2003.

Most diary studies are researcher led and the diary can become almost a form of self-administered questionnaire (Robson, 1993). The diary data in this thesis is particularly valuable because it is a genuine and self-motivated record of events as they happened. As the tradition of diary use in psychology is predominantly artificial, it is useful to refer to historical studies of personal diary keeping. I will therefore draw on literature that discusses English Diarists across the past four centuries (Ponsonby, 1923; Spalding, 1949; Brett, 1987). Much of the insight is relevant and applicable to any study of diary writing.

3.2.1 The Role of a Diary

Many people keep a personal diary at some point in their lives, although few maintain it throughout adulthood. Diaries have been used as social records of history, as the basis for autobiographies and as a vehicle for popular fiction. Most however, remain a private record of thoughts, feelings and events, and as such, many are destroyed. The immediate question then, is what drives most people to become diarists? Brett (1987), suggests that,

Maybe, at its simplest, diary-writing is a personal way of imposing some kind of order on the chaos of the world around us (p.xi).

This is an appealing supposition, that diaries enable us to re-organise and clarify our experiences. This view sees us as constantly bombarded by events; the memories of which we need to re-organise to fully understand them. It could also incorporate a desire to 'rewrite the self' (Freeman, 1993) by selectively recording the parts of our

life that reflect who we think we are, who we want to be and how we would choose to be remembered.

Perhaps however the reason for becoming a diarist is far more trivial. There are many practical grounds for writing in a diary; we might want to remember events of the past and appointments in the future and it is also a place to keep important notes such as emergency telephone numbers. Spalding (1949) recognises such practical functions of diary keeping, but maintains that these are only incidental, with the main purpose of a diary being to preserve experience for its own sake. Beyond this preservation of experience, Spalding (1949) identifies that there are a range of motives,

As varied as human nature itself. The results range for the commonplace day to day account of some limited period, for example 'travel diaries', to the pure diary, the outflow of the spontaneous impulse to record experience as such and so preserve it (p.21).

Once a person decides to keep a diary, there is still the question of what experiences they will actually record. Ponsonby (1923), states that,

Operations and prolonged illness will be noted by anyone who is keeping a faithful account of his days, because they are impediments to action and alter the whole routine of life (p14).

This is particularly relevant to this research as it is a perhaps overlooked source of data. If most people who keep personal diaries, record within them details of their experience of illness then this provides a potentially rich source of information on the way in which their everyday life is affected by their condition. In practical terms however, the personal diary is usually viewed as a private and therefore un-sharable document. Ponsonby (1923) adds that,

A carefully-kept analysis of symptoms may have considerable value from the medical point of view (p14).

This strikes quite clearly of one of the key motives identified by Rod and Ann in becoming diarists. They felt that it would be valuable information for informing professionals of what happened when and also for monitoring medication and care regimes. Doctors themselves however, could perhaps learn much about the experience of brain injury, of providing and receiving 24-hour care and of dying, through access to these documents.

I have had many discussions with Ann about the motivations behind the diaries that she and her husband kept. There is no one definite answer, but many valuable reasons. The first entry was on the day of Rod's initial seizure. The notes were kept as a record that could be shared with medical professionals. Over time, the physical size of the diaries increased, as did the amount of information they contained. They became part of Rod's daily routine and delved into areas of his wider life. At this point they served to provide a record for Rod; I was later informed that Ann was unaware of these early diaries. As Rod's illness progressed, the diaries were used to record daily routines including exercise, toileting, meals and medications, but details were sometimes fabricated to fill in the gaps. Therefore accuracy was not viewed to be as important as completion of the routine.

Slowly, Rod's condition became worse, and Ann began to make her own entries in his diary. At first she took over during a few days when Rod was too ill to write, but over time, her contribution to the text became more frequent and more lengthy. Sometimes Ann would clarify, or expand on, incidents that Rod had tried to document. At other times she would write in his place. Examining the text shows that these entries had many purposes; this is verified by Ann. Some entries serve simply as a record for Rod or Ann, but others are clearly aimed at a wider audience, with names omitted and facts clearly stated. Ann consciously used the diaries as a way to explain events to others. She showed the diaries to Rod's family, in the hope that it would aid their understanding of his condition and the extent of his deterioration. Ann also presented excerpts to doctors, in order to explain significant health events. Perhaps most poignantly though, as Ann finally took over the diaries, they recorded messages for Rod that he was no longer able to comprehend; they also became the sounding board that he could no longer be.

The diaries express both facts and feelings. They document experiences and particularly the frustrations along a downward trajectory towards death. They will form the basis of a case study in Chapter 7, and will be presented alongside interview data and other records.

3.3 Approaches to Analysis

Beyond the practical application of appropriate research methodology, we have to consider how the data will be analysed. There are many well-established qualitative approaches to data analysis. Ethnography is an obvious first consideration – but this is more than an analytical approach – it is a whole means of research and taken as a complete package it is not suitable for the data I want to collect. The remaining key approaches are discourse analysis, interpretative phenomenological analysis and grounded theory. Each of these will be considered in turn.

3.3.1 Discourse Analysis

Discourse Analysis (DA) is a social constructionist, approach that focuses on the minutiae of language used in everyday life. It takes inspiration from a wide variety of fields, including ordinary language philosophy (e.g. Wittgenstein), conversation analysis and the work of Michel Foucault, and on this basis has developed into a diverse field (Giles, 2002) with many different interpretations of how it should be applied (Parker, 1992; Parker, 1994; Potter, 1996; Potter, 1997; Potter & Wetherell, 1987) Key distinctions can be made between Foucaultian Discourse Analysis and the Loughborough school of Discursive Psychology. Discursive Psychology considers how people use language to manage their stake within social interactions and sees them as active agents within this process, whereas Foucaultian Discourse Analysis looks more broadly at the discursive worlds in which we exist and the constructive power of discourse to affect our ways of being, limiting people to positions available within this discourse. Discursive Psychology also sees experience as a discursive construction whereas Foucaultian Discourse Analysis makes moves to theorize experience and consider selfhood.

The work presented in this thesis is influenced by DA, in particular it shares a concern with how language is constructive and functional (Willig 2001) by looking at the work that people do in creating specific linguistic representations of events. However as an analyst I will be adopting a more positivistic stance towards epistemology, since I am also concerned with exploring how brain injury and the circumstances surrounding injury and recovery intersect with the adoption of discourses. In order to

do this I will present transcribed data organised around common analytic themes that allow for a modelling of trajectories of illness and recovery.

3.3.2 Interpretative Phenomenological Analysis

Interpretative Phenomenological Analysis (IPA) was developed as a method for exploring perceptions of health and illness (Smith, 1996). It is used to identify and build themes from texts, usually taken from semi structured interviews or diaries (Willig, 2001). Through it, researchers aim to explore the participants' experiences from their own perspective. Unlike classical phenomenology, IPA recognises that the analysis necessarily involves interpretative work and will therefore be affected by the researchers own personal views and their interaction with the subjects. Like Grounded Theory, early coding is worked into higher order categories (Giles, 2002), but it is more of a reductionist technique, typically used to summarize key points from the data in tabular form. It is seen by some as a less rigid version of Grounded Theory, in part due to its application in single case studies (Smith, Jarman & Osborn, 1999), from which it is difficult to make meaningful generalisations beyond the data. I intend to do something far more sophisticated where the richness of the data is not lost in the analysis. I also want the opportunity to look at the claims which people make and consider whether they reflect the reality of their situation.

3.3.3 Grounded Theory

In most traditional research methods, analysis begins after data collection is completed. Grounded Theory is different in that there is extended analysis throughout the period of data collection and beyond. As data is examined, it is coded and these codes are analysed for emerging themes. Strauss & Corbin (1998), define coding as,

"The analytic processes through which data are fractured, conceptualized, and integrated to form theory" p3.

The initial process is referred to as 'open coding', where transcripts are read through several times while notes and memos are created on any emerging ides. This gives an overview of the likely themes that are present in the data. Coding must then be redone at a more intensive level where the data is analysed in smaller chunks and

descriptive codes are developed to summarise the text (some of which will be *in-vivo*). Charmaz (1995) refers to this stage as 'line-by-line coding', but there are many lines of transcript for which useful codes cannot be assigned (e.g. when the interviewee goes entirely 'off-topic'). In response to this issue, Rennie (2000) uses the term 'meaning units' rather than codes so that although all data is still considered, only those that have meaning are actually coded.

Once the initial codes, or meaning units, have been assigned, there must be a process or focused coding, where the ideas generated to this point are integrated into broader conceptual categories (Giles, 2002). This categorising of the initial codes can be done by hand or by using an appropriate computer aided qualitative data analysis (CAQDAS) package (See Section 3.3.3.4). Once categories, or links between categories, are established they must be tested against all data, and negative cases should be identified and accounted for. In this way, categories are reshaped to fit the data from which they were developed. Further cases may be sought to elaborate or challenge these categories, drawn through a process of theoretical sampling until no further variation is found; the point of data saturation (Glaser, 1978).

As a positivist, inductive and interpretative approach that accords respect for the accounts of participants, I have chosen Grounded Theory as the overall framework for the research. It will enable me to collect and analyse data in a clearly defined and rigid way, but I will have the flexibility to follow patterns that emerge rather than attempting to impose preconceived theories. It will also allow me to explore a range of data sources that refer to the same people and the same issues, so that I can look for saturation beyond the core interviews with considerations of the extent to which representations reflect reality. Through the rest of this section I will expand on how Grounded Theory has developed, the issues that it raises and the tools available to implement it.

3.3.3.1 The Historical Development of Grounded Theory

Grounded theory was developed primarily within Sociology (Glaser & Strauss, 1965; Glaser,1978; Charmaz, 1991), drawing on the research tradition of Symbolic Interactionism. In recent years it has been employed in psychological (Pilowsky, 1993; Thunberg, Carlsson & Hallberg, 2001) and medical research (Wiener &

Wysmans, 1990). Although Glaser and Strauss established many of the fundamental principles in their 1965 work on the awareness of dying, it was two years later that the methodology was formally presented in <u>The Discovery of Grounded Theory</u> (Glaser & Strauss, 1967). However, there is some flexibility in the way that Grounded Theory can be interpreted and applied which has led to conflicts between some researchers in this field. Even the founders of this theory were divided in their understanding of how Grounded Theory should be defined and used

These differences became public after Strauss & Corbin (1988a, 1998) presented a version of Grounded Theory that Glaser (1992) felt was too prescriptive, suggesting that their method would force data rather than allowing themes to emerge. He argued that what Strauss & Corbin had described was not in fact Grounded Theory but a different and inferior method. At the core of their disagreement was Glaser's belief in the pure inductive method, while Strauss & Corbin favour some deductive analysis, in part as an acknowledgement that no researcher is without prior knowledge that will in some way sensitize them to themes within the data. My own use of Grounded Theory will be based on the position adopted by Strauss & Corbin since I am actively using my own knowledge of the research participants to inform my questions and interpretations. Although the themes I develop will be data driven, they will be informed by links with other established research.

3.3.3.2 Issues Raised by Grounded Theory

This thesis looks at broad social processes for dealing with a phenomenon that has biological roots. The categories I will give to these processes are restricted by what is in the data and involve minimal interpretation. Once these categories are established, they enable the definition of broad themes through which the data can be considered and discussed.

Grounded Theory will enable an exploration of the central processes and unfolding patterns which constitute living with ABI. Concerns such as the care and aspiration issue (see Section 5.3.1) are long term features and realistically, may be irresolvable, but awareness of them would allow service providers to be more sensitive to the needs of service users. There are misalignments between the networks of agencies; by

showing where they fit together and where they don't, and by addressing the central concerns of the service users, we can suggest ways of improving provision.

Researchers using this methodology do not mislead themselves with firm criteria, but must constantly test and modify their ideas. By seeking to refute initial assumptions, and not disregarding the 'outliers' (deviant cases) the researcher can make a claim toward objectivity. There will always be accusations of bias in research such as this but the sheer amount of variability and contradiction within this data will show that it has not been collected with rigid predetermined outcomes. As Wysmans (1990) explains,

Theorizing is not "putting your own prejudices on reality" if you are constantly and diligently testing your theory against incoming data (p.28)

Grounded Theory allows the researcher to develop theories and frameworks <u>from</u> data; however there should be opportunities to work not just within but between data. It is not a form of research that lends itself easily to direct replication but it does enable comparative work and I hope to identify links with other research i.e. similar trajectories across brain injury and perhaps other forms of disability e.g. chronic illness

Sample size is often questioned as a measure of how thorough a piece of research is, but the validity of any qualitative study depends more on the quality of analysis than on the size of the sample (Mitchell, 1983). In Grounded Theory, data collection stops at the point of saturation, where new data is simply duplicating the themes already generated. The decision to conclude data collection was made for this thesis following the 62nd interview.

As Wysmans, (1990) explains,

Grounded theory is as much a way of thinking as it is a methodology, a way of playing with the possibilities inherent in data collection and analysis. You are constantly challenging what you think against incoming data, not satisfied with the easy connection but rather looking for all the variations possible – asking (until you have saturated the chosen field of study to your own satisfaction) "what would happen if..." (p.22)

In summary, this is a qualitative approach that will be worked in an iterative fashion. Analysis will be organised around the data, as it is collected, and therefore emergent themes will not be restricted by pre-conceived findings. I am entrenched in the

community from which this data is drawn, but I will aim to be visible about my knowledge and systematic in my interpretations. I will present raw data alongside my careful elucidations and this will give the reader direct access to the core of each theme that develops.

3.3.4 CAQDAS

It was decided that the grounded theory methodology could be applied more rigorously with the assistance of NUD*IST vivo, a program designed for computer aided qualitative data analysis (CAQDAS). This stores coding and memos alongside the original data and allows them to be explored easily. Its advantage is not just its rigour, but also its speed, as a large corpus of qualitative data is difficult and time consuming to analyse purely on paper. This computerized tool gives greater time and freedom to pursue potential emerging themes. However it is important to keep returning to the original audio data as much of the nuances and emotion can be lost in text, which can foreclose on particular kinds of interpretations. Coding also has to be revisited as new data brings fresh interpretations.

Where CAQDAS is less useful is in the detailed analysis of short data extracts (Seale, 2000), but at least the program may help to identify these key extracts. NUD*IST also allows the creation of dummy documents that represent offline data such as handwritten forms. These can be coded and searched alongside the main text. Examples of coding and the use of node trees are presented in Section 3.5.

3.4 Integrating Information Sources

Arranging and conducting the interviews is in itself a lengthy process that involves a lot of contact time with the patients, allowing me to build relationships with each individual. This enabled me to gain not only a feeling of trust, but a fuller picture of each person's life. I have attempted to record and structure these observations by collecting many notes outside of each interview. Carer interviews were done only with families currently living in Leicestershire as my primary interest is in those who are actively involved in the lives of the patients. These interviews require the permission of patients, and obviously the carers themselves have to be willing to give precious free time.

I will be analysing multiple sets of data from different sources, including in-depth semi-structured interviews, grounded theory memos, health & social care records and personal diaries. These will be triangulated so that similarities and differences within and between data can be identified and explained. Where categories hold up against this rigorous process they will be presented in the final analysis. This process enables me to be confident in the internal validity of this research.

It should be noted that large sections of data will be incorporated into this thesis with the aim of bringing the reader closer to the original account and offering a clearer insight into the lives of the interviewees. This also functions to preserve the integrity of the data by not stripping it of its context. The concept of a 'trajectory' has been employed as a tool for integrating these varied resources to tell a story about the experience of brain injury. This final section of the methodology will attempt to show how this concept has developed and the relevant issues that it raises.

3.4.1 The Trajectory Concept

Between 1965 and 1970, Anselm Strauss and Barney Glaser conducted a series of studies into the process of dying (Glaser & Strauss, 1965; Glaser & Strauss, 1968; Strauss & Glaser, 1970), the focus being on the work that goes on around this process. They started by looking at the issue of awareness, describing the work that is done to hide death from patients (Glaser & Strauss, 1965).

Glaser and Strauss extended this research with an examination of the way in which people die at different paces that often fail to match the predictions of their families or physicians (Glaser & Strauss, 1968). The idea of the experience of dying being measurable and comparable in time and shape gave rise to the concept of a 'Dying Trajectory' (Strauss & Glaser, 1970). This trajectory was not simply described as a course of events, but also included perceptions and expectations of this course and the work that is done around it. Within the trajectory, Strauss and Glaser identified critical junctures (events, such as the patient being defined as terminal) that must be handled by all involved and they looked at the way the aforementioned expectations affect the way these events are dealt with.

The idea of the Dying Trajectory was later extended to chronic illness and became reworked as an Illness Trajectory (Strauss, Fagerhaugh, Suczek & Wiener, 1985; Corbin & Strauss, 1988). As was described in Chapter 1, the Illness Trajectory describes the physiological unfolding of a disease and also the organisation of work done around that. This takes into account the perspectives of all involved in that work, the patients, the carers and professionals.

The illness trajectory has between seven phases starting from trajectory onset, although the pre-trajectory, preventative phase is also sometimes referred to. The **trajectory onset** refers to that stage at which the patient develops signs and symptom of illness and it also includes the diagnostic period. The next phase is crisis, and this tends to be reflected in a life-threatening situation. There is then an **acute** period of active illness followed by a **stable** period where illness is controlled by a regimen. At the point where the illness is no longer controlled, the patient can be said to be in an **unstable** phase. This moves into a **downward** phase as their symptoms increase and their physical and/or mental status deteriorates. The final phase is that of **dying** and that encompasses the immediate weeks, days and hours before death. A patient can shift between these phases and may spend a significant proportion of the whole trajectory moving back and forth between the crisis, acute, stable and unstable phases. The illness trajectory concept can usefully be applied to acquired brain injury and it has already been applied to stroke research (Burton, 2000).

Going back to Glaser and Strauss' (1965) work on awareness of dying, this in itself can be linked to the experience of acquired brain injury, as full prognosis may also be concealed from these patients. Considering the initial work on the Dying Trajectory (Glaser & Strauss, 1968), with brain injury, temporal prognosis is also difficult and often unpredictable. Using the idea of critical junctures (Strauss & Glaser, 1970), a key event for a person with an ABI might be returning home from the hospital or regaining mobility.

Even before the development of the Illness Trajectory, we can see clear links between the work of Strauss and Glaser and the experiences of people with acquired brain injury. These links are even stronger with their more recent chronic illness work, as brain injury leaves people with disabilities that are chronic in nature (Department of Health, 1997). This thesis will look at people's experience of this disability and the

trajectory concept gives a useful way of ordering their stories alongside information from carers and professionals.

Within the illness trajectory, Wiener, Strauss, Fagerhaugh, & Suczek (1997) identify the further key concept of biography, to refer to the way in which our past experiences influence present and future actions. So whereas the original models (Glaser & Strauss, 1965, 1968; Strauss & Glaser, 1970) start at the point of illness, to incorporate the concept of biography, it is perhaps necessary to look at a trajectory which spans the whole of a persons life, but which focuses on the critical junctures around the injury and beyond.

The notion of a life trajectory has been modelled and developed by Dreier (1999). He states that we need,

A concept of personal life-trajectory to theorize how individual life-courses stretch across social time and space. Just as everyday personal social practice stretches across social contexts, so does the personal course of life. The flow of the life-course also has a spatial dimension to it. Across the life-span the person participates in a changing configuration of particular social contexts, and the person composes these changing contextual participations into a personal life-trajectory (p. 19).

This social practice to which Dreier refers has a commonality that allows our actions to be understood – but also influences them. There is no clear cut distinction to be made between persons and practices. Social practices define what we are, just as our actions realise the practice itself. Social contexts exist as part of the structure of social practice and cannot be understood in isolation, but should be considered in terms of the connections and separations with other social contexts. Related in practical terms to a life trajectory, a hospital may be one social context that a person experiences. Their expectations of social practice, and therefore their actions, will be influenced by their understanding of the hospital as a social context. This understanding may come from other similar contexts such as a doctor's surgery. Each new experience will guide our expectations across the space and time of our whole life trajectory, so our understanding of past events, our actions in the present, and our beliefs about the future, shift to fit with our recent social practice. For example, a negative hospital experience will be related and compared to other experiences in similar contexts. It will affect the way we remember medical intervention as a whole, our willingness to seek medical support in the present and the way we build our future around this altered concept.

Returning the focus to illness and recovery, the use of trajectories specifically for closed head injury was introduced by Bellaby (1991; 1995). Bellaby developed histories of sickness by making use of multiple accounts that could be triangulated. His work does not however appear to be informed by the chronic illness research already cited.

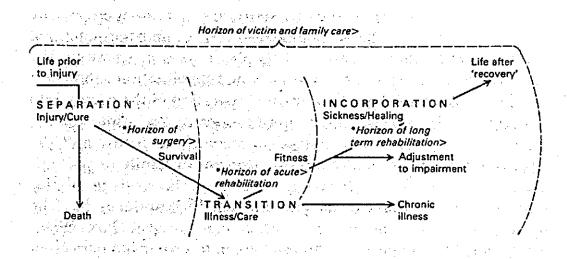


Figure 6. The Trajectory of Closed Head Injury: The Horizons of Victim, Therapists and Carers. Taken from Bellaby, P. (1991). Histories of sickness: making use of multiple accounts of the same process. In S. Dex (Ed.) Life and work history analyses: qualitative and quantitative developments; Sociological Review Monographs, 37. London: Routledge, p31.

This trajectory shows three horizons labelled as, 'Separation', 'Transition' and 'Incorporation', which represent the time of surgery, of acute rehabilitation and of long term rehabilitation. It is a very simplistic model that implies that all patients will either be chronically ill or will adjust to their impairments. Level of adjustment however is not simply a function of severity. As this model specifically represents traumatic head injury rather than acquired brain injury, it has a clear-cut start to the trajectory. Acquired brain injury includes conditions that are not instantly diagnosed, so to incorporate these, it would be useful to take Strauss & Glaser's (1970) start point of the first symptoms. Bellaby (1991) also presents social adjustment as a predictable outcome using a matrix that combines measures of recovery, support, therapy and adjustment.

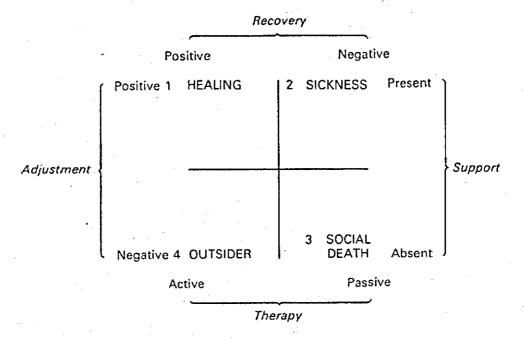


Figure 7. Recovery from and Social Adjustment to CHI. Taken from Bellaby, P. (1991). Histories of sickness: making use of multiple accounts of the same process. In S. Dex (Ed.) Life and work history analyses: qualitative and quantitative developments; Sociological Review Monographs, 37. London: Routledge, p37.

Four domains are presented, healing, sickness, social death and outsider, suggesting that a positive end status is only achievable with support, adjustment, therapy and recovery. So again we can see a very superficial model of outcomes following head injury where support is either present or absent and quality is not measured; patients adjust or they do not, there is no concept of levels of adjustment. They may be active in the therapy process or passive, suggesting that all therapy is one and the same. Finally, as is commonly seen in medical scales, recovery is measurable in simple terms.

A simplified form of trajectory mapping has also been employed by the NHS Health Advisory Service for the purpose of planning future care. It splits the needs of the patient into three time dependent phases, acute care, rehabilitation & community care and later care. Across these phases, we see a gradually improving clinical state and a smooth and predictable fluctuation in the planned provision of medical/nursing, therapeutic, social and non-statutory services.

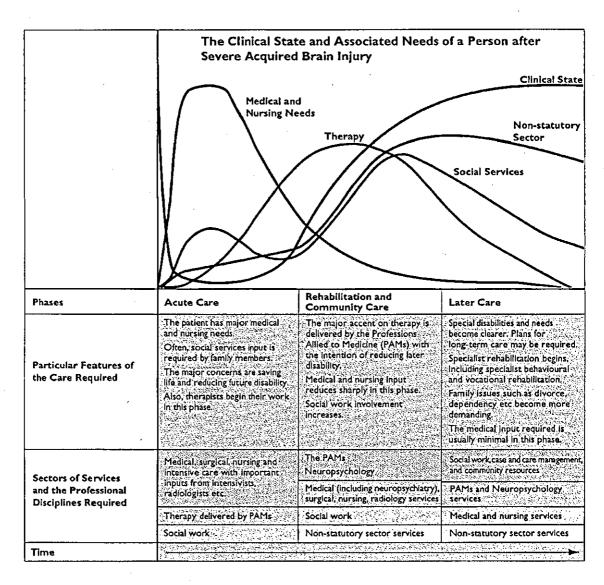


Figure 8. The Clinical State and Associated Needs of a Person After Severe Acquired Brain Injury. Taken from NHS Health Advisory Service, (1997). *Mental health services: Heading for better care.* London: HMSO, p75.

This trajectory suggests a clear and regimented pathway of care where recovery is expected and service provision is carefully coordinated. It seems to imply that care packages can begin to be planned without any knowledge of the individual patient and that as the patient's condition reaches a plateau; they will no longer need service intervention. As already discussed in Chapter 2, this is simply not the case. The issue of long term monitoring and provision will also be addressed further in Chapter 6.

Bringing together the different uses of the trajectory concept from dying (Strauss & Glaser, 1970), to illness (Strauss, Fagerhaugh, Suczek & Wiener, 1985; Corbin & Strauss, 1988), to brain injury (Bellaby, 1991; Bellaby, 1995; NHS Health Advisory Service, 1997) to the whole of life (Dreier, 1999), provides a range of ideas that have provided an orientation throughout the data collection and coding process.

3.4.2 The Broader Context of Health Research

Before moving onto case examples from my research, it is important to acknowledge the wider body of theory within which this thesis is positioned. There is a large corpus of work on health and illness, which looks at similar ideas of social representations, managing changing relationships, issues of identity and shifting interactions over time (Flick, 2000; Frank, 1995; Gerhardt, 1989; Hardey, (1998); Hodgetts & Chamberlain, 2000; Toombs, 1992; Zola, 1973); with work on chronic illness being of particular relevance due to it's long term, life changing, nature (Anderson & Bury, 1988; Corbin & Strauss, 1988; Horton-Salway,2002; Shuman, 1996). In particular it is worth highlighting the theories of Alan Radley (1994; 1997; 2000) and Claudine Herzlich (1973) as exemplars in the field of Health Psychology.

Radley (1997; 2000), discusses the occurrence of symptoms and illness within everyday activity and how it is only in the instance of failure that our bodies even enter our consciousness. As people continue their lives, health is measured through the ability to fulfil commitments and maintain social positions. Perhaps the key issue here is that illness as a state does not stand alone; life continues along a trajectory into which any sense or experience of illness must fit. Throughout this time, people facing illness or disability must exist in a world of health, where over time, the disruption of relationships can lead to social isolation and a loss of self (Radley, 1994).

Herzlich (1973) also looks at health and illness as being bound up in everyday social life; with the chronically ill being constrained by or excluded from society. She identifies three metaphorical representations of illness which focus particularly on the relationship between the patient and the meanings they ascribe to their own inactivity. The first conception is that of 'illness as destructive' where the patient feels that inactivity has been forced upon them by their illness, including the destruction of social bonds within the surrounding world of health. Herzlich suggests that patients with this conception are often unwilling to make associations with others who are 'tainted' by illness or to engage in palliative activities, which are simply de-valued by comparison with former capabilities. They may reject illness behaviour for as long as possible, avoiding medical support in order to maintain a state of denial, until

symptoms take over, forcing a more passive approach, which Herzlich suggests, is simply another way of not taking part in illness.

The second conception is of 'illness as a liberator' where inactivity is seen as a positive reduction of everyday burdens — with illness being an acceptable catalyst for the rejection of obligations, social constraints and even reality itself. Illness brings an opportunity for rest but in the same instance gives greater value to the experience of time, with possibilities for exploring new intellectual pursuits. There is also a sense of tolerance by society with greater freedom to be different, even irresponsible. The space afforded by isolation is valued rather than feared and can be seen as offering liberation of the personality from the pressures of society. This positive outlook is only possible as long as it is supported by others. If the patient sees themself becoming a burden, then they will no longer able to maintain their sense of freedom from the outside world.

The third conception is of illness as an occupation where the patient has a function of actively fighting their illness and struggling against their situation. Inactivity is seen as necessary to provide the resources for this ongoing struggle, which is the main focus of each day. In this case the patient fears and yet accepts their illness, seeing it as an almost inextricable part of them. The patient is likely to have a cooperative relationship with medical professionals and will be eager to obtain information. Their fight is both physical, using their 'reserve of health' and psychological; with any mental effort being aided by developing specialist knowledge of their condition.

These descriptions provide useful reference points for thinking about how people might conceptualise illness in relation to their life trajectories, with considerations of former health, future hopes and an ongoing sense of 'belongingness to society'. Herzlich's work gives a framework to consider how people move between states of health and illness and the identity work they do in perceiving and responding to disability in different, interchangeable ways (See also Stainton Rogers, 1991). Further reference to these conceptions will be made later in the thesis.

3.5 Case Examples

The best way to illustrate my use of grounded theory is by demonstrating the development of coding and themes on a specific topic. Section 4.3 of this thesis is "The Use and Loss of Memory". I was aware prior to doing the interviews that most people suffer some form of memory loss following an acquired brain injury. I was thinking about this in terms of classic concepts, i.e. short-term vs. long-term memory loss and retrograde vs. anteriograde amnesia. I was also sensitised by my time with this client group to some of the effects of memory loss on people's everyday lives (e.g. lack of understanding by others, difficulties in keeping employment when tasks are quickly forgotten).

I began coding these instances of lost memories using the classic concepts, but as the interviews progressed I began to use alternative categories, which are more meaningful in the way that people tried to differentiate between levels of memory deficit; complete, fragmented and lost. Complete and fragmented memories could then be broken down further into: not reconstructed, semi-reconstructed, reconstructed and false. To clarify, reconstructed memories are those which people pieced together from information given by others. Their status as reconstructed may be explicitly highlighted or implicit in the way that people discuss events.

More issues became apparent within these new categories of construction, for example, when memories are semi-reconstructed the information may have been censored by carers or professionals, so the patient is only allowed to remember selectively. In the case of false memory, there are studies of its neurological basis and when it seemed to be purely an expression of physical damage, I categorised it as 'genuine', but I also found instances where claims as to memory or its lack appeared to have an occasioned character, in which case I classified it as tactical.

To illustrate, I will present a few coded examples of actual transcription. In the first excerpt Geoff is telling the story of the assault that caused his brain injury:

FIRST OF ALL CAN YOU JUST TELL ME BRIEFLY WHAT THE CAUSE OF YOUR INJURY WAS?

Geoff: When I went out on the 29th of November, to get a packet of cigarettes of all things from a garage on St Matthews, I was badly assaulted and I was left for

Specific date Everyday activity Left for dead dead. At 12:40 a passing police patrol found me, I was rushed to the A&E at Leicester Royal and from there on rushed to the Queens Medical Centre, intensive care, this I only know cause of staff who told me and mates and family.

Specific time Rushed - crisis Rushed - crisis Memory reconstructed

I have noted his use of specific temporal markers and grounding in everyday activity, his reference to death that highlights the critical nature of his situation, the imagery of medical professionals rushing to save him and the admission that this story is constructed from the words of others rather than his own memories.

Rachel had an aneurysm that was treated through surgery. The following excerpt shows her explicit discussion of memory reconstruction following the operation:

Rachel: All the things happened before the operation, I can tell you, but after, for one year, I don't know anything, only that people tell me things and it's weird because, erm, how to say this? When something happens and you remember it, right, you've got a picture in your head. Like I'm here, I'm talking to you, if I remember this and talking to you I'll have a picture in my head. There'll be you, there'll be plants... YEAH

Rachel: ...and then what happened around it

YEAH

Rachel: When things, after the operation, for the first year,

I know them

YEAH

Rachel: But there's no pictures, there's no memory. I don't (pauses), my children told me things, my husband told me things, so I know what happened, but I don't remember, do you know what I mean?

Statement of ability Anteriograde loss 'It's weird' Constructs shared understanding of remembering Visual imagery

Linking events to images

Statement of ability

No pictures
Told by others
Memory
reconstructed

I have started by noting that Rachel presents her ability before her disability. This could function to show what she has lost or to affect the way in which she is perceived. She describes a form of anteriograde amnesia where her memories for a year after the operation are based on the explanations of others. I was interested in the way she makes explicit the 'weirdness' of her situation and the way she works up a shared understanding of what it is like to be in her position. I have coded her explanations of the difference between genuine, visual memories and reconstructed language based memories. As with Geoff the overall theme is reconstructed memory, but the contexts from which this theme is created are quite different.

Daniel also has a form of reconstructed memory, but this was created through his own thoughts and imagination rather than through the explanations of others. As such, many of these memories are of events that Daniel has not in reality experienced. In

this final excerpt, Daniel discusses the realisation that he must question his remembered past:

Daniel: The frightening thing is, because obviously the brain's been affected, a lot of what I thought had happened to me, it's in there, it's, it's, it's, it's part of my memory and has become so and so when somebody turns round and says, "No, you couldn't possibly have done that, you've been in hospital all this time" and I go, "Oh no I've not"

Frightening
Reality of thoughts
Ownership
False memory
Keepers of info
Stability of memory

I have tried to take account of emotions as they are so often overlooked in medical studies. For Daniel this appears to have been a frightening experience to find that his memory is not a true reflection of his life. The coding indicates his thought process as he tells the story; he starts with the emotion, and then the reason for this emotion. He has had to redefine his own sense of reality, as a part of him is not functioning as expected and he explains how it took interaction with others to make this apparent.
Although he tells the story from the perspective of someone who is now aware of his altered memory, he finishes this monologue by taking us back to his former self, and his belief in his own thoughts. In this way, he shows the progress he has made in recognising and accepting the fallibility of his own neurological record of events.

This information was initially organised using node trees on NUD*IST that I developed into models as shown in Figure 9 (on the following page). This early model allowed me to see the connections in my data as they unfolded and the computer package allowed for the flexibility to keep revising models according to the subtle changes that grounded theory analysis presents.

With a visual representation of key data I can then look in-depth at each theme, returning to the original audio data and other primary sources such as letters, diaries and health and social care records. Through lengthy analysis I will identify a set of data driven themes that explore the main issues raised by patients and their families. It is hoped that these themes will ultimately feed into a broad trajectory of illness and care that can be used as a model for understanding some of the needs and concerns of people whose lives are affected by acquired brain injury.

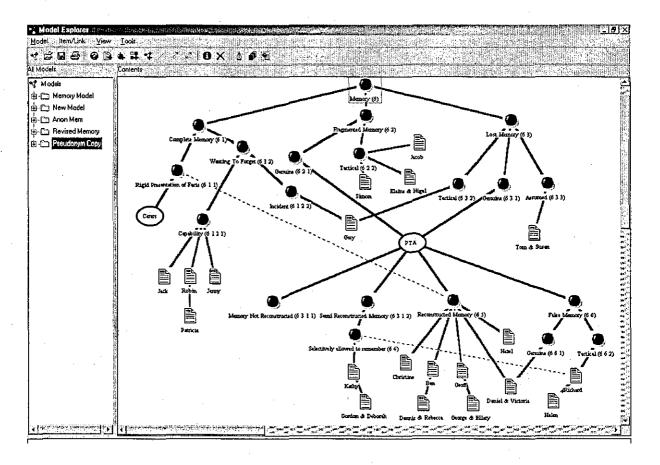


Figure 9. Example of NUD*IST Model Development

The data will be presented in four separate chapters. Chapter 4 will further address the issue of storytelling. It will then focus on information gathered mainly from interviews with patients, about their experiences of brain injury, how it has impacted on their lives and how they have adapted to their altered situation. Chapter 5 will focus on carers, looking at how their role develops over time and how agency shifts between themselves, the hospital and the patient. Chapter 6 will deal with issues of professional care delivery. It will tackle concerns raised by patients and carers about support and information sharing. It will also revisit the trajectory concept as a useful tool for professionals in planning and monitoring care. Chapter 7 is a case study of one couple's experience from the first symptoms of a brain tumour to death five years later. It will bring together themes from the preceding three chapters to give an indepth view of life within the trajectory. Finally, Chapter 8 will summarize some of the key issues, and highlight their implications.

Chapter 4 – Analysis (I)

Representation of Self Following Acquired Brain Injury

4.1 The Nature of Storytelling

Rebecca: You know, it's er... I mean obviously it's, we've had to go over it time and time, every, at every stage of hospital because in all I think... has he had five or

six brain operations? I can't remember now... it all, it all goes into one

Dennis: Without sitting down to think about it...

Rebecca: I know, but erm...

Dennis: Exactly how many he's had

Rebecca: ...at every level it's sort of been an amazing story to different people, but

you know

Dennis: Three, three shunts I think Rebecca: Yes he's got three shunts

This excerpt highlights an important factor in all of the interviews conducted; the people involved were narrating a story of part of their life, which may have been told in some form many times before. Rebecca and Dennis are recalling the series of brain operations endured by their son, Ben. In doing so, they reflect on the how Ben's experiences have been an 'amazing story'. That is, how these experiences form a coherent and compelling narrative, with its own structure and texture. This chapter will focus on these kinds of stories of and about people who have had an acquired brain injury. It is important to clarify that what was said will not be treated as undisputed fact, but as material to be analysed and interpreted. That is, of course, not to call into question the understandings of those interviewed, or to discount their experience, but merely proper to an analytic stance that is sensitive to the wider social functions that storytelling serves. In natural everyday storytelling, we pick out information that will be seen as interesting, engaging and maybe even amusing. Sometimes our stories are incredibly well rehearsed, although they may be adapted, depending on the audience. Stories are constructed to suit the situation and to fit in with present life. As Freeman (1993) asks:

Is autobiography itself – the telling of 'our own' life story – really possible? Isn't the very determination of what is significant and worth telling and what is not made by others, particularly in the form of the words, modes of understanding, and genres they send our way? (p. 79)

To give an example of the sort of storytelling that took place throughout these interviews, the following monologue came from Alex, who had a riding accident less than six months previously.

Alex: Yeah for twelve days I just remember nothing, erm, after that I do remember seeing the date and it was the 18th of December, I thought it was the 6th of December, I just thought what the hell was going on here? Erm, and I did have a lot of speech problems I tended to get jumbled up with words, or just forget, so they gave me, I think a naming exercise where I had to name fifty animals and things like and half way through I wanted to name a mongoose, I love mongooses, lovely animal and I just couldn't remember it, I can remember the animal, I can remember what it did and everything else, I just like couldn't actually name it. Then I must have spent about ten seconds thinking about it, and I just thought, I described it straight to my dad, it's like a, an animal in Africa that attacks snakes, it's a little bit bigger than rat size and he said mongoose. So I think I've just about got over that now. Er I think one of the main things was that I didn't have too many actual brain cells damaged, most of the actual original effects were mainly more brain bruising, I think apparently my brain went up about 10, 20% larger than it should have been, but then it all sorted out very quickly. So it looked bad to start with, and they thought it was going to be six months before I leave the hospital, that was the first thing my parents said, that it would be six months before I leave the hospital and then after six weeks there, I was fine. So after three weeks I did make quite a good recovery.

Having been asked about the early short-term effects of his injury, Alex starts with concrete facts; to illustrate his loss of memory, he tells us the first date he remembers and the date he thought it was. It was quite typical for people to provide some sort of temporal marker of when their injury occurred, usually near the beginning of the interview. Alex then moves on to his communication problems, this time illustrating with a far more detailed story. He does not tell us about how communication deficits affected his everyday life, instead he identifies them through an artificial testing process, where he was frustrated at being unable to name a mongoose from its picture. This is a somewhat obscure creature to use in a measure of this sort and although Alex describes this as a test of communication skills, naming ability is often classed as a memory issue. One way then of understanding this story, is that it reflects the individual's beliefs about what happened (albeit with slight factual inaccuracies). However, to treat the story in this way is to invoke an 'internal state' to which we cannot adequately claim full access. Radley & Billig (1996) suggest that researchers who wish to analyse discussions of health and illness, should shift their attention from 'beliefs' to 'accounts'. This is because beliefs are not simply objects that we carry with us, since people:

Construct their state of health as part of their ongoing identity in relation to others, as something vital to the conduct of everyday life. This means that the accounts that are given of health and illness are more than a disclosing of a supposed internal attitude. In offering views, people are also making claims about themselves as worthy individuals, as more or less 'fit' participants in activities of the social world. (p16)

In treating stories as accounts, we are then focusing on the sorts of claims and descriptions people offer and seeking to interpret how these elements cohere in the experience of patients and carers (see also Stainton Rogers, 1991). The stories told by these patients and carers obviously go beyond health and into their wider lives. For some, the opportunity to talk was constructed as a cathartic and much valued experience. The interview may have allowed them to share concerns that they had felt unable to raise without the 'permission to speak' that such an occasion grants. In this way, we can see that interviewing creates a highly unusual context. In particular, it can allow for a negotiation of status. For instance, for many patients and carers this was one of the rare occasions on which they had been able to formally discuss their experiences with someone other than a medical professional. In these interviews, people were not time limited and they had opportunities to talk beyond the questions, about issues that are important to them. Atkinson (1998), in his work on life story interviews, suggests that being able to talk about our life has great value:

Telling our story enables us to be heard, recognized, and acknowledged by others. Story makes the implicit explicit, the hidden seen, the unformed formed and the confusing clear (p7).

Beyond the social aspect of sharing stories, Frank (1995) claims that the telling is important for individuals as a way to make personal sense of their suffering; referring to patients in these situations as 'wounded storytellers'. He identifies three basic narratives of illness in restitution, chaos and quest. Restitution stories anticipate a return to health; chaos stories talk of the loss of control around ongoing illness, with neither respite nor hope; quest stories talk of illness as a spiritual journey offering the individual the means to become someone new. This categorisation of narratives is resonant of the conceptions of illness introduced by Herzlich (1973). It should be noted that these are merely examples of a growing body of research into narratives of health and illness (see also Atkinson, 1995; Horton-Salway, 2001; Kleinman, 1988; Mattingly & Garro, 2000; McAdams 1997). Particular use will be made in this thesis of the interpretations of Charmaz (1991) as her work shares roots in grounded theory with a focus on conditions which have no cure.

4.1.1 Presenting the Self

One of the first issues that becomes apparent in the conduct of interviews is the self-presentation of interviewees. There is obviously some stylising involved in this presentation, aimed at creating a favourable impression. However, for people with a hidden disability, as brain injury often is, this stylising goes hand in hand with decisions regarding whether to make visible, and if so, to what extent, the nature of their disabilities. A interviewee may decide to be entirely open about the problems s/he faces or they may prefer to present a more capable image that fits with their preinjury identity. Goffman (1963), in his work on stigma, summarizes this issue with great clarity:

When his differentness is not immediately apparent, and is not known beforehand (or at least known by him to be known to others), when in fact he is a discreditable, not a discredited, person, then the second main possibility in his life is to be found. The issue is not that of managing tension generated during social contacts, but rather that of managing information about his failing. To display or not to display; to tell or not to tell; to let on or not to let on; to lie or not to lie; and in each case, to whom, how, when, and where (p.57).

This potential need to manage information and impressions can be demonstrated throughout many of the interviews conducted. As an example, we can look at some talk from Rachel who had neurosurgery to remove an aneurysm. The resulting brain damage has left her with a range of deficits including fatigue, memory loss and left sided weakness. Rachel constructs her life prior to the illness as that of a high-powered career woman and she appears keen to represent herself as a strong and independent initiator. This representation does appear to shift however at one point during the interview when Rachel constructs a version of self as dependent and vulnerable:

Rachel: So he wakes me up then and tells me the clothes and everything and then help me get dressed, then he goes to work and then, I can't remember what I was saying, I was gonna tell something but I can't remember. No, it's gone. YOU WERE TALKING ABOUT THE WAY THAT YOU REMEMBER THINGS AND YOU WERE TALKING ABOUT TIREDNESS. YOU WERE GOING THROUGH YOUR ROUTINE OF GETTING UP IN THE MORNING AND WHAT YOUR HUSBAND DOES

Rachel: Yeah, yeah, I get up and then dinnertime he comes home. His dinnertime changes, I can't remember that, even though that's numbers because there's too many changes. Monday one time, Tuesday another time, Wednesday another time, Thursday another time, Mostly I can't remember what day it is

This is the only time during the 77-minute interview that Rachel mentions her husband's role in directly supporting her. We may interpret this to have been an unguarded moment since Rachel immediately claims to forget what she was talking about, allowing a change of subject. She quickly moves on to discuss her husband's changing routine and re-flags memory as an issue. This could be a genuine expression of memory loss, but it is the only time during the interview that she loses track of what she is saying. The co-incidence of this solitary lapse with Rachel's one admission of dependence does not appear to be incidental. This occasioned invoking of memory loss will be examined further in Section 4.3. What we might ask though is what does Rachel gain by claiming to forget? Throughout the interview she portrays herself as a woman in control, and this representation is somewhat weakened by her single admission of needing support. By quickly halting this subject and moving on, she regains her ground for establishing an image of confident independence. This is reinforced again when she talks emotionally about the problems of fatigue:

Rachel: I get terrible tired...

YEAH

Rachel: Sometimes I'm so tired I think I could cry...

YEAH

Rachel: If I was that kind of person I could cry.

She describes the fatigue as so bad that she could cry, but quickly tells us that she is not that sort of person; the implication is that she is stronger than that. She represents herself as fighting against her illness and its effects and this coping strategy is articulated throughout the whole interview. Other patients however tend to focus on their deficits and often present quite a vulnerable image. We many see this as reflecting a different coping strategy, where life is rebuilt around illness instead of the person struggling to regain their former self. This was particularly apparent in those who declared that others were to blame for their injury. It could be that where people are able to construct an account of their condition as having been inflicted by another this leads towards the adoption of a status of 'victimhood'. Geoff is one such example; he was mugged and assaulted by a small group of people while out walking late one evening. During open discussion where he had the opportunity to talk about anything that he felt was important, he quickly returned to the effects of his injury and to the people responsible:

Geoff: I've not had no epilepsy yet. Had a couple of blackouts and a, one or two convulsions, but that's all, but no fits. The longer, the longer I stop away from epilepsy, the better. So, as the doctor said, "You look a lot better now that when you did when you come in", He said, "Really", he said, "By all rights, should be somewhere else". And that's how close I come to leaving this life. All because of three or four people (getting tearful)

IT'S VERY SAD

Geoff: Yeah, I just hope they get caught, fifteen years each, no time off, 'cause they've made a mess of my life.

Epilepsy had not been mentioned previously, Geoff spontaneously states that he has not had this condition <u>yet</u>. This suggests that he has expectations of his circumstances getting worse rather than better. Throughout the interview he focuses on what he has lost and the damage that has been inflicted upon him. One possible explanation for this focus is that since the people responsible have not been apprehended it is difficult for Geoff to construct 'closure' to his situation which creates difficulties in addressing the prospect of future recovery. While he waits for justice to be served, he continues to present himself as a man whose life, as it was, has been taken away. He is adopting a 'victim' role and post-interview discussions revealed that he has an understanding that the worse his condition, the more his attackers will be made to pay, if and when they are eventually caught. Hence there is something at stake in emphasizing deficits. We might speculate that this tendency to emphasise his status as a victim has broader effects on his daily life. Ultimately, this might result in a reduction of the level of recovery that he can aspire to since the regaining of capabilities is not central to his construction of self.

Undermining capabilities can also be a positive strategy for some. There may be a variety of functions being served by this. For example, Edward was hit by a car after he stepped out of his vehicle. Like Geoff, he offers an account of any subsequent disability as being the fault of another person and he therefore has the potential to resign responsibility for recovery. During his interview, Edward represents himself as unable to work but afterwards, he stated that he was unwilling to work. The following three excerpts are presented in temporal order. In the first, Edward is talking about the need for access to people who can give information and guidance:

Edward: Erm, but where people go to, if they need to go in specialist erm, head injury units, or not I don't know, or whether they could live with their family or even on their own erm, it'd be nice to sort of think about but erm, just somebody who knew what they were on about could say look you are gonna face these problems YEAH

Edward: Where you gonna live and how you're gonna survive, either on the sick or, you know what other benefits you might be able to get

So Edward constructs the possible options after brain injury, as either being 'on the sick' or receiving benefits. The roots of this understanding are not made clear but they appear to have had some form of influence on his life. He has made a remarkable recovery and is a very capable person, but he cannot see himself returning to paid employment:

SO WHAT YOU'RE DOING NOW, HOW DO YOU THINK THAT COMPARES TO YOUR EXPECTATIONS OF WHAT YOU COULD, SORT OF...?

Edward: Erm, I don't think, being honest, I could have a nine-to-five job, Monday to Friday, because I'd just get that fed up with it, after about a week I'd tell 'erm to sod it, so...

AFTER YOUR INJURY, DID YOU EVER ASPIRE TO GETTING BACK TO THAT 9-TO-5 JOB OR...? ...ARE YOU HAPPY WHERE YOU'RE AT NOW? Edward: Erm, I think I'm happy where I'm at now, but I never sort of assessed that I wanted to get back to like a full-time job and erm...

YEAH
Edward: I did about four and a half years in Leicester Carriage Builders, building mobile shops and stuff like that and then erm, eight and a half years in the RAF, so erm, I know I couldn't get back to the Forces

YEAH

Edward: So, what I could have done, I wouldn't have a clue

It is difficult to identify the foundation of Edward's account. He says that he does not think he could do full time work, "Because I'd just get fed up with it". There are at least three possible interpretations, the first is that Edward has sustained neurological damage that has impacted specifically on his ability to stay motivated and to tolerate the pace of working life; the second is that Edward simply does not wish to 'rejoin the rat-race' when he has other financial support options open to him; the third is that Edward believes that his brain injury must affect his capability regardless of whether it does — such an understanding could be built from the expressed attitudes and expectations of others. Perhaps for some a restrictive understanding of one's current condition can in itself be a disability. The image of disability as negative, focusing on losses, is a cultural commonplace. However it is important to note that this negative representation of disability does not necessarily constitute an overall negative evaluation of self. Edward may never again work for a monthly wage. In terms of recovery statistics this is a negative outcome, but when I asked Edward whether he was happy, his response was more equivocal.

Edward: Yeah, I should think so, erm..., yeah

YEAH

Edward: But whether I could get another volunteer based, sort of job, erm, I don't know, or whether, mentally, I could cope with it, you know, being too rushed or you know, working three days a week er, I dunno

DO YOU FEEL YOU'VE REGAINED YOUR INDEPENDENCE NOW?

Edward: A bit yeah, it's erm, the only good thing about this accident is, it's bought my house. I don't think \underline{I} could've afforded a house, you know?

YEAH

Edward: Or I'd have a 25 year mortgage round my neck, which I wouldn't appreciate, eh?

Edward represents himself as gaining fulfilment by doing voluntary work as and when he chooses, but his time is his own. He used his compensation payout to buy a house and this gives him some financial security. With minimal outgoings he can live a comfortable life on benefits and he gives the impression that he is content with his lifestyle and level of recovery (this is resonant of Herzlich's, 1973, conception of 'Illness as Liberator'). After the interview, he admitted that he was exercising caution while discussing employment issues as he had been worried about 'incriminating' himself on tape in case anything he said was used against him in benefits checks or ability assessments. The overall picture though is that he appears to be content in his situation and does not want to work even though he may well be capable of doing so. Outside of the interview, he represents himself as facing many difficulties fighting back from brain injury and as deserving a rest. As long as he receives benefits he would prefer to maintain his current lifestyle.

A good contrast is with Owen, who was also involved in an RTA. He has found the benefits system more difficult to navigate and felt under pressure to return to work before he saw himself as physically ready.

OK, WHAT WAS THE CAUSE OF YOUR INJURY?

Owen: Erm, RTA road traffic accident in '96, Christmas Eve

YEAH, WERE YOU DRIVING? A PEDESTRIAN?

Owen: No I was a pedestrian going over the road

RIGHT, OK AND THE FIRST SIX MONTHS AFTER THAT ACCIDENT, WHAT

WERE THE PROBLEMS YOU WERE HAVING?

Owen: Well what it was is, here you are, this is a good bit, I was in hospital, I was in a coma for about a month and a half, more or less, you know

YEAH

Owen: Came out of hospital in about March time, near my birthday and I was still in me plaster

YEAH

Owen: Dole sending me letters saying right well you'd better go work or we're gonna stop your benefit, you know, I couldn't believe this, I was still in me plaster

Owen: They knew full well that I was in a coma.

YEAH

Owen: And all that, you know, and like, so what did I do? 'Cause I'm sure someone

told me in hospital, go for some counselling

YEAH

Owen: Or summat like that, you know, but I ignored that and done what the Government told me to do, you know, go work. Went work for about a full year and

then everything started going wrong.

Owen portrays the benefits providers as harsh, even threatening, "You'd better go work or we're gonna stop your benefit". Owen represents himself as a victim of the system; he says that these providers knew the extent of his injuries, which suggests that they were being unreasonable, but he does not elaborate on this claim. This all builds towards his, account of subsequently ignoring recommendations of counselling and returning to work. He is displaying how he offers a version of events where he picked himself up and got on with things. However these claims also build up an evidential base that allows for inference to be made about where blame ought to be apportioned when, "Everything started to go wrong". The message from Owen is clear, I did not fail, the system failed me. We may treat this causal account of events as another adaptive response; blame the injury, or blame others and negative experiences become easier to manage. Failings are separated from the person allowing for the possible maintenance of self-esteem.

4.1.2 Managing Sensitive Information

A clear concern for many interviewees is around the revelation of what might be considered sensitive information, particularly in the presence of a tape recorder. This information may concern bodily functions, sex, death or the injury and consequent brain damage itself. Sometimes the question of whether to divulge goes beyond the interview situation and boundaries became apparent between carers and patients, where carers had been put in a position of holding information that they feel is too sensitive to share with the person it most affects. Examples of this include parents who made the choice to have their daughter's pregnancy terminated while she was in a coma, a husband who refuses to tell his wife that her brain tumour is terminal, and as will be presented now, a wife who feels unable to tell her husband about the level of brain damage he has sustained.

Susan and Tom were introduced in the first chapter of this thesis. After the interview had concluded, Susan took me to one side to discuss an issue, which she felt to be

sensitive. She had tried to indicate the removal of brain tissue without verbalizing it during the joint interview, but had been concerned that Tom should not know. She did not think that Tom could cope with the knowledge that his neurosurgery involved some excavation and that this would limit his recovery. She therefore felt it necessary to protect him from this information (despite discussing it in an article published in their local newspaper). However, it is apparent that he is aware of these details

CAN YOU FIRST OF ALL TELL ME WHAT THE CAUSE OF YOUR INJURY WAS? WHAT ACCIDENT YOU HAD.

Tom: Well I think I had summat knocked out of here (points to head)

YEAH, HOW DID THAT HAPPEN?

Tom: It must be hit on something

YEAH

Tom: You know and er, summat were wrong on there, so they take it out

Tom quite clearly refers to the loss of brain tissue, first through the injury and then through neurosurgery. It is interesting therefore that his wife, who was present when he said this, will not discuss it in front of him, still believing that he has no knowledge of the tissue removal and that it would only be damaging for him to be told. It is likely that Tom has picked up this information from his sons or during his time in rehabilitation, when staff explained the accident to him through pictures. Tom goes on to discuss his recovery. He shows clear insight into the long-term nature and limits of his recovery – another issue which his wife believes he does not comprehend:

Tom: Yeah, you know, just go when I can, it's just that I wanna try and get together all the while, I wanna try and, like I used to be YEAH

Tom: You know, so I can do things but I don't know whether, you know, I've gotta try wait a long while DO YOU FEEL...

Tom: It could take a long while 'fore I get, get it something, if it, if it comes, it might not come though, you know what I mean? I don't know I'm just, wondering about it, you know.

The image represented is one of Tom struggling against his disability. He appears to know that he has limitations as a consequence of his injury, but represents himself as determined to push against these boundaries. He describes improvements as taking time and that some may never occur, but that he is working towards them. He also flags up his own uncertainty in this situation. We may wonder if Susan's desire to protect him from the truth makes it more difficult for Tom to jointly construct answers to many of his questions. By 'protecting' him, i.e. not discussing key issues — it may be that Susan reduces Tom's agency in the recovery process. Access to realistic goals

would conceivably help him to focus his energies on functions that he does have the potential to regain.

Lost function appears to be easier for patients to discuss than carers. This may be because either patients are more reconciled to the effects of brain injury, or carers felt that it was not their place to discuss sensitive issues. A subject which came up many times was incontinence; Lucy for example dropped this difficulty into her discussion of early problems:

Lucy: Well first I was totally paralysed, the only thing I could move was my eyebrows. Then slowly the right side came back, a bit, but speech didn't come back for nearly six months, and erm, I was incontinent most of that time, in fact, I think for about a month after I got home I was incontinent...and...basically the only way that Mum could get me around, even when I got home, was sling me across her shoulders, more or less. And so I couldn't cope, be on my own, without aid at all

For Lucy, incontinence is represented as an instance of a problem from the past. It is yet another difficulty that she has overcome, and therefore it is another marker of how far she has progressed. It plays a part in a story of triumph, where this represents one of her lowest points of bodily control, evidenced particularly by her description of her mother 'slinging' Lucy 'over her shoulders'. Its sensitivity as a topic is potentially diminished by its temporal context. For Maria however, incontinence is still a current issue, but within the interview context she was able to discuss it in quite a detached way:

RIGHT, AND BEEN ANYTHING ELSE THAT, SORT OF IN THE FIRST SIX MONTHS, BEEN ANY OTHER PROBLEMS THAT YOU...?

Maria: Er, I'm incontinent, erm, my left leg is half an inch shorter than me right leg and it's erm, sort or sent me pelvis out of tint, tilt, erm, what else? The vision in me right eye, erm, I, I used to have little black spots all in me vision, but they've cleared up, they've cleared up quite a bit

Like Lucy, Maria places incontinence within a list of other difficulties. This downgrades the implied status of the problem somewhat. However, although Maria is very open about her more sensitive problems, her husband (who acts as her full-time carer) does not appear to share this candour. He was interviewed separately and in the following excerpt he mentions regular visits from the District Nurse:

Jacob: Not had any Social Services for er, there's erm, there's a nurse that comes to see her
A DISTRICT NURSE?

Jacob: A district nurse, about once every couple of months, er, but she can't do anything because there's nothing for her to do really. Basically she only comes for a chat and see how she is but if there's anything that she's, wants doing, then she'll go and see one of the doctors in the er, in the practice and see if anything can be done. But apart from that, nothing.

The District Nurse's role in Maria's care is to monitor her incontinence, but Jacob carefully avoids this topic. He acknowledges the existence of this professional but then states, "There's nothing for her to do really". This is clearly a problematic statement since it invites the hearer to conclude that this professional was serving no practical purpose in Maria's life and was therefore a wasted resource. Jacob's apparent preparedness to risk such an interpretation can be taken as an indicator of the difficulty he has in discussing Maria's condition. In her separate interview however, Maria goes on to discuss treatment for haemorrhoids (a side effect of her immobility), which she describes as very upsetting because of her reliance on Jacob to cross personal boundaries.

Maria: And er, I have to have er, er, cream put up me back passage and it's very, very traumatic and very embarrassing. I've, I've gradually got used to the idea, and I mean, my hubby and I, we make a laugh over it, which you have to, I mean you have to, have to make light of it, but, in deep down, it's very embarrassing and er, but I think it would be a lot better if somebody could take the time to sit down with a carer, explain exactly what might be involved, you know, what might be involved, not what will be involved

YEAH

Maria: But what might be involved, and get them prepared, cause I, to be quite honest, I don't think my husband really realised what he was taking on YEAH

Maria: Erm, I'm not saying that he was, he wouldn't have taken it on anyway. Well he's told me he would, even if I was still bedridden, he said he would gladly have take, he would still gladly take it on, but touch wood, I've improved

Maria here flags up something of what can be at stake in being a carer. The realities of providing care are often very different from anything the carer might have been led to expect. Jacob is performing personal care tasks of a highly sensitive nature. Maria emphasises that together they use laughter to overcome the difficulty and embarrassment of the situation, but, Maria suggests that this is a show for each other. Underneath – 'deep down' Maria still feels mortified that they must share this process. This separation of what must be done to get through daily activities, and the complexity of Maria's feelings appears here as an uncomfortable aspect of how their respective roles have been negotiated.

The other striking issue in this is the way Maria repeatedly refers to their situation as something that Jacob has 'taken on'. Maria is orienting here to the lack of choice Jacob has been confronted with in making the decision to become her full time carer. For many prospective carers in the immediate period following the trauma, their loved one is presented to them in the process of recovery and there is institutional (and perhaps social) pressure to take them home. Many at this point are not in full possession of the facts and do not have expectations of caring as a full-time, long-term role. The developing change in perspective is often described as evolving slowly.

Sometimes an issue that would usually be considered as sensitive, becomes less so because of the relationship dynamics of those involved. Parents whose children had been brain injured before reaching adulthood had a greater tendency to talk openly about sensitive issues that involve their offspring. One interpretation of this is that if a child never reaches a point of breaking away to demand independence and privacy, then they will not be granted a separate private life. Just as parents discuss intimate problems of their young children, such as wetting the bed, parents of people who were brain injured as children do not seem restricted by the norms of privacy that would apply when discussing other adults. Ben for example is in his mid-twenties, but his parents feel quite at ease discussing his sexual development and his need to monitor his urine output. Ben took a toilet break during the interview and upon his return, his parents asked him to tell me how much he had done:

Dennis: That's why even now everything, you know er, Ben will tell you now, how

much he's just done Rebecca: Yes

I KNOW THAT BEN COUNTS IT.

Dennis: Yeah, well...

Rebecca: Well it's measured at home, it's actually measured

Ben: One litre fifty.

Rebecca: One litre fifty, right okay, now we used to have to write it down.

YES

Rebecca: Are you surprised at that? One litre fif...

THAT SOUNDS A LOT. Dennis: That's a lot innit?

Rebecca: That's, that's Diabetes Insipidus...

Ben's parents were trying to make a point about the reality of his condition, diabetes insipidus, but at the same time, they demonstrated how social taboos are broken down by an ongoing parent-child dynamic in which privacy never becomes a topic of

concern. We may suppose that the idea of the everlasting childhood could be a significant issue for patients and carers in this situation to negotiate. For example, Rebecca goes on to discuss Ben's sexual development; again she is very candid, despite the sensitive nature of the topic:

Rebecca: He's what they call asexual, that... because he's not gone into proper puberty, he's not got the feelings that anybody going through puberty has. And they suspect that he don't, he won't ever have, because there's not a lot there. His erm, testosterone levels are very, very low. Erm... when I asked, when he was about seventeen and a half, he'd lost all the hair on his body except the hair on his head, his eyebrows had gone. I mean, I can show you a photograph of him where his eyebrows were really thick and he was quite dark, bit of a moustache. But there's nothing now and we struggle to keep the hair under his arms and sort of down below. So Dr Hughes said to you, "Do you want to be Peter Pan?", you said you didn't mind.

Ben: He asked me that, yeah

Rebecca: He said erm, "I've been there, done that", didn't you?

Ben: Yeah

Ben was asked whether he wanted to be Peter Pan – the forever child. This question and Ben's response have remained noteworthy for his mother and feature in her expressed expectations of him. The point here is that particular events may be recalled and commemorated by carers and patients as marking significant moments in the negotiation of the post trauma identity. However the meaning and significance of those events may be reinterpreted over time. Rebecca orients to that particular conversation as marking the point at which her son declined further treatment to 'make him an adult' and accepted that he will 'never grow up'.

Also discussed in this excerpt is Ben's supposed inability to develop sexual feelings. Sex is often an unmentioned issue but it was raised as a topic of concern by some interviewees. Overall, this was discussed most by parents of people who were brain injured as children (i.e. more than by patients themselves). There were concerns around sexual experimentation in adolescent years, and whether their child could be taken advantage of. In one interview it was implied that someone who was meant to be caring for this young woman actually assaulted her. The same family raised concerns about their daughter's ability to say no in sexual situations and related stories of collecting her from dates in a state of partial undress. They requested that, these comments would not be presented in full due to the sensitive nature of the topic. The mother of a teenage boy discussed another particularly difficult problem, and again I was asked to treat this information carefully. Since his injury, this boy has

displayed unacceptable sexual behaviour, in particular, making advances towards his mother and trying to touch her in inappropriate ways. This has damaged their relationship considerably if not irreparably and this is among the reasons that he is no longer able to live with his family. These are the more extreme sexual problems but in general, sex is an issue for many of the patients interviewed. As a typical example, when I asked Simon whether there were any other services that could have helped him he made reference to sexual needs that are often overlooked after disability:

Simon: Well that, well, services for (coughs suggestively), but I do not think, you

could get them, but...

CAN I JUST SAY, WHAT SERVICES ARE WE REFERRING TO?

Simon: Erm services of the body, well you know ARE WE TALKING OF A SEXUAL NATURE?

Simon: Well ay, you could be saying that

SERIOUSLY, DO YOU THINK THAT THAT IS A PROBLEM FOR PEOPLE

WITH BRAIN INJURIES?

Simon: What?

THAT SOME OF THEM MIGHT NEED ASSISTANCE IN THAT AREA, I MEAN IT'S QUITE A DELICATE...

Simon: Assistance in what area?

WELL I'M NOT TALKING SPECIFICALLY ABOUT YOU BUT, I MEAN IT'S A WHOLE AREA OF DISABILITY ISN'T IT? THAT SOME PEOPLE FIND THAT THEIR SEXUAL NEEDS AREN'T BEING MET

Simon: Yeah, but all you have to do is like go out, like, go shop, there's always girls hanging round the shops, but if erm, but usually they're young, but if you go, no, if you go where I go they're a bit more mature but not too old like just a year or too older than ya.

SO YOU PERHAPS THINK IT SHOULDN'T BE A PROBLEM FOR PEOPLE TO SORT THAT OUT THEMSELVES?

Simon: Well no I can see it as a problem, but I don't suffer with that problem BUT DO YOU THINK THAT OTHER PEOPLE MIGHT BENEFIT FROM SERVICES IN THAT AREA?

Simon: Erm, well, other people, I'm sure would, yes

Having initially raised the issue, Simon appears to quickly distance himself from it. As he showed signs of discomfort, I re-presented the topic to him as a general concern rather than something specific to his own life. Simon then re-specifies the issues as that of knowing where to pick up girls – a task in which he portrays himself as something of an expert, but concedes that others may have difficulties. Although opportunities to meet potential partners is an important strand of this overall issue, there are many other factors, such as the effects of physical disability, changes in self image, reduced confidence and altered libido. It should not be forgotten that people who are in steady relationships also have sexual issues to address. Rachel was particularly candid about this:

OKAY AND FINALLY IS THERE ANYTHING ELSE THAT YOU'D LIKE TO DISCUSS. ANY OTHER BURNING ISSUES?

Rachel: Well no I don't think so...there's something that I've always never really understood, but then I don't think I've ever really asked anybody because it's er, a bit of a dodgy one. Before I was ill I had sort of a normal sexual appetite, for want of a better phrase, I don't have one at all now, it doesn't exist.

Rachel frames this as an important issue that has blighted her life for years but one that she has not found an opportunity to adequately discuss. Her main concern is how this diminished sexual appetite affects her husband because she perceives that his needs are not being fulfilled:

Rachel: 'Cause I feel very sorry for my husband because he hasn't changed he's still normal and I think it makes life quite difficult for him, 'cause I just don't have a sexual appetite I want to go to bed and go to sleep...

There is also the concern of how this reflects on Rachel's feelings for her husband. She describes sex in terms of a chore that she must complete in order to keep her marriage functioning.

Rachel: I don't want him to think that I don't love him.

YEAH

Rachel: Now if we do have sex, usually after a while I feel so guilty and I think yeah I need to, I suppose it's horrible to say and I wouldn't say it to him, but it's like when the sink gets full of pots you've got to wash em'.

Rachel here describes sex in very practical terms as a task that she must respond to in order to maintain good marital relations. It is something that she performs out of duty and in response to feelings of guilt. She articulates the interdependency of her own life with that of her husband and represents a concern that he should continue to feel valued and wanted:

Rachel: And it's also part of your value isn't it? If my husband is sitting there thinking, "Oh, well she doesn't want me anymore". It's not, it's sort of devaluing him isn't it? 'Cause it's, it's, I don't know. [Long pause]. It's just something that, it wouldn't occur to me, I wouldn't think about it.

YEAH

Rachel: And when I go to bed all I want to do is go to sleep.

YEAH

Rachel: And you know, John knows that so if he'd say to me to come home for his dinnertime, cos he has a long lunch, and he'll say, "Do you fancy it?" and I think, "Oh no". And yet it's not because it's unpleasant, because...

YEAH

Rachel: Every now and again it's like the full sink of pots I think, no I need to, yeah...

YEAH

Rachel: Okay then and it's great, it's a really enjoyable thing.

YEAH

Rachel: So why, why am I like that?

Again Rachel uses the pot-washing simile to express the nature of sex for her. She does not represent her sexuality in terms of personal desire, but as one of the necessities of life. She emphasizes that the physical pleasure of sex has not gone for her; it is simply the self-starting behaviour that has diminished. This may be a result of the extreme lethargy from which she has suffered since her injury.

Having discussed the sensitive issues of disability, personal care, and sexual problems, the final topic is perhaps the most emotive - death. Where most brain injuries are caused by road accidents, we must expect other casualties. Martin, was driving home from work when he had a crash that killed his passenger:

Martin: I..., I..., I'd been at work, I'd been on nights

YEAH

Martin: And I was travelling home, early one morning, after a night shift, at a

quarry, in Leicestershire

YEAH

Martin: Just outside Melton Mowbray, er..., my last place of work was Asfordby

YEAH

Martin: Just outside Melton Mowbray, where they'd got, they used to have a coal

mine, which has closed now

AND YOU HAD A FALL AT THE QUARRY?

Martin: No, I had a motor..., I was travelling home in my motor

RIGHT

Martin: And er, my car and a lorry were in a collision

RIGHT

Martin: And er, consequently I ended up in the hospital. I was fortunate because

someone who was riding in my car...

YEAH

Martin: Received injuries from which he didn't, he didn't survive

Martin starts his account by stating that he had just finished a night shift, which allows for the inference that he was quite tired. He gives some sense of location by talking about the quarry, which formed the starting point of his journey. I asked him whether he had fallen at the quarry as this is what I had previously been led to believe, but Martin corrects me and continues with his story. To describe the actual accident, he uses the phrase 'My car and a lorry were in a collision'. By placing the focus on the vehicles themselves, he minimizes his role as an actor in the events as described. His references to himself concern the time up to, and following, the accident, but not the impact itself. This attention to and management of issues of blame will be discussed further in Section 4.2.

Martin was the only patient to mention the death of another person within the interview. However, two of the other RTA survivors who participated in this study actually lost a brother. Lewis was in his early teens when he was involved in a car accident. In the four years that I have known him, he has never mentioned his brother and this fatality was not written into any of the records that I accessed. However, this became the main topic of my interview with his parents as they returned relentlessly to this tragic loss. It appeared to me at the time as though they had been grieving for almost all of the 25 years since the accident, and were taking the interview as a further opportunity to share their grief.

By contrast, Gavin has discussed his brother privately but in a joint interview with his parents, his brother was not mentioned at all. The key difference is that Gavin was driving and it may be that this restricts his parents' ability to openly discuss their grief. Gavin is vulnerable to depressive states, and it is conceivably the case that feelings of guilt, alongside all the difficulties of suffering a brain injury, are a factor in this. Focusing on recovery rather than loss may then be a strategy adopted by Gavin's family to protect him. Indeed his family has concentrated all of their efforts on nursing him back to health and has arranged a constant barrage of private therapy including acupuncture, physiotherapy and osteopathy. They are among the many carers who have sought out wide ranging information on the benefits and side-effects of different treatments and as such they present themselves as experts in this field. Claims to expertise are also made by patients, but the status of these claims is often complex.., as will be discussed in the following section.

4.1.3 Use of Medical Terminology

The use of medical terminology can convey a sense of expertise. It is perhaps of no surprise that both patients and carers often use this tool for conveying information about the injury; however in some cases it is used somewhat inappropriately. The patient interviewed here claims that following his assault he has developed cerebral palsy in his arm. Of course cerebral palsy is a developmental disorder (in some cases inherited), which can occur following certain infections, in unborn children through to infancy.

Geoff: No 'cause of me right shoulder and right arm and I've got cerebral palsy in me right leg as a result of the acc.., of the beating I got, which is to do with the muscles, the signals from the brain are not quite reaching the muscles and I walk like somebody with a stiff leg and it could go anytime.

It could perhaps be that Geoff has heard his movement being liked that of someone of cerebral palsy and he has subsequently retained the name of the condition. Equally it could just be his own idiosyncratic diagnosis. Both in and out of the interview situation, he is eager to put forward his former career as a care assistant in a residential home for the elderly. He uses this as a demonstration of his expertise in the field of health & social care, and was keen to make a point of his valuable background knowledge prior to the tape being switched on for the interview.

The following patient also set himself up as something of an expert, feeling that he knew more than many professionals thanks to his interest in the media reporting of advances in brain injury treatment.

Patrick: They don't seem to know anything about brain injury at all. I mean what I've learnt about brain injury myself and what's made me more positive is what, the information I've got myself from recent programmes on television and articles in the newspaper.

AND DO YOU THINK A FAIR NUMBER OF PROFESSIONALS ARE NOT UP TO DATE ON THIS SORT OF THING?

Patrick: Yes, I don't think they're up to date at all, because what they're doing in the United States of course, they are taking brain cells from people and getting them to replicate themselves in a petri dish in the laboratory, and then they're injecting them back into the brain and getting people to recover from strokes for instance. Nobody seems to know this.

Patrick is in all likelihood referring to the new stem cell technology, which at this time is still in experimental stages. Patrick is hopeful that treatment such as this could repair his brain injury and believes that professionals are unaware of current advances because they have not offered him this opportunity. He pins his hopes on a medical solution. More generally, Patrick, despite his ability to walk, chooses to spend most of his time in a wheelchair, which (due to access problems), means that he is virtually confined to his bedroom at home. Without exercise, he has steadily gained weight and this is beginning to affect his mobility. In time, using the wheelchair may become a necessity rather than a choice. We may reason that his emphasis on a complete medical solution serves some purpose in this regard.

Patrick worked in education prior to his brain injury and he presents himself as a very knowledgeable man with something to say on most subjects. However, most likely as a result of his injury, he repeats himself often, talks over people and makes comments that can be construed as quite thoughtless and offensive. For Patrick's wife, the access limits of his wheelchair can provide a welcome relief and allow her to claim space and time away from her husband. She is therefore discouraging of any attempts to walk and unwilling to make alterations to their house. Patrick pursues hobbies that require little movement and so he is generally content with his situation. It could be argued that attempts to improve his mobility, either in or out of the wheelchair, would have a detrimental effect on his marriage.

Perhaps for Patrick, waiting for the intervention of new technology, excuses him of his current acceptance of the disability/sick role. He has had an accident and will be disabled until someone else chooses to "mend" him. This way of constructing his current condition as a transitory period allows him to enjoy being cared for and he will often ask others to perform tasks that he is capable of completing for himself. However, as such he could be seen as in danger of developing a learned dependence, which in recovery terms would be considered as a major failing, but in this case his apparent happiness does not appear to be rooted in independence.

Through Section 4.1 of this chapter I have looked at different aspects of storytelling, particularly how descriptions are occasioned and fitted to broader accounts of injury and recovery. This theme will continue as we move on to look at issues of blame and control in the next section.

4.2 Blame and Self Determination

Responsibility is a key issue that appears in the data. There are attempts to determine who or what was responsible for the injury, with patients often finding others to blame for the occurrence or extent of the damage. Then there is the need to take responsibility for treatment and recovery – and the way people feel when their agency in this process is undermined. This section will explore both of these concerns.

4.2.1 Reasons vs. Causes

The first question that all interviewees were asked was,

WHAT WAS THE CAUSE OF YOUR BRAIN INJURY?

Initially this question was meant to check the background data on cause; to open the interview with a focus on the injury and to see how the person represents the incident. Interpretations of this question varied and the responses provided an interesting selection of data. Often, patients tried to explain why it happened rather than simply what happened. In this first example the interviewee, who had a haemorrhage, didn't mention what the incident was, just that her smoking might be to blame:

Hazel: Don't really know

RIGHT

Hazel: They seem to put it down to me smoking too much (laughter)

Blame is certainly a contentious issue and one which several people dealt with in the interview. After something as life-changing as a brain injury, people search for explanations of what happened. They may question whether they were in some way at fault or they may look to other people or environmental factors as a source of blame. Hazel refers back to her own contributing behaviour, but her description attributes this belief to others and offers no supporting statement. Stewart, by contrast, speaks directly of his own actions but he rationalizes that although he fell downstairs drunk, it is not his fault that he was in this state. He suggests that he had a mixed drink, explaining afterwards that he meant a drink that was spiked.

Stewart: My brain injury was when I fell downstairs on my birthday, drunk. WAS THAT AT HOME?

Stewart: At somebody's house. It could have been a mixed drink or something, I don't know that. I fell downstairs and banged my head.

However, much later in the interview he reveals that he has a drink problem; something that he discussed at length after the tape was switched off. So although Stewart implies some external blame early on in the interview, as he relaxes, he becomes more candid on the issue of drinking. It is worth noting that this reflexive treatment of topics only becomes apparent in an extended interview setting. During time-limited medical appointments, professionals are likely to only hear the initial, more guarded version of events.

WHAT ABOUT YOUR GP – HAVE YOU SEEN YOUR GP ABOUT ANYTHING

RELATED TO YOUR BRAIN INJURY?

Stewart: Yes I have seen him. HOW USEFUL HAS HE BEEN?

Stewart: He's been good as gold. I talked to him about drink problems and there

was another chap, one doctor said I could drink and the other said none at all, that

confused me a bit.

Stewart is explaining that he had conflicting advice of whether he could drink alcohol

following his accident. This is often an issue as many people have seizures following

their injury and are therefore given anti-epileptic medication, which should not

generally be mixed with alcohol. For some, the restriction of alcohol is very difficult

due to the social implications of being unable to drink. It is also an issue in terms of

the constraint of personal choice and freedom. Patrick also fell down the stairs and

like Stewart, he offers an extended account of the episode:

Patrick: I tripped on the skirting board at the top of the stairs, at night, because the toilet's downstairs and you have to go downstairs if you want to go to the toilet at

night, and I fell downstairs and that caused my brain injury.

Patrick establishes blame as due to the downstairs location of the toilet and the fact

that it was night, although the exceptional character of this particular occasion is not

attended to. Like Hazel, Stewart and many others, Patrick is trying to give a reason

rather than simply a cause, but the question of cause could also be taken quite literally

(i.e. as direct cause), as in this case, where the patient gives a one word answer by

naming the implement which caused the actual damage.

RIGHT, FIRST OF ALL CAN I JUST ASK WHAT THE CAUSE OF YOUR

BRAIN INJURY WAS?

Aaron: Screwdriver

AN ASSAULT?

Aaron: Yeah

Assault produces an interesting subgroup of responses and as will be discussed later,

the only people to claim no knowledge of the cause are people who were deliberately

injured by others. Aaron's quite shocking one word answer may reflect a similar

reluctance to discuss the events around his injury. Moving to another reported assault

case, records suggest that James was in a fight when he sustained his injury, but he

has always maintained that he was assaulted. This is borne out in both his and his

mother's description of the cause:

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James: Well I was told that I was assaulted, even though I can't remember what happened

The hedge phrase, "Well I was told", flags up the problematic status of narrative constructed on the basis of others recollections (See Section 4.3). James may therefore avoid being held accountable for the accuracy or veracity of his account. In a separate interview, his mother is far more direct:

Michelle: He was attacked

However, later in the family interview, his mother refers to his injury as an accident:

Michelle: when he first was taken to the Queens Med from the Royal after his

accident. Well not accident.

Lindsay: His incident Michelle: His incident

This is quickly corrected, but it constitutes a noteworthy slip. It may be that it is easier to demand support and to share the problems caused by brain injury if there is no question of underlying fault on the part of the patient. Shifting blame is a much repeated theme; to give another example, one patient that I worked with sustained a brain injury after an accident that was thought to be drug induced. She is careful to avoid any mention of the condition she was in when the incident happened and usually concentrates on an infection that followed.

WHAT WAS THE CAUSE OF YOUR BRAIN INJURY?

Emma: I fell on a stone floor and banged my head and I had viral encephalitis

She repeatedly rebuilds her account to avoid any mention of drug involvement and always portrays herself as a victim of a 'freak accident' or an unlucky disease. For some there is another person upon whom blame can justifiably be placed. Simon for example was a pedestrian knocked down by a car:

RIGHT. WHAT WAS THE CAUSE OF YOUR BRAIN INJURY? Simon: Well, it happened like this. I got ran over, and knocked over and than ran over by a person and, yeah, a person, an old woman. Yes. SO YOU WERE A PEDESTRIAN IN A CAR ACCIDENT?

Simon: Oh, most definitely.

He emphasizes the action of being run over and highlights that the driver was an elderly woman (from which inferences of culpability due to declining driving abilities may be drawn). Outside of the interview he has referred several times to his feeling that she was too old to be driving and somewhat incompetent, but he has also admitted that he was drunk at the time and therefore probably had reduced hazard awareness. Oliver was also hit by a car; in his case while on his pushbike. He gives a description which is quite emotive.

Oliver: Er, being knocked from my bicycle by a speeding car and jolting my brain

Oliver is one of the few people, involved in this study, whose injury was sustained during childhood. His descriptive approach is very matter of fact and straightforward but still manages to indicate blame by stating that the car was 'speeding'. To say that his brain was 'jolted' is simplistic, and we might infer that this term was offered to him by professionals at the time, and has subsequently been retained.

By contrast, Elaine was driving a car that caused an accident. She represents this as having had a huge emotional impact and she has sought psychotherapy to try and work through her feelings of guilt and the panic attacks that followed. She gave me copies of the tapes from her sessions to use as additional data. This excerpt has Elaine recounting the moments leading up to the accident:

Elaine: Well I was panicked because I'd gone across the road and I was panicked that I kept looking in the mirror, this chap, what does he think of my driving? And, oh he's going to let the police know, he's going to take my number and you know, I've sort of, made a dreadful mistake and I think panic set in a bit really, though I do know, I do remember straightening the car, I do remember coming back again. So I don't feel that caused the accident, but then again, I can't remember what happened after it so I don't know

As she recalls it, Elaine knows that she made a mistake while driving the car as she drifted across the road and remembers worrying what the driver behind her would think. She acknowledges this mistake and the panic it caused, but at the same time, she still cannot come to terms with the accident being her fault. Similarly in the interview for this research, when describing the accident, she built several mitigating circumstances into the story, including at separate points, that the road was dark because of all the trees and that the sun was in her eyes making it difficult to see.

Although in this chapter, the focus is mainly on data collected from patients, it is worth bringing attention to the blame issues for carers. They too search for reasons

behind the incident that changed their lives. In Mary's case, she blames her husband's employers, even though he appears not bear any such grudge:

OK FIRST OF ALL CAN YOU JUST TELL ME BRIEFLY WHAT THE CAUSE OF YOUR HUSBAND'S BRAIN INJURY WAS.

Mary: Erm, he was at work, it happened at work, erm, he was erm, mending erm, a door, not a door as such, these massive doors that they had on a building at a quarry and erm, somehow, he fell, and er all along you know, he should never have been working up there, but that's another story.

Mary has generally found Robert's disability more difficult to accept than he has, as Robert has adapted into a new life with revised expectations, whereas Mary emphasises that she is constantly reminded of the husband she has lost. We may conclude that to move on Robert has had to accept the past, but that Mary cannot. Her account that someone else is at fault and that she has a right to be angry appears to intersect with her continuing sense of loss.

Moving further away from the primary cause, some carers described the medical professionals who tried to help their loved ones as being responsible for the patient having a greater level of disability than 'necessary'. Doctors are generally expected to be without fault, but this expectation is easily crushed by perceived misdiagnosis or delays in treatment. Iris for example was incensed that the General Practitioner did not send her daughter Lucy to the hospital sooner when she had meningitis, or formally diagnose her as having this illness. She then represents the relationship with this doctor as irrevocably damaged, as he subsequently found it difficult to support them, and they held, and still hold, a lot of resentment towards him. This is apparent as she talks about the G.P. visiting after Lucy returned home:

Iris: We're coming to the bit where we're both going to start complaining bitterly in a minute because once we got home, we seemed to have been dropped, and the doctor... I think we were given a letter to take to the doctor which went into the surgery straight away and he came popping over quite, quite quickly and I think one of the other partners came and it was as if this child was a curiosity and they'd just come to look at her

YEAH

Iris: It, it was, I'm sure if he hadn't been so idiotic in the first place she could have been in hospital earlier and maybe she would never have got to this stage. He, he just pussyfooted around. But when it, when she was home he wanted to see.

As can be seen Iris actually marks the change in direction of her storytelling. She refers to 'we' to include her husband but dominates the conversation throughout. Iris constructs their position as that of parents very worried about their daughter's health

but feeling that the doctor did not take their concerns seriously. Her claims appear well founded. Lucy was having bad headaches and according to her parents these were diagnosed as, at worst, migraine. As it turned out, Lucy was one of the minority whose headaches were actually caused by meningitis, but by the time her G.P. acknowledged that she was seriously ill, the disease had taken hold and she was only a few hours from falling into a coma.

Iris believes that the G.P. should have been able to make an early diagnosis and it is this belief that drives her feelings towards him. She describes his actions as 'idiotic' and states that he 'pussyfooted around' (although the GP did admit Lucy to hospital when her condition deteriorated). This way of accounting for the injury has affected the way that they perceive medical support from this point and the post-discharge visit by the doctor was therefore seen in a very negative light, as the G.P. simply satisfying himself that his patient had survived despite his delays. The subsequent poor relationship with the G.P. can, in some cases, lead to a reluctance to seek support which can extend to any health and social care professionals, leaving some people in a pattern of full-time family care from which it is difficult to escape. In cases where it would be beneficial for patients and carers to receive external support, we need to look at ways in which new relationships between carers and service providers might be negotiated, which overcome issues of blame.

As a balancing note, many patients and carers praised the support they received, particularly in the early stages. Jason for example, also had meningitis in his teens, but this was diagnosed quickly and correctly. Like Iris's daughter, he too went into a coma and has disabilities that are most likely permanent, but because the doctor fulfilled his role as it was perceived, Jason and his family are very positive about the medical profession and its role in helping Jason. For them the focus of this view is his survival rather than his level of disability.

Jason: Doctor Panchal has been absolutely fantastic, he's been brilliant. He's the one that sent me into hospital on Christmas Eve in 1999 and then saying that it was meningitis, but I didn't have that many signs, I didn't have a rash or anything YEAH

Jason: He like, (coughs), he said it was meningitis and sent me to the hospital and then when I went to the hospital I just went into a coma apparently. I mean I can't remember anything from the first three months of the hospital so, I don't know

Jason's G.P. sent him to hospital even though he did not have a rash, which is the most commonly recognised symptom. He is therefore viewed in a very positive way and this extends to the medical care that followed. Since Jason's discharge, his family have been keen to secure external support and Jason is now in full-time rehabilitation. Their trust in the system has given them space to breathe from the pressures of 24 hour care and it has given Jason the opportunity to push against the boundaries of his recovery. Although he describes himself as initially concerned about leaving his family he has now made a positive choice to work towards his own personal development. The fact that he could have refused this programme means that he is asserting his independence in choosing to be there. Some patients however, find that their right to make decisions for themselves is overlooked. This will be the focus of the next section.

4.2.2 Issues of Choice and Consent

The opportunity to give or refuse consent is a fundamental and often taken for granted human right. It symbolizes our status as responsible adults, in control of our own lives. We ritually sign consent forms and tick boxes, to agree to the completion of actions and the sharing of information. In hospitals, consent is given for operations to be conducted, for treatment to be administered or withdrawn, and for resuscitation orders, including the DNR (do not resuscitate).

Great importance is placed on the need for consultation and choice by most interviewees. Whereas the common assumption is that this right will always be accorded, after a brain injury there is a formal issue of whether the patient is able to give 'informed consent'; for a conscious adult this can impact on both identity work and esteem levels. Decisions may be deferred to the primary carer or next of kin, although legally:

In England, Wales and Northern Ireland, no person can give consent to medical treatment on behalf of another adult (although there are proposals for this to change in England and Wales). As the law currently stands, doctors may treat a patient who lacks capacity, without consent, providing the treatment is necessary and in the patient's best interests (BMA, 2003, p8).

The concession is made however that:

Even where the views of people who are close to the patient have no legal status in terms of actual decision making, it is good practice for the health care team to consult with them in assessing the patient's best interests. This may also be a requirement of the Human Rights Act. Any such enquiries should, however, be mindful of the duty of confidentiality owed to the patient (BMA, 2003, p8)

In several interviews, it was reported that consent was taken out of the hands of both the patient and their family.

SO HOW MANY YEARS WAS IT BETWEEN YOU ORIGINALLY GETTING SYMPTOMS AND ACTUALLY HAVING THE OPERATION

Rachel: 1989 started, and '96, operation

SO SEVEN YEARS

Rachel: Yeah. August 24th, the first time, '89. May 16th, no May 20th '96 operation

YEAH

Rachel: Now I, I said, "Why didn't you find this on the scan before?" And they said, "Oh, we haven't got the scans". They said they didn't have them and everything. So I don't know what happened but it was a nightmare. Then I went, after complained, no problem. Went in, but when I went into the hospital (coughs), I was supposed to go into the hospital on the 16th, but then two days before, hospital phoned to say that the surgeon was in France so I didn't have to go in until the Saturday. I have the operation on the Monday. I thought, "Good, I'm not going to have to be there so long then". Then on Saturday I ringed in the morning, "Yes, you're coming". I went into the hospital, I got there, got to the ward, on my letter it said, and they didn't know why I was there. The nurse said, "Why, why are you being admitted?" So I said, "An aneurysm". So she said, "Well you look very well". I thought, "Shit, I wish I feeled it". But all the aneurysms in there had broken and mine hadn't but they didn't know.

YEAH

Rachel: Saturday that was. Sunday the surgeon was supposed to come to see me, now he was in France. Sunday, 6.00 come, night-time, and I thought, "Oh he's not coming". Monday's supposed to be operation. Half past nine, 'cause I said to the nurse, "He's too late now, he won't come will he?" So he said, "No they do, he does". Half past nine he came, he pulled a chair, sit at my bed, and he said to me, "Consent form, sign it", and he said to me, this is exactly what he said, he said, "I'm not going through all this lot again, you know what it's all about, just sign here". But he'd written a big long bit like this and I daren't argue with him, you know

Rachel: I just go away and leave it alone and pretend everything's alright. And then, I had the operation and my husband came to see me and he touched me and I was freezing and he was frightened 'cause he thought I was dead. Reading note, but I was the guinea pig, that cools you down, because where it was, the time they had wasn't enough to do it

YEAH

Rachel: So I was the first person, they was waiting for somebody

YEAH

Rachel: To cold you down

TO REDUCE THE BLOOD FLOW

Rachel: I, yeah, and they didn't even tell me, or my husband

YEAH

Rachel: My husband came to see me in intensive care, and he touched me, and he was terrified

SO WAS THAT IN THE THING WHICH THEY TOLD YOU TO SIGN BUT NOT PEAD?

Rachel: Yes, but I couldn't have read it anyway, writing's funny, but they never told me...

YEAH

Rachel: ...till afterwards

HOW DID YOU FEEL ABOUT THAT THEN?

Rachel: I was cross

YEAH

Rachel: Yeah I was cross because I am sensible, I know what I had, I know if it wasn't operated I would die, I know that. I didn't have a choice, I had to have that operation, so if they'd have said to me, "Right well we're going to cut up all your leg and your stomach as well", I wouldn't still have had any choice, I would still have to have it done. And if I'm going to be a guinea pig, I would rather you told me, but I think probably they didn't because they thought well we don't want her worrying and everything because you didn't know if you're going to come out of that, they told me

During this lengthy extract, Rachel describes her anger that neither she nor her husband were kept fully informed of the procedures she would undergo. She presents herself as a rational and intelligent woman, fully capable of understanding and giving informed consent, but by contrast, she felt unable to stand up for her rights in this situation. The surgeon is in a position of power, and in Rachel's account he arrives when he pleases, without the time or the inclination to discuss the upcoming procedure with her. Status also plays a part in the way the nurses are presented as making value judgements on Rachel's arrival on the ward, based on the fact that she did not fit into a pre-conceptualised sick-role in which there should be visual signs of illness. Rachel refers to herself as a guinea pig; as though she were a dispensable testing agent without the ability to make a choice. She suggests though, that for her, choice over the procedure was not the issue, but the right to give informed consent. Returning to the guinea pig concept:

IS THERE ANYTHING ELSE THAT YOU'D LIKE TO DISCUSS? Geoff: While I was in hospital, when I went back to Queens Medical Centre, which I've still got to go back to regular, three times a year, it turns out that there's no real medication for brain injury at the moment. I was one of the guinea pigs, but it appears, it saved me life.

No matter how well tested a treatment is, if it is presented as new by the doctor then the patient will lay their own interpretation on this. They may consider it in terms of an opportunity to be valued, or they may de-value themselves as the guinea pigs chosen to test it, as it appears Geoff also does. In 2001 the British Medical Association responded to complaints on the procedures for gaining consent, by publishing a new guide for doctors (BMA, 2001, 2003). However guidelines such as these do not solve issues of time pressure that are often at the root of unsatisfactory consultations.

Consent and choice is also a major issue in the design of respite packages. Many carers described themselves as feeling unable to use traditional respite services due to the implications of sending their loved one away to an institution or 'foster' placement. A primary concern was that it meant an application for respite care amounted to an admission of 'not coping'. This statement may not only be heard by friends, family, professionals and the wider community, but it is perceived that it will affect relations with the patient. The element of 'sending' the person away gives unwanted signals with the potential to cause significant emotional upset. Some carers would rather cope with the incredibly high stress levels induced by constant round the clock care, than admit to their loved one that they need some space. Helen is a typical example of a carer in this situation:

Helen: But I mean, it, it was terrible, I mean, <u>absolutely</u> terrible, it used to be, I mean he would <u>pick</u> something up and <u>grind</u> it into my <u>head</u> you know [bosh], don't really, I <u>don't</u> know how I survived it, you know

DID YOU HAVE A LOT OF FAMILY SUPPORT OR...?

Helen: Well er, well my son was really concerned, my eldest son, he was all ready to, to, well he had started to write a letter when we'd gone there for a Christmas, and he'd started to write to the doctor and he said he was going to get in touch with them, and I pleaded with Carl, and I said to him, "He's the, he's only one I've got". I know I've got my children

YEAH

Helen: But they're all married and everything

YEAH

Helen: You know. He's the only one I have got, and I don't want some, because the way that he was I could have had him put away

YEAH, YEAH

Helen: Right, but I didn't, I didn't want that, you know. I mean, I would never have forgiven myself

YEAH

Helen: It's like people, it was <u>fine</u> him going on these holidays, that was giving me, a rest, but never at any time could I have, like people do have respite

YEAH

Helen: And they, they go to the cottage hospital, he is too, his mind is, I don't know how to explain it. If I put him away in something like that for a fortnight

YEAH

Helen: While I had respite, you know

YEAH

Helen: He would think to himself that I was thinking that he was potty or something and I don't, I couldn't do that to him

WHEREAS A HOLIDAY IS A VERY DIFFERENT SITUATION

Helen: It is

YEAH

Helen: It's a very different situation, you know, but, you know, I wouldn't mind paying anything you know, but I wouldn't, I couldn't do that, top put him into the cottage hospital with all the elderly people and all the rest of it, you know YEAH

Helen: So

IN HINDSIGHT IS THERE ANYTHING THAT WOULD HAVE HELPED YOU AT THAT TIME?

Helen: I suppose if something had come up like holidays

YEAH

Helen: Where I could have said, "Oh Richard, you'd love to go on that"

Richard is Helen's husband, for her, he is 'the only one I've got' despite the drastic changes in his character following his injury. She acknowledges the difference in his personality but it does not change the fact that he is her partner around whom much of her world is organized. She does not want to 'send' him away but she would like him to have opportunities for enjoyment that leave her free to enjoy a little time and space of her own. There is then a key dilemma in the way in which respite packages could be designed which constitutes them as potential threats to the emotional stability of the relationship between carers and patients.

There are also choice and consent issues in the development of home-care packages. Professionals will assess the needs of a patient and will design a hospital discharge package based on these needs and available resources. However, the help provided does not always consider the patients wishes, as is displayed in the following extract:

HAVE THERE BEEN ANY PROBLEMS COMING HOME OR HAS IT BEEN FAIRLY STRAIGHTFORWARD?

Daniel: As far as I'm concerned, straightforward, I don't think I've had any (looks at girlfriend who appears to disagree)

Victoria: What? (Laughter)

Daniel: I'm probably going to be told different here, go on then

Victoria: Well he'd got this care package together and it was worst-case scenario

YEAH

Victoria: You know, who was coming in, how many times a day, what, what they were gonna do and that. Come through the door, "No thanks, I don't need any help", that's Daniel. Course he doesn't do anything himself. "I don't need any help".

Daniel: (Laughter)

Victoria: So then he's knocked all the help on the head so when you come round, there's all his washing, everything, still left to do. "I'm independent, go away". "Yeah, thanks Daniel"

(LAUGHTER)

Daniel: Yeah, I admire your grit for that one, yeah, I've been terrible

Victoria: The only thing he'd let them do is wash the pots 'cause he never did that,

but the rest of it, he couldn't give a stuff, could you?

Daniel: It's what?

Victoria: Didn't give a stuff about the rest of it. Still not found the hoover have you

dear? How long have you been here? Eight months?

Daniel: I know exactly where that is

Victoria: Yeah, not gonna pick it up though are you?

Daniel: It's alright (Laughter)

Victoria: Yes, so at the moment we're, we're re-educating him on the care package. They're going to have set days where they watch him do it rather than him get them to wash the pots and then tell them to sling their hook

A care package was set up for Daniel to assist him through his daily living activities, but such a system is based on the assumption that the patient will readily accept any help that is offered to them. If care is not negotiated with the person who will be receiving it, then we cannot expect it to be smoothly integrated into their life. Daniel

had been in hospital for over a year and would have accepted any conditions to him returning home, but as soon as he was where he wanted to be and he had the right to exercise a choice, he rejected almost all professional support. He describes himself as preferring to be independent and for some things just not to get done rather than to accept help from strangers – except for letting them complete the most hated menial tasks. Daniel's partner talks about him being 're-educated' but also admits that Daniel does not mind if domestic tasks are not completed, and some were actively avoided prior to his brain injury. Clearly an adequate understanding of pre-morbid functioning and personality is critical to the acceptance of care packages.

As a final note to this section, being in control of situations goes beyond medical procedures and service provision. For some the issue is a far wider sense that they are no longer in control of their own lives. Elaine revisited this situation several times during a psychotherapy consultation:

Elaine: Erm, well you're not in control, you can't, you can't connect with anything, you can't erm... When you're in control, you're somebody, you're in control of what you're doing, erm, you can direct your life or direct what you're doing. When you, when you can't remember anything, you don't know who you are or where you've come from or where you're going or... it's as though you're in another dimension

For her the loss of control stems from an inability to remember the past. Without a past she feels lost in the present and somehow disconnected from 'normal' life. Of all the deficits that people discussed in their interviews, memory was the most prevalent concern. A loss of memory was the disability that seemed most connected with a loss of self, and it was also an often hidden problem that brings forth issues of whether people choose to make their disability visible. It is to this complex web of issues and the priority given to this deficit that I will now turn

4.3 The Use and Loss of Memory: Beyond Neurology

One of the most common problems associated with acquired brain injury is a memory deficit (Powell, 1994; Walsh, 1991). In fact measures of memory loss are used as a key tool in the assessment of brain injury severity as typically all people with moderate to severe brain injuries will suffer some level of post-traumatic amnesia

(PTA), although a combination of these scores usually forms the basis for early assessment. Post-traumatic amnesia (PTA) is a loss of memory for events surrounding the incident which caused the neurological damage. It can range from a few minutes of lost time to many months (see Section 2.3.2). People with acquired brain injuries may also be identified as having short-term memory, long-term memory or prospective memory problems.

Short-term memory problems amount to difficulties in retaining new information for a sufficient length of time. This may apply to fairly abstract things, such as remembering a telephone number for long enough to dial it or it can be all encompassing, to include orientation around people and events. For some this can be experienced at quite extreme levels, where almost nothing is remembered beyond the moment in which it happened. Long-term memory problems are often linked with PTA, where people lose access to chunks of their past, in some cases though, there may be a deterioration in the ability to retain new memories. This can leave people relying on written records or on other people to recount some or all of their life since the injury. Finally, prospective memory is the ability to remember future events such as appointments, taking medication and the completion of routine tasks. Deficits in this are often overcome through simple memory aids such as lists and diaries.

The states of memory and memory loss so far described could be considered as neurological in basis and as such are used in the neurological assessment of disability. However, memory is not merely a physical process; it has a rich social and emotional context which is rarely considered in brain injury research. It became apparent through conducting both patient and carer interviews that a broader view of memory is needed if we are to understand the described experiences of those involved. People talked more in terms of https://www.neurological.org/ assessment of disability.

A model was developed during the analysis, to encompass both the implicit and explicit memory issues raised by the interviews. At a basic level, memory for specific events may be complete, fragmented, or lost. A complete memory is defined as one which contains no gaps in information crucial to the story, as identified by the interviewer or interviewee. A fragmented memory is one where key elements of the

story can be told but there are important omissions. A lost memory is where the interviewee claims no recollection of an event.

A complete memory may be offered as a rigid presentation of facts, often with dates and sometimes even times, no matter how long ago the event occurred. It is probably a story which has been told many times to many different people and may change little, regardless of changes in context or questioning. This was fairly typical of carer interviews. Where patients appeared to have a complete memory, there was sometimes the issue of wanting to forget, this could be wanting to forget what happened or wanting to forget their former, more capable, self.

These different states will be explored further through the following sections, but having identified the memory problems that can be expected after brain injury, it is perhaps useful at this point to present a brief insight into the everyday reality of these deficits. Sophie had a sub-arachnoid haemorrhage in her early twenties. She regularly attends Headway and relies on a Social Services provided taxi to get her to and from the day centre. During a stay at the hospital, she was returned to the NHS grounds but could not remember her way back to the ward. Sophie's expectation was that she would be escorted to her room, but without knowledge of her memory problem, the taxi driver had no reason to do this.

Sophie: Erm, well I had erm, a short-term memory loss...

RIGHT, OK

Sophie: And erm, I came to Headway one day...

YEAH

Sophie: But a taxi man picked me up...

YEAH

Sophie: And brought me here...And then the taxi man fetched me from here, took me to the hospital, and then he <u>dropped</u> me, he didn't take me in or anything like that, he just dropped me and I couldn't remember where I was going. Anyway, Mum worked, used to work at Leicester Royal and so I went to the..., to that place and I think I found, finally found my way back, to..., not to the off..., to the room I was in, but to the main entrance, and I could ask there

YEAH

Sophie: But some of these people, they don't understand really

Sophie had been unable to form new memories of where she was staying but knew she was meant to be in the hospital and had old memories of navigating between her mum's office and the main entrance. Without this prior knowledge, it would have been a far more frightening experience. It is easy to overlook the emotional impact

that memory loss can have, but for the person involved it can be truly scary. Rachel discusses her experience of forgetting faces:

Rachel: Like, I'll tell you something and I, it frightens me to death, it scares the living shit out of me. I don't like to go out because, couple of times its happened an' it really frightens me. One day, I was with my son somewhere, out, and this lady come running up to me an' she's all goin' like this (arms out) and how are you and all this lot, and I didn't know who she was, and it frightened me and I kept saying to Mark go home, go home, I wanna go home, I wanna go 'cause I don't know what they're gonna ask me, I don't know what they want

Rachel went on to give other similar examples of feeling frightened in situations where people she does not recognise show behaviour that indicates familiarity. This makes an otherwise hidden disability visible. Her description of the situation above also suggests that she is uncomfortable with the expectations of others.

I wanna go 'cause I don't know what they're gonna ask me, I don't know what they want

If she is unable to meet these expectations then this may negatively affect her social identity and this seems to worry her greatly. This is an issue that will be discussed further in Section 4.4. Beyond the emotional impact of memory problems, there are also many practical difficulties. Pam for example has become notorious among her friends for forgetting to do things and for not remembering what she has done in the past. As a result she has lost skills that require her to use her memory, such as cooking and she often forgets important items when she goes out, the classic example being that she regularly leaves her purse at home. She deals with these problems in good humour and has well rehearsed stories of the mishaps that this deficit has caused:

Pam: Well you know about that one where I set me purse on fire as well, but... NO, WHAT WAS THAT?

Pam: Well I, when I, I used to hide me purse, I'm always hiding that, I thought "Oh where can I hide me purse tonight?" This was before I went to bed. I thought, "Oo I'll hide it in the oven". So I hid it in the oven and then Saturday morning, I always get up Saturday morning and do a Sunday dinner and a Saturday, and a Sunday so I don't have any cooking on a Sunday. So I put the oven on, I thought, "I'll put me roasties in while I nip over Safeways". So I lit the oven and carried on doing summat else. "(Sharp intake of breath), Summat burning". I looked in the oven, I said, "There's summat burning in there" and found me purse was on fire (laughs).

Pam appears to have adapted to her memory problems in a completely different way to Rachel. Whereas Rachel is anxious to avoid situations that make this deficit

apparent, Pam goes about her daily life and accepts that this is now a part of who she is. By making it a topic for humour she appears to be able to deal more readily with the everyday problems that it creates.

4.3.1 Systematic Vagueness

As most of the memory issues raised were around deficits, the following sections will concentrate on the latter two categories, starting here with **fragmented memory**. This can have a neurological basis and may be an expression of PTA, however, it may also be used in an occasioned manner. For example, apparent memory loss can act to change the subject of conversation, it can be used to avoid giving detail which is considered sensitive or it can be used, arguably, to manage personal issues of blame over the cause of injury.

James was assaulted in 1996. Since his injury, his main difficulties have been emotional/behavioural. He and his family were interviewed separately. James lists memory as one of his problems and in this extract he displays some level of fragmentation – although this may not be an issue of neurology:

SPEECH THERAPY?

James: Speech therapist, yeah.

DID YOU HAVE A SMALL SPEECH PROBLEM THEN?

James: Can't remember CAN'T REMEMBER?

James: Well I remember the speech therapist, I had to see her at Northampton. She was a good looking girl and she sat in front of me and goes right, do this with your tongue, and I was at the inappropriate stage and it just turned me on. Not to the extent where I did anything, I just found it amusing.

James remembers the minutiae of his speech therapy sessions, but claims that he cannot remember whether he had a speech problem. It seems that the detail of his disability is inconsequential to the story he is telling, with the aim of the story perhaps being to entertain rather than to provide information. There are two obvious possibilities: either James truly cannot remember whether he had a deficit in speech or he is claiming memory loss to divert the story back onto his preferred topic, allowing James to present a more rounded version of himself rather than focusing on loss and disability.

We can see a similar situation with Simon, who was hit by a car in 1994. His interview was vibrant and full of description but he seemed uninterested in talking about certain people with whom he made no connection:

HAVE YOU HAD A SOCIAL WORKER?

Simon: I've got one now but I ain't seen her for years, forget what she looks like YOUR CHOICE OR HERS?

Simon: Well both, I mean like she's old, wrinkly, so what more can I say HAS SHE BEEN HELPFUL TO YOU AT ALL THOUGH IN THE PAST?

Simon: Ai, she probably has but, I can't remember

Again it seems that fragmented memory achieves a topic change in the conversation. These social functions served by claims of memory loss have already been explored with Rachel in Section 4.1.1, but the issue here is that such claims may be repeatedly mobilized as a conversational resource. Just as people often talk of 'selected hearing', so 'selective memory' may be identified by carers as a phenomenon amongst patients. Helen for example, expresses her frustration on this issue:

Helen: When my daughter took him back to the hospital, for a check up, he just went st..., and you know hospitals are like a maze aren't they?

YEAH

Helen: Straight there, no problem at <u>all</u>. Kelly couldn't believe it, she said, "I couldn't have found my way mum"

YEAH

Helen: She said, "He just went <u>straight</u> to it". She said, "I would have had, where's this and where's that?" You know, but erm, some of his memory is just <u>astounding</u> and so sometimes I get a bit uptight, not with him, within myself, because I think, if you can remember that, why can't you remember something that I told you, just a while ago? Which he, I said to him, "I told you that Richard". "No you didn't".

We could seek a neurological explanation for this phenomenon, as separate parts of the brain are used for different memory functions and sometimes one skill may be left intact while another is damaged. The most common confusion comes from people's short-term memory being reduced when their long-term memory is virtually unaffected. This occurrence was cited many times by carers, but in Richard's case it seems appropriate to look beyond neurology. He and his wife spend a great of time together and Helen reports considerable friction in their relationship. It may then be the case that sometimes Richard simply ignores what Helen is saying and then claims that he does not remember.

Moving on to lost memory, this can also be a genuine expression of PTA or it can be studied as a conversational resource. Alternatively it can be assumed by carers,

although it may not be a true reflection of the patient's abilities or cognitive state. I am using lost memory to refer to the loss of far more substantial chunks of information than in fragmented memory. It is not simply details that are missed, but the whole story. To illustrate this I want to focus on one particular patient.

Gary is in his late thirties and sustained his injury at 26 years old. He was the only interviewee who refused access to his family for a carer interview and he was very concerned that nothing he said should be discussed with them (even after his confidentiality rights had been explained). He lives in what is arguably a fine balance of dependency, seeking the independence of his own flat, but using professional carers and living two doors from his parents. We might see him as being concerned with emotional rather than physical boundaries as he sets limits on what he believes he should do as a 'disabled person'. His independence is restricted by the fact that he will not cross roads in his wheelchair; he prefers to be taken to the toilet rather than to go alone and he expects others to provide his food, even though he is capable of preparing his own. He has fully taken on board the 'sick role' but has disregarded the expected work of 'getting better'. The following transcript shows how he claims lost memory in response to a question about the cause of his injury:

RIGHT FIRST OF ALL CAN YOU JUST TELL ME VERY BRIEFLY WHAT THE CAUSE OF YOUR BRAIN INJURY WAS? THIS IS JUST FOR STATISTICAL RECORDS

Gary: Er, there wasn't any reason why I had one

RIGHT, DID YOU HAVE SOME SORT OF ACCIDENT?

Gary: I was at home at the time

PARDON?

Gary: I was at home, and then I suddenly woke up in hospital

RIGHT

Gary: But I weren't given any reason why it were done

RIGHT, DO YOU KNOW WHAT ACTUALLY HAPPENED, DID YOU HAVE

SOME SORT OF HAEMHORRAGE OR SOMETHING?

Gary: No, all I know is it was on the right side

This man was brutally assaulted by people known to him. We would expect this to have long-term emotional consequences beyond that which is experienced by other patients, whose injuries were sustained in less emotive circumstances. This begs the question of whether Gary can remember what happened. If we took his responses at face value, then it would appear that he does not, since he does not mention the incident itself. However, according to professionals who have supported him, he does

remember and has discussed it on several occasions. It is even noted in a Social Services report from 1998 that, "He can articulate and give a clear history that is usually factually correct".

So does his response represent an alternative interpretation of the question? He uses the word "reason" twice, suggesting that he is treating the question as a matter of why it happened rather than what happened. Since why it happened may still be a significant issue for him this may be a more pressing matter than what happened.

We might be tempted to consider that the experience has been repressed, in the classic Freudian sense (Freud, 1894, 1896). This would, however, lead us into an irresolvable question of the level of conscious effort involved in such repression. A more parsimonious explanation is that it is simply easier not to discuss (or remember) these painful events in certain kinds of situations. This would account for some of the variability found on measures such as the Glasgow Outcome Scale mentioned in Chapter 2. The difference in the measured levels of recovery found by doctors and psychologists could then be treated as an artefact of the contextual dynamics that lead patients to offer different facts and express different emotions across conversational settings. One way to overcome this is for professionals to share detailed information, which brings forth further issues of time and structural constraints. It is however a point worth emphasizing that in the isolation of one context, only a selected part of the patient's situation will be visible.

4.3.2 Reconstruction of Memory

Where memory is genuinely lost, in whole or in part, there is a further level to consider, where reconstruction of memory takes place. The person may be told what happened and remember that description rather than the event itself. It may be the case for an individual that memory is not reconstructed at all because no-one has told the patient what happened or else that they don't remember being told. Alternatively memory may be semi reconstructed, reconstructed, or false. As Freeman notes, this process of joint reconstruction may be difficult to distinguish from an apparently unreconstructed memory:

"As a general rule, however, our histories begin not in memory, but in the stories told to us by others. Indeed, these become our pasts" (Freeman, 1993, p53)

Semi-reconstructed memory appears to develop when carers or professionals are selective over what information they will or will not share, in effect deciding what the patient is allowed to remember. Events or parts of events, may be concealed if they are particularly emotive or if memory of them is likely to cause conflict. An example of this has already been explored in Section 1.4 where Susan told Tom about his accident and about needing surgery, but not that he had actually had brain tissue removed. Similarly, the parents of one patient chose to conceal her pregnancy and resulting termination when they helped her to rebuild a story of her past, reasoning that there is no point in raising such painful issues for the sake of completion.

Reconstructed memory, even more so than complete memory, often appears to be quite rigid and rehearsed. It is not always made immediately or explicitly apparent that patients are recalling what they were told rather than what they remember of an event.

FIRST OF ALL CAN YOU JUST TELL ME BRIEFLY WHAT THE CAUSE OF YOUR INJURY WAS?

Geoff: When I went out on the 29th of November, to get a packet of cigarettes of all things from a garage on St Matthews, I was badly assaulted and I was left for dead. At 12:40 a passing police patrol found me, I was rushed to the A&E at Leicester Royal and from there on rushed to the Queens Medical Centre, intensive care, this I only know cause of staff who told me and mates and family.

Geoff begins telling his story in the style of a report. Given the level of details, this appears to be a rehearsed sequence of events, and this is mirrored in the description he gave to local newspapers and a Headway newsletter. It is notable though, that subtle facts change in each telling and emphasis alters according to the context. For instance, in the Headway account, Geoff starts by saying:

I went out to buy some cigarettes on the night of 30th November 2000, just over one year ago and was set upon by four men for no apparent reason. I had very little money or anything of value on me. My attackers left me in a pool of blood and if the ambulance hadn't been called so promptly by a 'Good Samaritan', I believe I might have died.

So again he creates a framework for the events that followed, but he is confused by the date, as it was somewhere around that crossover between the night of the 29th and the morning of the 30th. He also claims in this account that it was a 'Good Samaritan'

that alerted the ambulance service, whereas all other accounts suggest that he was spotted by a passing police patrol. The overall difference in this story as a whole though is that it is one of support, recovery and overcoming the odds. It is an emotional tale of how one person has dealt with their disability, published to increase awareness of brain injury and the purpose of Headway's service. Many of the readers are other people whose lives have been affected by brain injury so this acts as a model of how they too can be helped. Perhaps it is in this light that the 'Good Samaritan' was included in this version of events. It is interesting that he also uses the phrase, "Left me in a pool of blood" as this was used in four of the five newspaper articles that featured his story. It is a strong visual image that he cannot personally recollect, but that has stayed with him. Returning to the original interview quote, it is only at the end of his story that Geoff says, "This I only know 'cause of staff who told me and mates and family". He here acknowledges that these memories are reconstructed from the words of others. Many patients made this acknowledgement in a slightly less explicit way:

Hazel: I fell down two stairs, not from top to bottom

RIGHT

Hazel: And er, I, apparently I'd lost control of me bladder, and my son come home from work and found me, and managed to get me into the bathroom and, you know, find the necessities and shut the door

YEAH

Hazel: For me to sort myself, and put me to bed, and er, a bit later apparently, I was holding me head and crying, and all that, and er, he phoned for the doctor, and he said he'd come out at the end of his surgery, and I'd arranged to see me best mate that day. She came round, ooo, ten, half past ten ish, and found me in bed, and, crying and screaming with headache, so she rang the doctors, again, and er, they said he'd be out at the end of his surgery, and apparently she turned round and said, "No he won't, he'll be here now, there's something seriously wrong". And with that, he did come. He came straight out and he rang for an ambulance

With Hazel, the key word in this talk is 'apparently' as this tells us that she is recounting events as they have been described to her by others. These 'others' are not directly identified, perhaps because they are incidental to the main narrative thrust of the onset of her injury. This example is fairly typical of the way that patients subtly identify periods of amnesia. Rachel however is far more explicit about the reconstruction of her memory.

Rachel: All the things happened before the operation, I can tell you, but after, for one year, I don't know anything, only that people tell me things and it's weird because, erm, how to say this? When something happens and you remember it, right, you've got a picture in your head. Like I'm here, I'm talking to you, if I remember

this and talking to you I'll have a picture in my head. There'll be you, there'll be plants...

YEAH

Rachel: ...and then what happened around it

YEAH

Rachel: When things, after the operation, for the first year, I know them

YEAH

Rachel: But there's no pictures, there's no memory. I don't (pauses), my children told me things, my husband told me things, so I know what happened, but I don't

remember, do you know what I mean?

Rachel knows what happened in the year that followed her brain surgery, but she feels that the memory is not her own as it was actively reconstructed and learned as a story rather than being naturally seen as a visual image of 'real' events. It is interesting to compare Rachel's observations with the experiences of Helen Keller, as described by Freeman (1993). Having lost both her sight and hearing in early childhood, Helen relied on the signed stories of others to explore the world around her. She would talk about visual experiences as if they were her own but was keenly aware of the extent to which her memory was constructed from books and from the words of her friend and teacher, Annie Sullivan. 'Pictures' – i.e. visual representations – are intrinsic to most of our memories and without them, the sensation can feel somewhat alien. The words that Rachel and Helen refer to as their borrowed memories are in fact memories in themselves but their construction and the shaping role of others is more explicit. This makes their status as memories problematic for the patients concerned. This can become particularly difficult in cases where memories are subsequently proven to be false, as we will now see.

4.3.3 False Memory

False memory is perhaps the most psychologically interesting of the different levels of recall. Here, patients are filling the gaps with information that is inaccurate, or blatantly untrue. This can have a strong neurological basis and serve no obvious purpose, or we may treat it instead as a way of fitting fragmented events and ideas together so that they make sense (that is, 'effort after meaning' as Bartlett, 1932 put it). However given that all memory is in some sense a reconstruction (as Freeman put it "Memory cannot help but deform the reality of the past" 1993: 52) we should be wary of taking the notion of 'falsity' as a complete contrast to other forms of memory. Rather, we should seek to elucidate what functions false memory appears to serve. Daniel, for example, was bedridden for over a year following a brain haemorrhage.

During that time he slipped in and out of a fantasy world, often greeting his visitors with tales of excitement and adventure. He is now living independently at home and slowly regaining his mobility. He knows that a lot of what he talked about in hospital is fantasy, but he cannot separate these imaginary happenings from real concrete memories. It is only by repeated feedback from others about what is likely and unlikely that he can piece together his own history:

Daniel: The frightening thing is, because obviously the brain's been affected, a lot of what I thought had happened to me, it's in there, it's, it's, it's, it's part of my memory and has become so and so when somebody turns round and says, "No, you couldn't possibly have done that, you've been in hospital all this time" and I go, "Oh no I've not"

He states that it is frightening that his brain has been affected in this way, although he actually uses the phrase, "The brain's been affected", perhaps distancing himself from the damaged organ. He refers to the fantasies as, "Part of my memory", emphasizing how interwoven these daydreams are with past realities. Separating them out requires the assistance of others such as his long-term girlfriend, Victoria, who has been one of the main "keepers of the truth", helping Daniel to sort out fact from fantasy.

Victoria: Ooh he's done all sorts I tell you, pearl fishing in the, was it Japanese

ocean? You name it

Daniel: Oh yeah, yeah. I've done it all

Victoria: Completely mad

Daniel: I've been there I've done that, I've been

Victoria: He wouldn't have it was a lie, it was a complete truth, you could not talk

about it

Daniel: Me and James Bond were like that, apparently at one stage

Reference to his flights of fancy are open and jovial, suggesting that they are both comfortable with this unusual consequence of his injury, and despite Daniel initially describing it as frightening, he enthusiastically recounts many tales. Victoria tries to make a distinction between truth and untruth, suggesting that statements which do not reflect reality are lies, but this has no particular negative connotations. As Victoria concedes, Daniel's loss of real memory is in some ways a blessing:

Victoria: That place where you <u>were</u> was very depressing. To go there every day and see, see old, old people, and know like, that that's what you've got coming, and to have to <u>live</u> there, I, I admire him for staying so long, he's lucky he didn't have the memory.

Daniel: Lucky I didn't what?

Victoria: You didn't have a good memory

Daniel: I probably was really

Victoria: 'Cause you'd have had to live through that with a memory

Daniel: Yeah

Bearing in mind the fact that Daniel was confined to a hospital bed for so long, his ability to slip into a vivid fantasy world probably had quite a protective function. The problem, it might be argued, is perceived as his inability to let these fantasies go, but then what alternative would fill the gaps? Who would choose staring at the ceiling over life as a secret agent?

False memory as a term is generally thought of as something disturbing, indicating a loss of self. As shown with Daniel this need not be the case, but the second instance that is presented now, is of a man whose memory apparently was altered either by the influence of his wife or by a need to preserve his self image. Richard had herpes simplex encephalitis in 1996. He and his wife were both interviewed separately. Near the end of Richard's interview, he spontaneously mentioned how he had given up smoking:

IS THERE ANYTHING ELSE THAT YOU'D LIKE TO DISCUSS ABOUT YOUR EXPERIENCES OR ABOUT THE HELP THAT YOU RECEIVED, ANY OTHER THOUGHTS?

Richard: There is one thing that is strange actually, erm, and that is when I went into hospital I smoked and when I woke up, I couldn't remember I smoked, and I've never smoked since.

In this description Richard merely forgot that he had ever smoked and therefore stopped from the point at which he woke from his coma. His wife however had a different story to tell:

Helen: Of course Richard used to smoke and this was something that I had to get him, out of, because Dr Thomson said, "No way", because if he put a cigarette down, he would forget where he'd put it, we'd all be gone, you know. So he, he, he's not wanted to have a cigarette for about 4 years now, I mean at first it was, you know, and then of course, I suppose the anger and that could have been the fact of not smoking I mean because it is a drug isn't it

IT MAY HAVE CONTRIBUTED

Helen: Yes, it may have contributed and I've only just thought of that now YEAH

Helen: But he used to say that I wasn't, I was mean with money and I wasn't giving him any money so that he could go and buy his cigarettes, you know and that, so, I don't know

Helen takes personal credit for stopping Richard smoking and emphasizes the difficult times when he was unwilling to comply. In return, we have to ask then what work Richard's story does? I have no reason to doubt that he believes what he told me – it is a story which I have heard him tell many times before. So either he has forgotten

what happened and is filling in the blanks, or he has found a psychologically more acceptable way of remembering the past, which gives him some level of control over the situation. His actions would classically be defined as confabulation (Baddeley, 1990), but there may be something more at stake here. Many of us have aspects of our past that are uncomfortable to deal with. Perhaps the opportunity to rewrite the past on our own terms is a blessing rather than a deficit. In the words of Oliver Sacks (1985):

In adulthood, life, higher life, may be brought to a premature end by strokes, senility, brain injuries, etc., but there usually remains the consciousness of life lived, of one's past. This is usually felt as a sort of compensation: 'At least I lived fully, tasting life to the full before I was brain-injured, stricken, etc.' This sense of 'the life lived before', which may be either a consolation or a torment, is precisely what is taken away in retrograde amnesia (p39)

To give a sense of reality I will end this section with Lynne's description of what life with memory loss is like:

WHAT'S YOUR MEMORY LIKE FOR STUFF THAT HAPPENED A LONG TIME AGO?

Lynne: Erm, some of it's there, some of it I think is there

YEAH

Lynne: I sort of think to myself, oh I can remember the lads saying this or doing that and then I think, "But can I? Is it what I'd like 'em to have said or done?" And I can remember some holidays, but er, there's not a lot there, which is disconcerting sometimes.

Lynne is clearly troubled by her inability to recall everyday events. When she feels that she has a memory of some event, she questions it and by consequence, questions her own sense of reality. She relies on external aids and constant reminders from other people to give her a sense of place and purpose. It is strategies such as these that will be explored in the next section.

4.3.4 Implementing Strategies

Having focused throughout Section 4.3 on losses, it seems appropriate to end with the strategies that people use to make gains. For some, appropriate strategies come as a natural consequence of using the skills that remain. Rachel for instance describes herself as finding words very difficult to retain, but numbers are still very salient to her. She therefore uses numbers as a code to guide her life:

Rachel: Numbers...Oh yeah, writing, I can't do that

YEAH

Rachel: Numbers, no problem. So, if I'm going somewhere, I can remember the

way by doing numbers. Gail,ok

YEAH

Rachel: She lives, 1 3 3 1 3 1 7. Now I can find my way from my house to her

house YEAH

Rachel: Like that

RIGHT

Rachel: Go to the new road

YEAH

Rachel: 1 is turn off first turn

YEAH

Rachel: Go up this ramp, 3 is roundabout, third one, 1 3

YEAH

Rachel: 3, 1 and the number is 17, 17, I can do like that

SO BASICALLY YOU'RE USING NUMBERS AS A MEMORY AID, YOU'RE

LINKING WHAT YOU REMEMBER INTO NUMBERS?

Rachel: It's the only way I can remember anything

Rachel works this strategy in a novel way. It is derived from a classic peg technique but instead of pictures, she uses numbers. This is obviously a technique that Rachel has come across before as she describes it later in the interview when referring to management training that she once attended:

Rachel: Keys right, I know from teaching, that when you teach somebody

something, you always try to give them a key, no a hook, summat to hook it on. If

I'm teaching you something new

YEAH

Rachel: I have to relate it in a way

TO SOMETHING THAT YOU ALREADY KNOW

Rachel: That, that will be your hook. When you think of that thing, it will bring

what I am teaching you into your mind

SO LIKE IN SOME WAYS, YOU USE THE NUMBERS AS HOOKS DON'T

YOU?

Rachel: Yeah

YEAH

Rachel: But that is, don't work for me now. Sometimes, now and again I can get it to work, but mostly, because I think this space is smaller so I don't think it will hold

many things in. I might get away with remembering 3, 4, things

YEAH

Rachel: But if I put a 5 one in, another one is gonna fall out

YEAH

Rachel: You know, it's this big. I can fit 4 in there comfortably ok. If I put 5 in,

then something's gonna come out.

In this second piece of talk however, she admits that her strategy does not always work as her memory in general seems more limited since she underwent brain surgery. She pictures it as a smaller space in which less items will fit, but knowing her own limitations, she is able to work around them. Rachel has worked out her own ways of dealing with her memory deficits, but most of the strategies that were

explicitly discussed seemed to have been developed by or with carers. The most complex system to be revealed came from Lynne and Andrew. Andrew has set up a series of routines using a variety of external aids. His wife Lynne is constantly reminded of what she is meant to be doing by a weekly routine board and daily to do lists. Many people with memory deficits forget to actually use the lists that have been created for them, so the obvious question was:

AND DO YOU ALWAYS REMEMBER TO LOOK AT THE LIST?

Lynne: Yes YEAH

Lynne: Yes I always do look at it, it's erm, it's very good er... If I'm sort of sitting here, I'm thinking, "Well what should I be doing?" And I'll go and have a look in

the kitchen just to see what I should be doing

YEAH

Lynne: I do, I can't say I always do it (laughs), but I do er, go and have a look

YEAH Lynne: I do

Andrew: That's another thing, you have to work things out as you go along actually. It's like the day of the week, 'cause she, she can't remember what day of the week it

is actually

Lynne: No I can't

Andrew: But erm, see if that's on the floor there (leafing through open TV guide), I

have to remember to put that TV paper Lynne: Turn it over to the right day Andrew: On the right day for the date

AH, RIGHT

Andrew: And she knows what, what day it is then

Lynne: Yeah (laughing)

Andrew: Then she can look at that list (laughing), the weekly list

Lynne: Yeah

Andrew: If she's in here

Lynne: It's er, it's terrible sometimes, you know, you, you, you think to yourself, you're so erm... I'm <u>not</u> that far gone that I can't think how stupid I am (*laughs*), if you see what I mean. You know, I sort of er, I sit here and I think, "God Lynne, what the hell are <u>you</u> up to?" And then I sort of look at me paper and I think, "Gawd" (*laughs*), but erm, if it wasn't there, I'd just... I should be lost, I know I would. It's, I just have to sort of look at it and think, "Ah... right" or I'd, I'd probably be thinking, "Where's Andrew?" And that'd frighten me, whereas I know he's at work because it's Monday, even though it does say Sunday on there

Lynne's husband telephones her to remind her to look at the lists and asks her to read out her next task. She can check the day by looking at the television guide, which Andrew leaves open on the appropriate page and then she can record what she has done, by ticking off her lists, taking photographs and making voice messages on her digital recorder. She then transcribes these messages each night to read over and remind herself of the day and this is also checked by her husband. In essence, all of her memories are stored externally. Her 'personal memory' is materialised in this system of techniques and technologies. Such a complex set of routines works, but it is time consuming to set up and it means that people must acknowledge the extent of

their memory problem (this overwhelming focus of life built around disability is resonant of Herzlich's, 1973, conception of 'Illness as Occupation'). Simple strategies are more often used but are also more likely to fail. Helen recalled during the interview how confused her husband Richard was when he first returned home:

Helen: He used to say that I had changed things around in the house, I had moved his clothes, he was putting my clothes on and saying, "You've shrunk this, it won't fit me". You know a jumper...

YEAH

Helen: Or something. I mean one day he had my knickers on (laughter) he was saying, "These are so tight, what have you done to them". I said, "Well let me have a look" (laughter). He'd got mine on (laughter).

This is presented as a comical story, but the anguish caused to Richard also brought Helen a lot of upset. She describes herself as having looked for commonsense ways to indicate to Richard where his belongings were kept, so that there were fewer opportunities for confusion:

Helen: We'vé had a new, some new bedroom furniture

YEAH

Helen: And I've had to tie a red ribbon on the drawer

RIGHT

Helen: Because, I go into the room and, I did with our other furniture, we had two separate tallboys

YEAH

Helen: But now I've bought a big one that is all in but I have put the stuff in exactly the same places, like his drawer with his bank statement, his cheque books, and all the rest of it, there, and mine's underneath and then the bottom is his golf drawer, with golf balls and that, and he will keep going to this side, and getting the towel, opening the towel drawers and he'll go to mine, where my bank statements and all the rest of it, and he says to me, "You've changed these drawers around, these drawers are all changed around". I said, "No they're not Richard, they're in exactly the same situation as before". So now I've got a piece of ribbon and I've tied it on one of the little knobs, so that he'll know, but he still does it, he goes to another drawer and there's this ribbon, and I did say to Wendy, I said, "You know the problem is, he's gonna forget why the ribbon is there".

As Helen suspected, the ribbon was meaningless to Richard and therefore the strategy did not work. Just as people forget to look at lists unless they are prompted, Richard forgot why the ribbon was there. Where patients have quite profound memory disturbance it is difficult to find ways that will enable them to function independently, so in terms of recovery, a memory deficit can be one of the most serious problems that a brain injury patient will face. One mother points to her son's struggle with reality by highlighting a trick that she has played in the past. She starts from a neuropsychology interview where the memory loss was discussed:

Rebecca: Erm... it was ink spots and erm, making lists and remembering things, and I mean I wasn't in the room and I just went back in the room and he just said erm, "It's actual blackout, time loss". I mean we have fun with it don't we? I mean I was awful I went into him the other night (laughs) quite late. "Come on then Ben..."

Ben: "Time to get up".

Rebecca: "Time to get up". And he believes me, because to Ben, he doesn't know how long he's been in bed and (laughs) I don't do it very often.

Ben: Seven o'clock in the morning and dark outside, it's winter (laughs)
Rebecca: I don't do it very often, but I do like to wind him up now and again.
Ben: And ermm... I've come home off me, me school bus from Ashfield in the winter before now it's been getting dark so I've gone up to, to the stairs to the loo I've gone and got ready for bed afterwards thinking it was night time.

Rebecca: Carried on cleaning his teeth, had his wash ...

Ben: (Laughs)

Rebecca: ...in his 'jamas, "Mam I'm ready". "What you ready for?"

Ben: "Bed" (laughs)

Rebecca: "Bed". "Ben, it's only quarter to six". "Oh no I've done it again". And just occasionally, I mean I never tease him the other way, if it's time to get up it's time to get up, well I do say if it's not, I say, "Oh no, you can have a lie in". But I did, I said to you didn't I? Couple of nights ago, I just couldn't resist it, because erm... he'd nodded off to sleep and I was giving him his tablets. And I says, "Come on", I says, "You've got to be..." but not rushing I says, "You'll have to get up, you're going to be late"

Ben: "You'll have to get up soon, you'll be late"

Rebecca: And he was quite happy to get up and he'd only been probably asleep about half-an-hour...

YEAH

This may seem like quite dark humour but for some carers it is incidents such as this which enable them to deal with the day-to-day difficulties of providing almost constant support. Although it is recollected as an amusing event, Rebecca goes on to express her worries in relation to this:

Rebecca: ...but he was quite happy it wouldn't of bothered him to of got up he's just got no idea and that's going to be Ben's problem. I mean the reason I worried about it, when I mentioned it to Mr Jones is the tablet taking, erm...it's hard to explain. The only... we've got one of those things with the Monday, Tuesday, Wednesday, Thursday...

YEAH THE MEMORY PACKS.

Rebecca: Yeah, the only day he would know was right would be Monday if that was absolutely full of all his tablets, but from then on in, if Monday was empty and he was supposed to be taking Tuesday he would think.... How would he work it?

Dennis: I don't know what you're trying to say

Rebecca: Well he's... the day doesn't mean anything to him does it? Cos he doesn't know what day it is.

Clearly Ben's inability to manage his medication independently might have severe consequences. His parents did send him on a residential course to try and overcome this deficit through strategies, but he was given lists and tick-boards that like many people, he was unable to use effectively. If he became distracted, he would forget to tick things off and as his parents point out, a double dose of his medication would be almost as dangerous as not taking it at all. We might then see that so long as Ben

remains dependent on his parents, his memory loss is a subject of humour rather than despair. By accepting this dependence, Ben has, arguably, shaped his identity around living with his parents and needing support. The issue of identity management will be the focus of the final part of this chapter.

4.4 A Fragile Identity

The orientation towards identity I adopt in relation to the data follows Goffman's (1971) classic definition of two forms of identity, social and personal:

By 'social identity' I mean the broad social categories (and the organizations and groups that function like categories) to which an individual can belong and be seen as belonging: age-grade, sex, class, regiment, and so forth. By 'personal identity' I mean the unique organic continuity imputed to each individual, this established through distinguishing marks such as name and appearance, and elaborated by means of knowledge about his biography and social attributes – knowledge which comes to be organized around his distinguishing marks. (p. 227)

Goffman here sees our identities as organised around our past experiences, our 'distinguishing marks' and our social attributes. Identity is seen as something that can evolve throughout a lifetime, but that is also vulnerable to sudden restructuring when our distinguishing marks come to include something that is stigmatised. Considering events such as imprisonment, mental health problems or disability, Goffman (1963) explored the effects of stigma on identity. He suggested that people who are stigmatised experience a similar 'moral career' where they learn more about their predicament and about their altered conceptions of self. He defines this moral career as the,

Cause and effect of commitment to a similar sequence of personal adjustments (p. 45).

This is different from the career of stigma itself. Goffman (1963) identifies four patterns to this moral career, which can usefully be thought about in terms of disability and particularly acquired brain injury. The first three focus around the time of life at which the 'stigma' is acquired, so Goffman's initial category is that of inborn stigma, in which the individual is socialized into a disadvantaged situation. In terms of brain injury, if you are born with a disability, you may judge yourself against others but you will never experience life without that disability. It is a part of who you are and it is an aspect of you that will always have been known to others. It may

have affected the way other people treated you but this, to some extent, is immeasurable and unknowable. Adaptation is part of the natural growing process just as a child without disability must learn to use their mind and body according to its capabilities. Identity is built around the self as it was created and how this is reflected in the social opportunities we are given. A person born with a disability may be limited more by broader cultural conceptions than by any physical deficit if they are socialised into believing that they must live within preconceived boundaries without their abilities being pushed and truly recognised.

The next critical period identified by Goffman (1963), is childhood. If stigma occurs at this time, their family and others close by may protect the child from society's conceptions. This protection stays in place until the child makes a move towards independence, such as attending a mainstream school, or taking up employment. Again, in terms of brain injury, if a disability develops during childhood, then the people who know that child must deal with change. Depending on the age of the child, they may or may not be aware of their own transition. They may be protected from societal expectations by being grouped with others who have similar obstacles to overcome; for instance, a child who has never studied in mainstream education may not have a realistic concept of whether or not they could achieve in that environment. Realisation of their own strengths and limitations may only arrive when they are able to compare themselves to, and be compared by, wider social groups. If they are 'protected' throughout their lives then identity may never truly be questioned.

The third life-stage referred to by Goffman is adulthood or 'late life'. If a person becomes stigmatised at this stage then they may or may not face radical reorganisation of their past depending on their own view of their self as 'discreditable'. So if a person sustains a brain injury and they had already developed a view prior to this incident of what it is to be 'normal' versus some conception of what it is to be 'stigmatised', then they will either have to fit their altered self into the preconceived idea of what it is to be brain injured or they must redefine their past thinking. Goffman suggests that in this case, the individual presumably has,

A special problem in re-identifying himself, and a special likelihood of developing disapproval of self. (1963 p.48)

For an adult who sustains a disability, there is an inevitable sense of loss. We build our lives around expectations and aspirations that disability can delay or even destroy. After a person suffers a serious brain injury, they may find that all of their most basic assumptions about their life must be reconsidered; relationships, career, home, and all aspects of independence. This is one of the key issues that defines brain injury from the developmental disabilities with which it is often categorised.

The final pattern identified by Goffman is that of individuals socialized into an alien community who must then:

Learn a second way of being that is felt by those around them to be the real and valid one. (1963 p.49)

Goffman here refers to the pattern of shifting social worlds that stigma can bring. So a person who is identified as having had a brain injury, may then be expected to live and circulate within a different community of people. They may no longer be seen as 'fitting in' with those that they previously considered as being their friends and neighbours. It is assumed that they will make friends with others who have experienced similar circumstances and that this will be a more suitable social grouping. So not only must a person redefine their personal identity, but others redefine their social identity. Goffman sees this as then reflecting back into the person's own feelings on who they feel comfortable with:

When an individual acquires a new stigmatised self late in life, the uneasiness he feels about new associates may slowly give way to uneasiness felt concerning old ones. Post-stigma associates may see him simply as a faulted person; pre-stigma acquaintances, being attached to a conception of what he once was, may be unable to treat him either with formal tact or with familiar acceptance. (1963 p.49)

So through Goffman we can gain a sense of a trajectory through which people reidentify their own sense of place in the world. Change in status was a key issue identified by patients such as Lynne who had a haemorrhage while out on a community care visit, as part of her job at that time.

Lynne: It was, it was mostly me mind (laughs), not having a very good one in the first place. But er, it was memory, I could see someone and think to myself, I know them, but I couldn't tell you where I knew them or their name or anything. Which was very awkward 'cause I used to be a carer (laughs), and now all of a sudden it seems I need somebody to care for me

Like many others, Lynne refers several times to her previous role and the difficulty of being unable to return to that. Occupation is a recognised marker of status; our job says something about who we are and it gives focus to our days. After a severe brain injury, most people do not return to work, or if they do, it will generally be at a lower level, completing menial tasks. For many it is easier to be unemployed than to take a job that confirms their loss of status. Lynne has such extreme memory difficulties and resultant disorientation (as discussed through Section 4.3), that she would be unable to work in any capacity. The irony for her, as she indicates, is that she has gone suddenly from being a carer to being cared for. Her identity is now shaped to fit with her conception of her former clients.

We may see Lynne as demonstrating a classic reorganisation of personal identity. There are others though who feel much the same in themselves, but who are aware that their social identity has changed. James feels that through rehabilitation he has regained much of his former self, but he perceives others as holding him back because of their assumptions about what it is to be brain injured. He focuses particularly on his fight to regain his driving licence:

YEAH, IS THERE ANYTHING ELSE YOU WANT TO DISCUSS?

James: At Northampton, their, their thing was to teach you to be independent and I'm very, I like to be as independent as I can but, there's agencies and that, that are stopping me. I feel like I'm being held back a hell of a lot.

WHO BY?

James: I mean I'm having loads of trouble getting my driving license when I know I can drive. It's just, I find it so, I don't like to use the word patronising cause it's not strong enough. I find it so, that they don't let me drive. That they don't let me have a license. It's so, it's awful.

AND WHY DO YOU THINK THAT IS?

James: They think I'm unstable.

James had spoken earlier of having an anger problem, so I asked him if this was the reason that he was seen as 'unstable'

James: I'm not suffering from denial, I know I've got a problem, but I'd say 99% of the population has a problem. I'm no worse than anyone else. I'm not a violent person. I've never been a violent person.

His response is oriented to the implication is that he is violent. What is also at stake here is that his injury was caused by an incident which he strives to represent as an 'assault' rather than a 'fight', and we may grasp this as the reason why James is generally concerned to present himself as 'non-violent'. I mentioned a possible

contradiction with his earlier description of an incident where he had got into trouble for standing in the road shouting at a car driver for being inconsiderate. This earlier statement was:

James: I do still get aggressive, like yesterday I was crossing the road at a roundabout and a car hadn't indicated so I crossed, and the car came into the, my way where I was crossing and I stood in the middle of the road and shouted at the car, which was behaviour of an eight year old, mental. If I think I'm in the right, everything is black and white, I don't see the grey areas.

In response to this, James states:

James: Yeah, yeah, I shout at people, yeah. I do shout at people.
AND YOU THINK YOU'D BE ABLE TO CONTROL THAT WITHIN A CAR?

James: Probably not, no, but everyone does. Before my head injury I used to be like that.

So James recognizes an account of himself as having a tendency towards emotional outbursts but feels that this is part of his pre-morbid personality, and therefore he believes that it is unfair for it to be attributed to his brain injury and used as a reason for him not to drive. He justifies this further by pointing to his sister's personality

James: My sister's got degrees and that, she's got a really good job but when I'm in the car with her, she's effin and blinding like a trouper at other people.

SO IT'S REALLY DIFFICULT THAT ITS ALLOWED FOR OTHER PEOPLE WHO'VE NOT HAD A HEAD INJURY TO BE LIKE THAT?

James: Yeah, exactly. I'm not always like it. I'm not, it's once in every blue moon, once in a while. You know, it's not all the time. Not as if I'm like it all the time. Even though you probably think I am (laughter).

By highlighting his sister's qualifications and occupation he is making claims to her status. He then justifies his own behaviour by implying that it is broadly comparable. This blurred line between pre-morbid functioning and post-brain injury experiences can sometimes be difficult even for patients to define. Sometimes the label of brain injury gives people a category into which they can fit any failures or other negative experiences. Robin for example had some level of learning disability prior to the car accident that caused his injury. However his mother asserts that he has an unrealistic view of his prior abilities:

Patricia: He's got a good insight into what his problems are, but <u>again</u> he doesn't have the insight into probably saying, "Well that <u>isn't</u> anything to do with the head injury, <u>that is me</u>". Erm... when he, he'll talk to me about certain things, I'll say, "Well we all feel like that Robin sometimes. You know, that is, that's normal, we all feel like that, you know, we all have our off days, or we all have a day where we're fed up or we all have a day, you know, that's not unusual to you. We all get scared at

times, we all get panicky at times". It's like Robin wraps whatever happens to him he wraps the whole lot up because it's the head injury that causes it.
YEAH

Patricia: And he's very focused on that, and that's the <u>one</u> thing that does concern me. Because I feel now he's more focused on that, than he was at the very beginning.

Patricia is worried that Robin's brain injury has become the focus around which he builds and explains his life. She describes Robin as unable to separate the injury from himself and it has become an all-consuming part of his identity. He has, she argues, reconciled himself to the effects of brain injury and this has left him with a negative outlook where instead of fighting to recover lost functions and to deal with difficult emotions, he accepts that they are an inevitable and permanent result of neurological damage. This form of adaptation might be considered quite dysfunctional, but we might argue that it is what allows him to deal with his problems. If blame can be laid then at least Robin is spared the burden of responsibility. Strategies of adaptation such as this, will be explored further in the final section of this chapter. In the next section however, I will focus on the use of labels and how people such as Patricia and Robin define their expectations and behaviour by them.

4.4.1 The Use, Misuse and Non-Use of Labels

This section will explore the use of labels and what this means to people in terms of their identity. It will look at the definition and purpose of labels and how this shifts between contexts. It will also explore the choices that people make about defining others and avoiding or trying to avoid personal labels.

4.4.1.1 Using Labels

The most commonly used label is 'disabled'. It is the way that many patients refer to themselves, and it is used as a way to describe their situation. Aaron provides a classic example of this use:

SO I MEAN YOU'RE NO LONGER USING THE WHEELCHAIR, BUT HAVE YOU STILL GOT SOME PHYSICAL DIFFICULTIES?

Aaron: Oh yeah. Er, disabled

His response to the question of whether he has physical difficulties is simply, "Oh yeah. Er, disabled". It is used as an all encompassing explanation and it adds a

suggestion of permanence. There is no positive or negative sense attached to it, it is merely a tool for expressing information efficiently. 'Disabled' is a term that is also used frequently by carers to describe the person that they care for:

Patricia: And it bugs him, he <u>hates</u> being disabled, and he hates having a head injury, 'cause I live with that on a daily basis.

Here, 'disabled' is used as a negative label that represents what is wrong in someone's life. Patricia's son Robin has communication difficulties which he finds particularly frustrating, along with problems of emotional lability and pre-existing learning difficulties. These separate problems are grouped together as his disability and Robin defines himself as 'disabled'. Patricia says that Robin accepts this label but hates it, although discussion with both mother and son suggests that he does little to struggle against it.

Labels can of course function straightforwardly as stereotypical categories that are used to separate and exclude those who are so labelled:

James: I mean, I know that people are afraid of me. They see me as someone who has had a head injury, brain injury, they see me as a nutter. I know you shouldn't bother about what people think about each other, it's what you think about yourself. I know that's what you should be like.

James feels that people no longer see him as just another person. He is defined by his injury and believes that people are afraid of what they do not understand. His injury has caused him to sometimes exhibit quite manic behaviour and in his words, he is perceived as 'a nutter'. Perhaps for some the label of 'brain injured' helps them to justify and understand his behaviour but it can also bring many misconceptions. General awareness of how brain injury might affect people is typically poor, and often involves quite unrealistic conclusions.

Some labels might be considered as derogatory or offensive and are therefore usually avoided, but at the same time, they can sometimes offer a shared understanding of a given situation:

Rachel: When I asked what the prognosis was, the answer I was given was, the first scenario is you don't come out of it, the best scenario is you're blind in one eye, the worst scenario is you're a vegetable.

The term 'vegetable' is clearly problematic, but in terms of describing consciousness, it is an effective tool. A vegetative state is clinically defined and can only be determined through extensive testing, but this does not need to be understood to have an idea of what Rachel means by 'vegetable'. At its simplest, we might define this as non-responsive with little likelihood of recovery. So the label does its job. For Rachel it also emphasizes the risks <u>she</u> faced after developing an aneurism; by using an emotive and evocative term, she makes a clear point about what could have been.

Labels can also act as summations of otherwise inchoate feelings and attitudes.

Gordon and Deborah, when discussing their daughter's early state, liken her to a sack of potatoes; a heavy, inanimate bulk which they must move from place to place.

Gordon: We didn't get an ambulance or anything to bring her home, we had to bring our own car

RIGHT

Deborah: And take her out

Gordon: We had to wheel her out in a...

Deborah: It was like a sack of potatoes weren't she?

Gordon: Put her in a wheelchair, and we wheeled her out and that's it, two of us put her bodily in the car, bring her home like a sack of potatoes. Yeah, carry her in

home and put her on the bed.

This imagery is used to show the state that their daughter was in at the point where they discharged her. It indicates the battle that they had ahead and the level of desperation that they must have experienced to want her home at that point. Perhaps however, this inanimate labeling also tells us about how their daughter had changed and going back to the first label discussed, how she was from this point defined by her disability. The next section will explore how patients and carers define others through the use of labeling.

4.4.1.2 Stratifying Others

Labels are frequently used to stratify others, giving patients a means for social comparison. They will often label others as a means of separation, looking to prove a higher level of function in themselves. Edward for example, was quite typical in his view of Headway:

AND WAS IT USEFUL GOING THERE?

Edward: Definitely yeah, because I didn't feel so freakish, you know, being erm, so moody, and realising that there's other people who've had worse injuries than me,

a lot worse, so er..., so yeah it was good meeting people there and made good friends, stuff like that

Edward is placing himself on a scale, comparing his current self to a prior self and to others. This in-group stratification is explored by Goffman (1963):

The stigmatized individual exhibits a tendency to stratify his 'own' according to the degree to which their stigma is apparent and obtrusive. He can then take up in regard to those who are more evidently stigmatized than himself the attitudes the normals take to him (p130).

Goffman's description has some utility for many participants as they labelled others as less competent and then either acted in a way which might be seen to reinforce dependence (i.e. taking on a controlling, caring role), or socially excluded them for being, 'not like me'. Helen's husband, Richard, attends Headway, but is often mistaken for a staff member as he takes on a role of doing work to support others. For Richard, this gives him a taste of his prior life where he had a supervisory job, in which he could guide other, less able people. In his description of Headway, he states:

Richard: My family would hate me to miss a day and actually I have treated it like work, I've tried to make anything of appointments round Headway, because it seemed to me that, that was the sensible track to go down.

He is however uncomfortable with some of the other clients. As Helen explains it:

Helen: He doesn't like some disabled people. I don't know if he can see some of the chara'ristics of himself in them, I don't know if that is what... he says, "I don't want to be with all these disabled people". You know, and I don't know if that's what it is.

We may interpret there being some conflict in the way that Richard sees himself and the role he is carving out. He has been assigned to a group and the only way that he can cope with this is to define a superior place within the perceived pecking order; but those who he sees as lower down seem to make him feel uncomfortable, perhaps because he realises that this may be how others see him. This phenomenon is again explained by Goffman (1963):

When the individual first learns who it is that he must now accept as his own, he is likely, at the very least, to feel some ambivalence; for these others will not only be patently stigmatized, and thus not like the normal person he knows himself to be, but

may also have other attributes with which he finds it difficult to associate himself (p50).

Some people appear to experience less difficulty in accepting labels and associating with others who share similar problems. In some cases, people would refer to issues as belonging to 'their group' even when it was obvious that they were talking specifically about their own individual struggles:

Emma: I think when people have brain damage, and it's recognised that somebody has brain damage, people should be aware that it is going to be difficult for the brain damaged person and that the brain damaged person won't necessarily understand what is happening. They need to take the time to explain things slowly and to go over things until it goes into the brain damaged person's head. If a brain damaged person gets stressed its for a reason and I think doctors especially should be educated to sort of know that it's not all an act, it's not all put on - to know that it is all very real. It's not all doctors, but some doctors

I have highlighted Emma's use of the terms brain damage and brain damaged to emphasize how she is using these categories to try and express her own issues as belonging to many others. Emma has had particular conflicts with a doctor who suggested that she is more capable than she admits. She has taken on board a disability role into which she relates most of her feelings and consequent behaviour. Either she assumes that others in her accepted group must have the same experiences or perhaps more likely, she is justifying her behaviour by saying, it is a part of who we are, rather than, it is a part of who I am. For her, we can interpret the use of the label as protective and as providing her special allowances, but when this view is not shared, it can create conflict.

As a final example of how labels can create external conflict, Rebecca took her son Ben for a psychological assessment and was shocked to find that Ben's willingness to label himself was directly challenged and seemingly viewed in a very negative way:

Rebecca: So sent him to this professor up at the university and he hadn't given her any feedback so she was starting from scratch. So we sat in front of her and she said to Ben, "Tell me about yourself?" So he said, "I'm disabled". And she went, "What's that, that label? Who's told you you're disabled?" So erm... he didn't know what to say and I never said much at this stage

The Psychologist appeared to view labels as detrimental and later reflected Ben's definition of himself back to his parents, suggesting that they were overbearing and acting as barriers to his independence. However this assertion on the part of the

Psychologist obviates the variety of functions which the ownership of a label serves. Such labels can serve to act as points around which to summarise what can be quite complex and demanding phenomena. Indeed some people feel a need to label in order to make comparisons and to find a place that fits with the needs associated with that defined status. Returning to Rebecca, she states:

Rebecca: Ben's a little bit different with his medical condition...

YEAH

Rebecca: He's not just, I mean we don't know what to label him as. He goes to MOSAIC, which was the Guild for the Disabled. He went to a school, that were for disabled children because they'd got a bone problem. Ben did stand out as being bit of an odd one out didn't he?

Dennis: Yeah, yeah

Rebecca: With his memory problems, and his visual problems. You know, there weren't many of them that had got erm, sighted problems but they coped with him

and he coped with them

So Rebecca expresses a need to label, but also a recognition that no single label quite, 'does the job'. There is an expectation that we should be able to define and categorize people, finding a box into which they fit. One of the problems with brain injury is that it throws up many issues in combinations that are unique to this group. So labels, if they are to be used, must be chosen carefully as the assumptions they allow can be misleading. Some people are particularly concerned with avoiding labels and the assumptions of others; this will be explored in the next section.

4.4.1.3 Avoiding Labels

It is unsurprising that people do not want to be defined by their disability and as a result some fight against being labelled. To avoid labels, people must conceal the aspects of themselves that could allow others to define them. In James's case this means not discussing any of his difficulties, even with doctors:

James: Well, I'm the sort of stubborn person who's very bloody minded even though things aren't alright, I don't trust strangers. I'll say to strangers that I'm alright, I won't say to a stranger you know, I won't, I won't talk to a stranger, meaning doctors or whatever. I don't, it takes me a long time to get to trust someone.

If he cannot tell his doctor what his problems really are then, arguably, he will not get the most appropriate support and this is the key issue here. If people choose to present an image that they are coping, or that they have no real difficulties then this will often be taken on face value. It is only with time and the opportunity to build relationships that people may open up about their genuine needs. Returning to Richard, Helen has already discussed his discomfort with the disability label. She goes on to describe his efforts to avoid visual representations of this label:

Helen: Erm, I told him to get something, erm, a sticker, for the car, for my

daughter's car, if she took him out somewhere

PARKING? Helen: Parking

YEAH

Helen: "Huh, I'm not having that", he says, "I don't want a <u>disabled sticker</u>". And then I, I tried to persuade him, and I mean, you don't have to be disabled to have

those, you know those little motorised...

SCOOTERS? Helen: Yes

YEAH
Helen: Because it's quite a long walk, to the allotment

YEAH

Helen: When he gets there, then he's got to start the work

YEAH

Helen: And then he's got to walk back. I said, "Why don't you buy one of those?", I said, "You know, you can use it on the pavement". "I'm not having one of those, I'm not disabled". You know.

Richard is described here as not accepting that his problems constitute a disability and as choosing to conceal the difficulties that he has from those who 'do not need to know'. Richard's life could, she reasons, be made easier by taking opportunities to reduce the amount of physical exertion involved in his daily life, without restricting his lifestyle. Since his injury, he gets incredibly tired and maybe if he had to walk less, he could actually do more, but he would rather not be identified as needing help. Issues of concealment will be explored further in Section 4.4.3, but it seems appropriate to first look at issues of visibility.

4.4.2 Visibility and Medical Blindness

Visibility was a common theme in the data. Brain injury is not visible in the same way that a disability such as paralysis is and this can affect the way that it is perceived by others. A basic concern was the way in which disability is measured for the purpose of accessing benefits and other support. Owen was one of the people who discussed the medical assessment process:

HAVE YOU HAD ANY PHYSICAL PROBLEMS SINCE YOUR INJURY?

Owen: Not really, well (coughs), I were telling me medical the other, the other week like that I do still have trouble with this arm

YOUR LEFT ARM

Owen: Yeah, for some reason... yeah, this arm, yeah, for some... 'cause you know I can, I can lift it up to a certain point but... and then it starts hurting if I lift it right up YEAH

Owen: You know, and when I went to this medical it were like, "Well can you lift a bag of sugar up? Can you do this? Can you do that?" I turned round and I says, "It's not really physical, it's what's in me head, what's going round in my head"

The problem is that disability is often assumed to be something that can be seen and brain injury is by its nature, a hidden disability. The lack of visual evidence can lead to people missing out on support that they desperately need. Later in his interview, Owen went on to complain that his emotional problems are not visible enough to be recognized

Owen: Oh well, just 'cause I'm not foaming at the mouth and rocking in me chair and stuff like that, you know, don't see these things so what then? Oh yeah, you'd better go work

So for some the lack of a visible indication that they have a disability means that their needs and capabilities are misunderstood. Owen struggles with depression, emotional lability and motivation but because he has difficulty in expressing these problems and how they affect his everyday life, he has had to have a lot of assistance getting his disability accurately assessed. In another case that was recounted to me, an assessment was conducted verbally where a patient was asked questions such as, "Can you stand from a seated position?" His response was, "Yes", but with limited ability to deal with anything beyond direct questions, he did not elaborate that although he can stand, he will immediately fall over. Problems such as balance may again not be immediately visible, but can limit a person's capabilities and leave them in need of support. The doctor was not aware of this patient's communication difficulties, as he had learned to respond appropriately with the words 'yes' and 'no' but someone who knew the patient came in at the end of the assessment queried the answers. Once they had made the disability more visible to the doctor the whole assessment process was restarted.

Where there are visible signs of disability there are then issues around how people feel about these and whether they conceal them. Goffman (1963) cites visibility as a crucial factor in a person's social identity. If a disability can be seen by others it may affect how they will treat that person. Physical signs though may only have meaning to those with some medical knowledge. Simon for example has deeply scarred legs from a procedure to stop his muscles wasting:

AND HOW DO YOU FIND THE WALKING NOW? IS THAT STILL

IMPROVING?

Simon: Better than it was, but, I don't like my legs, because thing down here, I can't

build 'em up, with muscles.

IS THAT HOW THEY'VE ALWAYS BEEN THOUGH?

Simon: Well, (rolls up trousers to show deep scarring on both legs) just counting

this bastard

AND THAT'S FROM THE ACCIDENT IS IT?

Simon: Yeah, one of, no that's erm. Well my legs, something happened in the coma,

stopped my legs being chopped off, they made two slits.

This combined with balance problems makes walking difficult. He has visible signs of the operation to his legs but keeps them covered so once again, a lack of visibility becomes an issue. His injury has also left him with slurred speech and together with his mobility problem this is often interpreted by strangers as a sign of drunkenness, which has caused a range of further difficulties such as not being let onto buses and being refused entry to certain places. Simon does have one other visible sign, a tracheostomy scar to his throat. Many people who have had brain injuries will have needed assistance to breathe, particularly those with traumatic injuries, so in this group the tracheostomy scar is quite common, but it does not make disability visible because it is not a widely understood sign. Goffman probably expresses this best when he states:

The decoding capacity of the audience must be specified before one can speak of degree of visibility (1963 p68).

So if visibility of more subtle signs requires medical knowledge, then those who do not recognise such signs could be classed as 'medically blind', and this will account for most people that you are likely to come into contact with. Of course, if they have the opportunity and choose to do so, patients can explain their scars to the uninitiated; this will be discussed in the next section.

4.4.2.1 Visibility as an Aid to Memory: Reading the Scars

Memory has already been discussed in terms of neurological loss, strategic loss, adaptation strategies and reconstruction. In this section I want to consider how memory is also rooted in physical evidence, specifically in the scars people gained, either directly from the initial injury, or from any surgery that followed. While the injury or operation may not be remembered, the existence of scars gives concrete

proof around which new memories can be built. As an example, Lewis was in a car accident as a child and his memory of the injury is a construction based on the explanation he was given for the scar on his head:

OK, CAN YOU JUST TELL ME VERY BRIEFLY WHAT THE CAUSE OF YOUR BRAIN INJURY WAS

Lewis: Erm, a car crash and erm, I went through the windowscreen and erm, my

head hit a brick, you know

YOU WENT THROUGH THE WINDOWSCREEN AND YOUR HEAD HIT A

BRICK

Lewis: Yeah, I've got a big dent here, I have, where is it? There. Feel that, it's

grown out a bit

YEAH

Lewis: Kind of, you know

YOU'RE PROBABLY MORE CONSCIOUS OF IT

Lewis: Quite deep, I think

Lewis describes himself as self-conscious about his scar and feels that the indent in his skull marks him out as different. In reality it is barely visible, but he most likely describes it as big because of the significance it has for him. Like Lewis, Steven has had to reconstruct the events around his injury. He though has the added complications of severe memory and language deficits. One part of his past that he can be sure of, is that like Simon, he had a tracheostomy. He has the scar as proof and uses it to describe events without the need for an extensive verbal monologue:

Steven: Air-hole (pointing to tracheostomy scar)

YOU HAD TO HAVE A TRACHEOSTOMY DID YOU?

Steven: Yes

I was only able to fully interpret Steven's meaning because I already knew about this procedure. For those with extensive scarring, reading the visible signs of their injury can provide a complex story. Joanne has had at least six operations in association with her brain tumour and the scars provide a visible map of this history. She is understandably self-conscious about this and tries to cover the scars, so it is interesting that her husband draws attention to them, but Joanne plays along and is perhaps more relaxed about the visible signs in the privacy of her home:

SO HOW MANY OPERATIONS HAVE THERE BEEN IN ALL?

Damian: Oo. Shall we count on your, 'cause here....

Joanne: (Pointing to scars on head) Left Shunt...

Damian: ...you can see the scars on her head

Joanne: ...right shunt...

Damian: Biopsy

Joanne: De bulk, biopsy, left shunt, right shunt, de bulking, de bulking, remover

Damian: That's six in't it?

Joanne: Six, yeah

SIX

Damian: Yeah, yeah about six in't it?

Joanne: Six in er...

Damian: There might be one other there, but it's about six

Joanne: Six in...

Damian: About seven years

Joanne: Nine year weren't it?

Damian: Something like that innit?

Joanne: Yeah

Damian: Yeah. Plus the er year last January she had er, radiotherapy as well

So much has happened over so much time that details are hazy, but the scars reinforce memories of the many surgical procedures that Joanne has had to endure. Daniel has a similarly extensive map of scars, which he accepts as part of who he is today. He is still learning about his time in hospital and because he has no direct memories of this period, he describes it as 'an alien story'. His scars arguably provide an anchor to reality, especially bearing in mind the false memory issue discussed in section 4.3.3

Daniel: Yeah, it's just that, you know, from my point of view, I'm hearing things all

the time about, you know, how bad I was and that

YEAH

Daniel: And it just seems like a, an alien story

YEAH

Daniel: You know

YEAH

Daniel: "Oh no that's not me"

YEAH

Daniel: But you know obviously I've got the scars to prove it and I've got the big, I've got a lump, lumpy head to prove it, both sides, and there's a hole there where

they drained me off apparently

Victoria: Yeah, that was the first one, the first one

Daniel: That's where they can screw the tap in I think (laughter)

Victoria: Cause I mean you looked madder than you actually are cause by the time

they'd finished the shaving

Daniel: Excuse me

Victoria: They had to do that bit and then shave this bit and then they shaved the back so there were all varying degrees of growth of hair, and some of it had been left completely so he'd got a big quiffy bit, oh dear. Soon as all his cuts and everything were healed, we took one of those buzzing hair things in

YEAH

Victoria: Buzzed his hair. It was the first time he looked like anything like, you know, normal intelligence (laughter)

Daniel: (Makes 'loopy' noise! - fingers up and down lips) (Laughter)

Victoria: As I say, his son, he were just like tears in his eyes 'cause he looked like

his dad again

Daniel: Mmm, bless him

This conversation turns from one of reading the scars to one of visibility and how distressing it can be to see a loved one in a poor physical state. Every new procedure required more of Daniel's hair to be shaved, but instead of shaving his whole head, it was done section by section, which left an upsetting image for his family. Simply

being able to return Daniel's hair to an even length was incredibly important to his son and perhaps should have been considered from the outset. As Victoria states:

He were just like tears in his eyes 'cause he looked like his dad again

As a final note to this section, while physical signs might make a person's disability visible, emotional ties can equally make it invisible. Ben has a range of problems caused by a history of brain tumours, diabetes insipidus, and the side effects of related treatments. His face is swollen by steroids and has a child-like quality due to delayed puberty; this is also the most likely cause of him being quite small in stature. To his mother though, he does not, 'look disabled', even though she labels him as such:

Rebecca: Ben really he looks so good, I mean, I don't know, we don't know what he looks like to other people, because we had a, a perfectly able bodied little boy. Alright he was born with a tumour...

And here is the point, "We don't know what he looks like to other people". The visible signs of disability will always be open to interpretation as will the actions of patients as they try to deal with their changing circumstances. The ways in which they deal with this change will be the topic of the final section in this chapter.

4.4.3 Strategies of Adaptation

Part of the process of recovering from any long-term illness or disability is to adapt to it. Adaptation can take many forms; it can mean that a person accepts their limitations and works within them, developing a new identity around their disability; it can mean that a person ignores their limitations, focusing on what they can do, but sometimes building unrealistic expectations of their immediate capabilities; in many cases, people will struggle against their limitations, trying to push back boundaries and focusing on becoming 'the person they were before'; for many there comes a point where they must reconcile themselves to their illness/disability and the limitations it places on their daily life.

Charmaz (1991) defines resonant states of adaptation as four distinct levels of acceptance: to accept illness; to ignore illness; to struggle against illness and to reconcile to illness. By defining these states as levels, Charmaz suggests a degree of separation between them and the use of the term 'acceptance' gives a ring of

permanence. Although she provides a framework that could be applied wholesale to the data from this thesis, to do so would be to force the data into a set of categories which may not necessarily fit with emerging themes. For this reason, I have treated Charmaz's (1991) categories as potential 'strategies of adaptation', which can shift through time and across contexts. I have applied these strategies to my data, as a useful tool for organising and discussing the patients' explicit and implicit representations of their ways of coping. I have also developed two further categories to explore data not sufficiently attended to by the Charmaz model. It should be noted that other models such as Herzlich's (1973) conceptions of illness as destructive, as liberator and as occupation could equally have been applied in many instances.

The first identified strategy is to **ignore** illness, which Charmaz (1991) defines as "Looking over and beyond illness" (p.46). There may be periods where people try to ignore their limitations but for most this is not a long term strategy, as reality forces them to face the issues of their present situation. In general, the participants who might be included in this category are people without mobility problems as their disabilities are less visible, such as Emma:

Emma: I didn't realise that my brain was so severely damaged before I went for job training. I did think that I would be able to go on and work.

Emma's experience highlights an important issue in this category, ignoring illness often works only as a short-term strategy, as critical junctures such as returning to work can bring home the reality of a person's limitations. Sometimes, people who try to ignore their illness also try to conceal it. Richard had encephalitis and this caused prosopagnosia, which is an inability to recognise faces. He underplays this disability whereas his wife often makes explicit reference to it.

Richard: Yes, er, faces, erm I don't remember faces er, very often, but erm, I remember names and I can put names to faces and all the other things, I just don't seem to be able to remember the faces that go to the names.

RIGHT, SO, BUT IF YOU, WHEN YOU SEE PEOPLE THAT YOU'VE SEEN

BEFORE DO YOU RECOGNISE THEM OR...DO YOU THINK, OH I KNOW THAT PERSON?

Richard: Ah, yes invariably, yes, yeah.

BUT IF YOU'RE THINKING OF A NAME YOU CAN'T NECESSARILY

VISUALISE WHAT THEY LOOK LIKE?

Richard: No.

So the impression given by Richard is that he is absent minded with faces, not that he doesn't recognize them. Helen is far clearer about Richard's condition.

Helen: This illness has left him so that he doesn't see faces

She goes on to describe a visit from a research Psychologist who tested Richard on famous faces:

Helen: It was when Princess Di died, now we had her for breakfast, dinner and tea didn't we?

YEAH

Helen: She was in every magazine, every paper, yet when the guy put her photo down and he said, "Who's this" and Richard didn't know, and he said, "I am astounded that your husband didn't know that that was Princess Di, but when he told him who it was...

YEAH

Helen: ...he could then tell him all about it and like there was one of um, Dean, Dean, James Dean

YEAH

Helen: One of James Dean, and er, he said to Richard, "Do you know who this is?" and Richard said, "No". He said, "It's James Dean" - and he told him all about James Dean. Marilyn Monroe, which I think everybody knows.

YEAH

Helen: He didn't know, but he knew all about her, so this is what I'm saying, you know

She continues with several stories about incidents caused by Richard's prosopagnosia, particularly in situations where his condition is not known to others.

Misidentification has caused many mishaps. Richard chooses to overlook these incidents, but his wife Helen is keen to avoid them. She therefore chooses to explain his difficulties to others:

Helen: You see, yes I've, I've told them and I've told people that we've met, like last year we met some nice people in the hotel, the first night we were there actually, and the next morning he went straight past the guy, so I then explained to him, I said, "If Richard goes past you, it's not that he doesn't want to talk to you, it's just he doesn't recognize you".

YEAH

Helen: So I more or less forewarn people

According to Charmaz (1991), by ignoring or minimizing his impairment, Richard may be able to preserve his self-identity and his sense of unity between body and self. This strategy may be difficult to maintain though with the regular reminders from his wife. The issue of whether people should disclose their difficulties is contentious, as was explored Section 4.4.2, to gain appropriate support, problems need to be made visible, but then it is perhaps more important to some people to maintain their

established identity. The way in which carers may overlook rights such as this will be explored further in Chapter 5.

The next identified strategy is to **struggle** against illness, to have hopes and make efforts towards a full recovery. As Charmaz (1991) defines it, illness can become a, "Personal enemy to confront, to challenge, and to conquer" (p.46). A common theme in the data was people overcoming a poor diagnosis. This might initially just be people surviving and regaining consciousness, but this is a difficult situation to claim a high level of agency in. The next step however, of regaining physical capabilities, is one which patients can identify as a personal achievement. It is an opportunity for them to struggle against adversity and to be recognised for it. Where a negative prognosis is given, it is also a chance to prove medical professionals wrong and show that with determination, any limitation can be overcome:

Patrick: The main factor in my recovery to be quite honest is my own determination, because the doctor said I'd never walk again and I was determined to be able to walk again, and that's what's enabled me to get around really with a walking stick which I can now.

HOW EARLY ON IN YOUR RECOVERY WAS IT WHEN YOUR DOCTOR SAID THAT YOU WOULDN'T WALK?

Patrick: Straight after I'd had my accident and come out of Wakerley Lodge, a couple of weeks, no more than that.

AND WHY DO YOU THINK THEY THOUGHT THAT?

Patrick: I think that the doctor was speaking from his experience, and it was only my determination that really got me over that hurdle.

HOW DO YOU FEEL ABOUT THE DOCTOR TELLING YOU THAT?

Patrick: I think it was a bad thing to tell me really

Patrick expresses pride that he has regained some mobility against all expectations but proving the doctors wrong has left him with doubts about the medical profession. It is a difficult balance for medics to tread but a prognosis that does not mirror the eventual level of recovery seems to affect the long-term attitude of some patients to the advice of professionals. For others though, exceeding expectations is constructed in a positive light. Staying with wheelchair use, most patients will follow a guided physiotherapy programme of treatment and exercises and sometimes the gradual pace of this can be frustrating. Daniel provides a clear example of where the patient decides to speed up this process by attempting to reach milestones before they are 'scheduled' to do so:

Daniel: And er, I was told by one of the physios that er, I'd never get out of that wheelchair

YEAH

Daniel: And er, excuse the language, I said, "Sod that for a bloody lark", you know,

"You just watch me"

HOW DO YOU FEEL ABOUT THEM TELLING YOU THAT?

Daniel: (Sighs) Not very happy at the time, but looking back I can see why she did

it. Perhaps it's a piece of applied psychology, who knows?

Victoria: I think she said it as she saw it

Daniel: I think she did to be fair, I mean I was, I was pretty poor at one stage wasn't

1?

Daniel had been told that he would never walk again but describes himself as having been determined not to accept this diagnosis and struggled hard against this potential outcome. He suggests that this is maybe even what the physiotherapist intended for him to do, although his girlfriend feels that it was simply a realistic assessment of his state at the time. Daniel decided that if he was not going to be pushed by others, he would push himself. He did this by 'acquiring' another patient's mobility aid.

Victoria: They came round the house and were looking at sort of what would be a problem for him and he was wheelchair-bound as far as they were aware, couldn't walk any distance at all. He stole somebody's zimmer frame in the hospital

Daniel: (Laughter) (LAUGHTER)

Victoria: This bloke, he'd got him giggling. Him and this old bloke, he'd got this

really big nose hadn't he? Kept catching you sat watching the football

Daniel: Oh yeah

Victoria: Like a pair of kids they were, giggling away and then he said, "Give us a go with your zimmer", and the bloke said, "Well not when the nurses are here".

They caught him, confiscated this poor buggers zimmer

Daniel: (Laughter) (LAUGHTER)

Victoria: And you got in trouble didn't you?

Daniel: I did...

Victoria: But from that ...

Daniel: ...got a bollocking for that

Victoria: ...they let him have a go properly, with the nurses holding him.

YEAH

Victoria: That poor bugger never got his zimmer back

Daniel: Well I made a point at the time, I said, look, I wanted to do it because it was

an extra aid to me getting mobile

YEAH

Daniel: I wanted to prove to myself that I could do it, so in my own fashion, I did that. Which, I can't think of his name now, chap in the next bed had a zimmer frame so I thought, "Oh, I'm gonna have a go at this". So I did (Laughter), off we went (Laughter), like a pair of old cronies (Laughter)

Victoria: And then after that he'd got an escape committee

Daniel: Got what?

Victoria: An escape committee going hadn't you?

Daniel: Yes, apparently I was the leader of the escape committee, according to these

old boys

Victoria: Daniel, Daniel tried to escape times, he'd packed all his belongings into

his lap YEAH

Victoria: Put his coat on

Daniel: Yeah

Victoria: So he could hardly see, cause he'd been there some months, he'd got a lot

of stuff

YEAH

Victoria: Easter eggs as well, it was Easter, and he weren't going to leave them

behind

Daniel: (Laughter) (LAUGHTER)

Victoria: Bloody great big thing in his lap, thinking, thinking nobody would notice, with his coat on. "Daniel, where are you going?" "Nowhere". "Oh right yeah, why have you got all your belongings in your lap?"

Daniel: Oh yeah (laughter). I vaguely remember that, I think, I think it was, was it

Jeanette that caught me? Yeah, she was funny she was.

This is an incredibly engaging piece of storytelling. Daniel pushed throughout his time in hospital to achieve some level of mobility and to be discharged, even to the point where he decided to, 'escape'. He had a lengthy and frustrating wait in hospital while arrangements were made to adapt his home but after just over a year he was able to leave. Daniel is now able to walk without any form of mobility aid and he feels that this achievement is down to his ongoing struggle against disability. He took every opportunity to get out of his wheelchair and to practice standing and walking. His partner worried that by taking risks he was endangering his health and his long-term mobility prospects, but in his case, the struggle paid off.

For some, the struggle against illness is not so much physical as mental. It is a belief in themselves and in their ability to survive and recover. Rachel talks about this with regards to the brain surgery that was required to stabilise her condition:

Rachel: Before I went I couldn't say goodbye to my husband because I thought that was dancing with the devil, (laughs), I had to say I'll see you later.

YEAH.

Rachel: I had to believe I was going to come though

YEAH

Rachel: Whatever the odds, they weren't that great but I had to believe it.

YEAH

Rachel: And anyway I've got too many things to do still to die, the kids were too

young my son was only 14.

She describes how it is that her belief helped her to come through and then beyond the operation, she describes how occupational therapy taught her to struggle:

Rachel: She was very good. She'd give me first hope I think really, 'cause she told

me, she got me here

YEAH

Rachel: It was her did that, and she told me ways of doing things that I just felt then

that I couldn't do the things

YEAH

Rachel: Cause I try it and I couldn't do it, but then she would show you that, ok if

you try it that way and you can't do it, then try a different way

YEAH

Rachel: And keep trying until you can do it. 'Cause I used to get cross, if I, I still do, you know if I drop something, I get cross, I <u>kick</u> it, I think 'cause I'm cross because I've dropped it

YEAH

Rachel: And I used to throw things 'cause I couldn't do it, but then she said do it different way and I, I do that now automatically. I try a different way of doing it, if one way I can't do it then I sit and I think about it, 'cause quite often, it's hard for you to know, a very simple thing, is physically very hard to do. To get into a packet of cheese...

YEAH

Rachel: ...is virtually impossible. I cannot get into a packet of cheese. So instead of knowing I can't get in a packet of cheese, after she'd finished, now, I get the cheese and I hold my arm on it and then I get a knife and I stab the packet

YEAH

Rachel: And cut it

YEAH

Rachel: But if she didn't come, I wouldn't think that

YEAH

Rachel: I'd just think I can't get in that cheese

So Rachel was given back belief in herself and her ability to do things. By finding strategies to complete everyday tasks she has been able to regain a good quality of life. For some though, the struggle is against insurmountable odds. Joanne has a terminal brain tumour but her husband has chosen to conceal the fact that she will not recover. Joanne shows determination to struggle against her illness and the effects of her injury:

Joanne: I'm not interested what he told you, because I'm getting better now.

She clearly states that she is not interested in what the doctor shared with her husband. Her belief that she is getting better may even help her, as a positive attitude can be incredibly valuable to both recovery and emotional stability. The question is whether it is her right to know, and whether it is the right of others to conceal her fate. This will be explored further in Chapter 6.

The next category to be considered is where people reconcile themselves to their situation, in other words, they tolerate the effects of their injury. Charmaz (1991) asserts that most people do this. "It means acknowledging and handling pain, slowness, or fatigue. It means following a regimen or creating a routine to manage or mask the symptoms" (p.47). An example of this category applied to the current participants is Lynne with her complex set of routines designed to deal with her severe memory deficits. I would also define this category though as including people who tolerate their current state but do not exhibit total acceptance. They remain in a

static situation where it is difficult to move their life on. Jenny for example is reconciled to the effects of her injury but in what might be seen as a negative way:

Jenny: I'd like to explain that I've got a very negative outlook on life. Everything for me is ruined now. I mean like I remember my life before I was, I was like this, and it hurts so much. I don't, I, like, people, other people see change in me, but I don't see a thing, I just think how I was and that like I'll never be as good as that again. So I don't know, but like there's me here, I mean like you're supposed to have a head injury, but I can remember everything, like, before me accident. Like I can remember everything now, it's just that I can remember just like what any ordinary person would and it just really ... me off.

She tolerates her disability but describes herself as not having come to terms with it. She is still focused on her losses and therefore cannot value what she has left. The fact that she has no memory deficit, instead of being presented as a blessing, it is described as a curse. If she cannot be the person that she was, then she does not want to try and prove herself right (this is resonant of Herzlich's, 1973, conception of 'Illness as Destructive'). Hazel also looks to the past but represents herself as starting to see a way forward:

Hazel: Brain injury itself is bloody awful when you're used to being, or when you was so independent

HOW ARE YOU COPING WITH IT?

Hazel: Erm, not too bad. We still have weepy moments and weepy days, but on the

whole not too bad

DO YOU THINK THAT THERE'S ANY MORE THAT ANYONE COULD DO

TO HELP YOU DEAL WITH THAT OR ...?

Hazel: I don't think so. Its something I gotta sort out myself

YEAH

Hazel: Stop feeling sorry for myself on the days that I do

She recognizes the negative cycle that she has been in and has decided that she will doing something about this, suggesting that she is moving towards acceptance. To accept the injury is the final category. As Charmaz (1991) defines it, "Acceptance shapes the future as well as the present. It assumes accepting the identities others deem to be 'appropriate'" (p.48). The data showed a tendency for those who have grown up with their disability to be more accepting of it, such as Ben who is actually writing an autobiography to share his experiences with others. Perhaps with little experience of life without injury, it is easier rebuild their identity. For adults, acceptance can be a slow process. Geoff identifies a conversation that prompted a change in his strategy from ignoring to accepting:

Geoff: Pretty useful, I've found a lot of the time that, it's emotional support more than anything I need 'cause as one said to me one day, he said you're going to have to accept the fact that you've got a disability and that day everything else 'll sink in and take into place. Sure enough I'm beginning to accept now, more and more that I've got a disability, even though I don't like it much.

Although he is still to an extent struggling with his changed life, he represents acceptance as an important step forward. Those who have accepted the consequences of their injuries and perceive this as a milestone can then use this as a measure of superiority against others, in the same way that labels are used to place people on a scale against which the individual can compare themselves favourably. William gave an explicit example of this:

William: I'm more acc..., I suppose I'm more acceptable than other people. I know what has happened to me

YEAH

William: So I got to <u>live</u> with it, you know, other people don't want to know do they? You know like, what has happened to me, my hand hurts, my face hurts, and things, you know, you have to <u>live</u> with that, you know and other people don't want to know. They say, "Oooohhhhh" (groaning) and they do this all the time (wincing), but I got to get, it's called the pain barrier

YEAH

William: You know, as soon as you want to do something, erm, I can't do every things with my hands, you know I went to, I went to watch, I went to play ten pin right, I couldn't do it in this hand, this is the one, but I've got to do it in this hand now

William presents acceptance as a milestone that has allowed him to move on. By accepting his physical deficits, he has been able to step back and look at compensation strategies. This does not however work for all in a positive way. Gary for example has accepted what he sees as the disabled role. He is one of many who were told that he would never walk again, but is one of the few who seems never to have struggled against this.

Gary: The only thing I miss doing is not walking

YEAH, AND HAVE YOU, DID YOU ACTUALLY GET ANY SECOND

OPINIONS ABOUT THAT AT ALL?

Gary: No, everyone else that I've tried to speak to have just said to me that I'll, I'll never walk again, the doctor told me it.

RIGHT, AND DO YOU THINK IT'S BEST THAT THEY TELL YOU THAT

STRAIGHT OUT OR WOULD YOU RATHER?

Gary: Well with me saying that, I'm glad that it's out

YEAH

Gary: Yeah, and if he'd held it back, that would, I would think that would have made it worse

He is dependent on others and describes himself as making no effort to work towards regaining independence. This strategy clearly invites disapproval, but for Gary we

may see it as adaptive in so far as it allows him to reach some kind of resolution with regard to his brain injury. Each strategy of adaptation clearly operates in a distinct way, and we should not assume that a given individual will need to pass through these strategies in a linear fashion. An individual's unfolding trajectory of care determines the extent to which each strategy may be adopted. For example, to ignore illness may work to preserve identity as long as it can be maintained. To struggle may help people to push the boundaries of their recovery, but at a point where progress is no longer made, perhaps it is better for people to reconcile or accept. These latter two strategies are closely linked and movement between them can be expected. They may be seen by some as giving up, but acceptance in particular can open up opportunities to rebuild life around remaining strengths.

In conclusion, this chapter has highlighted the influence of context through storytelling, presentations of blame, experiences of loss, issues of identity and strategies of adaptation. Together these form part of the patient's input into their own trajectory. The next chapter will focus on carers and how they interact with patients. It will look at their contribution to the developing trajectory particularly in terms of agency and it will explore how their role develops through time.

Chapter 5 – Analysis (II) Development of the Carer Role

5.1 The Caring Career

What it is to be a carer is something that is difficult to realistically conceptualise from the outside. Interviews with carers' emphasize the total shift in life roles as their whole world is turned upside down. Many find that they must put their life on hold and jobs may be quit or hours reduced so that they can devote time to their loved one. Parents return to a parental role, in some cases taking this to an extreme where they become 'ultra-parents' who seemingly devote their whole lives to caring for their child. With partners it is often more difficult. Unlike most parents, they have lost their main emotional support, they are dealing alone with their loss but at the same time trying to cope with the practicalities of supporting someone with a brain injury. They may feel that they have been forced into a 'pseudo-parental' role, drastically altering their own identity.

Day-to-day life as a carer is hard to conceptualise from the outside but we can listen to the accounts of people for whom this is a reality. Patricia for example is mother to Robin. Her son was injured as a child so there is no point in his life when she has not cared for him. He is now in his mid-forties:

Patricia: Erm. But yes he can be very, very emotional. And sometimes, I'll be quite honest when he does it sometimes I think you could slap him. Whether I'm doing right or not, I honestly don't know because with a person like Robin you're dealing with so many issues. Sometimes you try understanding; sometimes you try being sharp, depending upon what the situation is and how it is. And also to be quite honest I'm human, depending on how I feel at the same time. That is, that's one of the, I think one of the toughest things, really.

Patricia here articulates the real life concerns of being a carer. She has her own issues to contend with and describes her own shifting emotions. These impact on the strategies that she uses to deal with Robin and she admits that sometimes she gets things wrong. As

she emphasizes, "I'm human". She gets frustrated and she gets angry, but at the end of the day her role does not stop; this is a 'twenty-four seven career':

Patricia: I'll be honest, sometimes it can be tough. Can be tough sort of thing, and you think, "Oh God", and I think also that, it's never going to end and you know it's not.

Caring for a person with an acquired brain injury can be emotionally exhausting, with effects on the family being particularly visible when the individual has experienced behavioural or cognitive changes. (Frank, Haut, Smick, Haut, & Chaney, 1990; Mintz, Van Horn & Levine, 1995). Not only may the person seem to be different in personality, temperament and intellectual capability, but these changes may be invisible to others. Full time care work can tend to be overlooked by the outside world when the patient does not fit into the classic perception of disability. Perhaps this lack of recognition makes it harder to seek help and therefore to break out of an exclusive relationship of care. This chapter will explore such relationships, looking first at how carers become channels for agencies and the critical juncture of bringing the patient home from the hospital.

5.1.1 Becoming a Channel for Agencies

The first point at which a carer can become a channel for agencies is in calling for initial medical support. None of those interviewed were present at the time of a traumatic injury, but several were involved in the diagnostic process around organic brain damage, then making some claim as to the importance of their role. Helen gave the following story when asked about the cause of her husband Richard's injury:

Helen: On, it was in 19, 1996, on October the 14th and he'd had a really bad cold and he'd gone to the doctor and they'd just said it was sinusitis and they gave him some tablets but he was acting really kind of strange and I, I couldn't put a finger on it, but he was doing strange things. Well I phoned one of my sons and I said, "Will you phone up in a little while and don't let you daddy know that I told you, but will you talk to him and see if you can see anything strange in the way he's talking to you". So he said yes. And then [my son] said to me, "Yeah, he, he does seem strange somehow". Anyway, erm, I phoned the doctor and I said, "Will these tablets make him a bit strange". And Dr Thomson said, "They shouldn't, if they still are acting up, then come and see me tomorrow". Well, that night, it was, well early hours of the morning, about 5 o'clock in the morning, erm, I'd gone into the loo and er, Richard was walking round the bedroom, and I said, "What are you doing?" and I had tapes on one side and he was just, got them in his hand. I said, "Come on, get into bed" and he was, started to get into the bed and then he made this horrendous sound, absolutely awful. Anyway, I got the ambulance and

er, they took him to the hospital, and they thought he'd got meningitis, they thought he was going to die, anyway, erm, it wasn't until the afternoon that er, there was a space in erm, Walsgrave Hospital for a scan, and they found that he'd got this herpes simplex encephalitis, and water on, fluid on the brain and on the spine, and as I say he almost died, you know. Erm and it was the fact that he didn't know anything, he didn't know who we were, he didn't know how to walk, the only thing he knew how to do was feed himself.

Helen here describes how she was concerned that her husband was not acting as she expected him to, so she gained a second opinion from their son, as someone who knew him well would be more likely to recognize the change. She reported her findings to the doctor and was offered an appointment the following day, but in the early hours of the morning, Richard entered a crisis phase of illness in which, as Helen emphasizes twice, 'he almost died'. It is Helen who assessed that there was something wrong, she followed up with the doctor and she called the ambulance. In her account, she represents herself as highly proactive in assessing and organizing care, right from the first symptoms. So by the time Richard entered the hospital, Helen had already carved out a clear role as a channel for agencies. All of the patients interviewed for this thesis were at some point hospitalised, and there then followed a period where any continuation of support would have to be arranged. Usually this would be done through the primary carer and being a channel for agencies was often the first step in formalising this carer role. Sometimes there would be a feeling of shared responsibility, with the patient involved at some level:

Robert: Somebody come to see me up there...

RIGHT, OK

Robert: ...and says oh, "We're from Headway, we deal with people with head injuries"

YEAH

Robert: And that was, again, well she spoke to the missus more than me 'cause I was...

YEAH

Robert: I couldn't underst...Well I was gone sort of thing

In Robert's case, services were arranged through his wife. He tended to be present at these meetings but he was considered to be too badly affected by the injury to deal directly with information gathering and decision making. It is in these early stages that carers are asked to listen and speak on behalf of patients and so their role develops. However, as the patient's health improves, the carer does not necessarily relinquish this status. In some cases, being a channel for agencies can be a role that totally excludes the patient from care arrangements or even from important information about their condition:

Damian: I knew, I know more about Joanne's condition than Joanne does because, you'll vouch for this, sometimes when we've gone to see Doctor Johnson, who was the surgeon. I've asked Joanne to go outside while I've asked him questions that I wanted to know, and he told me frankly, the answers. And that helped a bit, even if the answers were negative a negative kind of, no it's not going to help or. But, basically all I'm going to say even if the answers were horrible, negative answers it helped, helped me. Because once I can realise something what's gonna happen, then I can, I can tackle it, it's not knowing. I absolutely hate not knowing, so, it's like, once Joanne had the, the, the er scan, it was murder, pure murder every single minute of that day, or for the, the days that happened until I knew, once I knew what was wrong then I could handle it better.

YEAH. JOANNE?

Joanne: Yes

DAMIAN HAS JUST SAID ABOUT SPEAKING TO PEOPLE WITHOUT YOU SOMETIMES, ARE YOU HAPPIER NOT KNOWING CERTAIN THINGS OR? Joanne: No I'm not......

OR WOULD YOU LIKE TO BE INVOLVED IN THIS?

Joanne: I want to know everything about myself, yeah of course I do, I shouldn't think anything should be in the way even if it's, bad.

RIGHT

Damian: See when you've gone tonight, I'll get the third degree, why what did Johnson say to you in the surgery, you know, what's this what's....

Joanne: No you won't...

Damian: Oh you can, it will happen but I won't tell her, because what you don't know won't hurt ya, even if it's good news, Joanne it won't. I will not tell you what Johnson told me, because, it's, you know, it doesn't matter what he told me. You know, I know exactly what...

Joanne: I'm not interested what he told you, because I'm getting better now.

Damian: Well, that...

Joanne: I'm improving a lot.

Damian: That's it, that's it, that's it.

After the tape was switched off, and once Joanne had left the room, Damian went on to discuss his wife's condition. He stated that the consultant had told him that Joanne only had a few years to live. Five years ago, she was given 8-9 years maximum, but her condition has since worsened. Damian has chosen to conceal this information from Joanne, allowing her to believe that she is slowly recovering. This raises several questions, the first of which is how and why Damian has come to be in this position? This is an issue of professional responsibility, as not only has the patient's need for information been overlooked (see also Section 6.3.1) but the burden of whether to share that information has been placed upon her husband. Damian is now in a position of power that has been given to him by the doctor. His expressed view that he is entitled to know more about his wife than she is, has in all likelihood been reinforced by interactions with this consultant and this in turn affects the dynamics of the caring relationship. He feels that she needs to be protected from reality, as he puts it:

But how likely is it that he would conceal good news? This is a fact that Joanne is almost certainly aware of. Damian complains that he will 'get the third-degree' about what he knows but makes it clear that he has no intention of sharing his knowledge even though Joanne clearly states that she wants to know everything about herself. So is Damian acting in Joanne's best interests and is this what he truly believes? She claims a positive attitude to her recovery and perhaps Damian's withholding of information allows her to maintain this, but without the knowledge that her condition is terminal, she is effectively unable to prepare herself. She may want to grasp more opportunities in the life she has left, to fulfil ambitions and to have new experiences while there is still time, but she may not know how little time she has left until she is too ill to make the most of what remains. The decision of whether to tell could be considered as a great burden and perhaps it is a conversation that Damian simply cannot face. If he tells Joanne of her fate and she sinks into depression then he may regret this course of action, but by maintaining some semblance of hope, he may perhaps convince himself that she is protected from sharing what is now his burden. I would argue that he is here acting as a keeper of information and has taken the role of being a channel for agencies to the exclusion of Joanne. Whether or not this situation is his own doing or the responsibility of the agencies who allowed it is a matter for debate, but being the source of knowledge, whether shared or not is a common role; this will be explored further in Section 5.2.1. In the next section, we will consider the way in which the carers' role develops at the point of hospital discharge.

5.1.1.1 Leaving the Hospital

Leaving the hospital is a critical juncture in the care trajectory. It is the time when patients really begin to learn about their altered self and it is the point at which carers get their first experiences of the day-to-day reality of providing support at home. The timing of this is not always based on clinical need or even the readiness of the family; it is often part of the balancing act of sharing limited resources among almost unlimited patients. Pressure may be put on families to take patients home if they show little sign of improvement, but if carers realise that they are not ready then they may refuse:

Michelle: They wanted to get him back to the Infirmary, and they wouldn't have him back. I think it was because he'd got his, it was when he'd got his minder, and they couldn't supply him with a minder at the Infirmary, so wouldn't have him back. Yes and they wanted me to take him home. He used to live in a flat you see. And then they wanted me to take him home and I wouldn't.

WERE THEY OFFERING ANY SUPPORT FOR YOU AT HOME?

Michelle: No, no, nothing.

Lindsay: It was when he was allowed to go home, and they actually I think told James I think as well so James was confused as Mum and Dad wouldn't take him back and it was very unpleasant

Michelle: It was, yeah

Lindsay: But in the end, I think you phoned Headway didn't you?

Michelle: Yeah. I'd got a niece who used to do voluntary work at Headway and she told

me to ring Sarah something

SARAH SMITH

Michelle: And I rang her and explained what was happening. She said under no circumstances have him back until he can cope for himself or I would have no help, I would be on my own. She said it will be very hard for you, she said but refuse.

Many patients are transferred out of county for neurological treatment but due to issues of funding and local prioritisation, their stay is ended as soon as the acute need has passed. In James's case, he was sent to Nottingham, but once he had received the necessary treatment, his local hospital in Leicester refused to readmit him. His mother believes that this is because they were unable to provide the one-to-one staffing that he needed. She claims that this put her in an incredibly difficult position as her son was told that he would be going home, and Michelle followed advice and refused to take him. It was only due to this steadfast refusal that access to a residential rehabilitation programme was organised. Most carers in this situation however, would take the patient home, quickly discovering the difficulties of providing full-time support with little or no professional backup:

Amanda: What other problems did he have? Well for six months, well you see he was in the hospital for nearly five, so we didn't really see many problems. He got aggressive when he was coming home at the weekends. He'd hit Susie and make her cry and want to know...

IS THAT HIS SISTER?

Amanda: Yeah, ...want to know why she was crying and we, we didn't see much really until everything, when he came home, and everything wasn't in place. And then he went sort of like, downhill. 'Cause he enjoyed OT and he used to enjoy the physio and everything. Because he was having them every day...

Amanda: ...he was willing to do them, but once they sent, sent him home, he didn't, he didn't have physio, in fact she couldn't take him on and we're still waiting so, that's how

busy she is. Erm, OT, Clara took that on but it took about ten weeks to get him a place, because of Jason's age, he wasn't a child and he wasn't an adult, he was in-between HOW OLD WAS HE?

Amanda: He was sixteen when he had the meningitis

RIGHT

Amanda: And you're only a child until you're sixteen, and adults, they don't take them till they're eighteen, so in between you're, you're lumbered. And then we got him into the gym er, to do like physio, but he wouldn't do it for us.

Amanda presents the very specific problem of a services limbo for patients aged between sixteen and eighteen years; too old for paediatric support, and too young for adult services. Jason was sent home with the agreement that a discharge package would be set up, to include a scaled down rehabilitation programme. In reality, little was provided and Jason's parents felt that they had been left to cope alone; as Amanda describes it, they were 'lumbered'. It seems to be assumed that families can support each other and the patient, so services are not as urgent in these cases but as Amanda later described, the pressure of caring almost destroyed her marriage, and they are only now piecing back together their lives since securing some residential rehabilitation. Like many families, they did not realise the full extent of Jason's problems until he came home and instead of seeing steady improvement, without the support he received in hospital, they had many frustrating months of watching him go downhill. Their story will be explored further in Section 5.2.2.

Partners were also put under pressure to take patients home. Daniel was in hospital for over a year, and when he had reached what seemed to be a plateau of recovery, pressure was put on his girlfriend to accommodate him. Although they had never lived together, Victoria was expected to take this step in order to care for Daniel. This was apparently an issue of limited resources but it was presented in a somewhat flippant way and this has been a source of much anger for Daniel:

Daniel: The doctor who was in charge, Thomson, he really got on my goat, because of his insistence towards the end that er, he wanted that room back, or that bed back shall we say

Victoria: He seemed to be... Daniel: It's a, what he said is...

Victoria: ...trying to use Daniel to get the system moving, but I mean he, he couldn't remember most of what the bloke had said anyway so why he was trying to use Daniel to chivvy things along, but all he did was make you cross and want to thump him, didn't he?

Daniel: Make me what sorry?

Victoria: It was the first time you'd showed any emotion really, about him

Daniel: Yes, and I wanted to murder him, that's a hell of an emotion, you know, I really did, I felt so annoyed, because he dragged Victoria into it as well he was saying, "Oh I think you'll you know, get you out of here, you've been here too long". I still that's not a very social attitude is it, the caring NHS you know

Victoria: Terrible that was. He wanted out.

Daniel: "Can't your girlfriend go and buy you a bed?" That's what I got. I said, "I beg your pardon?" He says, "Well plenty of shops sell beds, send your girlfriend out to buy one". I says, "Are you being serious?" You know, I really had a go then and I, bloody hell, I wish it had been recorded

Resources issues such as this will be explored further in Section 6.1.2, but in terms of developing carer roles, the doctor in this case was assuming that Victoria would be Daniel's carer and therefore attempted to shift responsibility to her. The point here is that not all people who become carers make a positive choice to do so. It is a role that they can slip into or be pressured into without having time and space to consider the consequences. Victoria is actually one of the few who did negotiate her role with the patient. She made a short-term arrangement to stay with him immediately after discharge, but worked hard to set up a Social Services care package that would allow her to return to the role of girlfriend, therefore protecting their relationship from the day-to-day difficulties of being a carer. Daniel however was determined to regain his independence and as was discussed in Section 4.2.2, he rejected much of the care package. This has meant that Victoria now takes some responsibility for monitoring Daniel but for both their sakes, she lets him manage as much as he can for himself.

Readiness to leave the hospital came up again and again as an issue of concern, in some cases however, it was the patient who exerted pressure to return home. With limited resources, this was often welcomed by the hospital but was not always in the patient's best interests:

Damian: She were coming out with, with a drip. It's like they just chucked her out with a drip on her arm, because she had a problem, err, she, she. One of the operations, I can't even remember which one, she said, "I'm alright to come out, I'm alright to come out", me and Joanne's mother said, "No you're not, you're not right to come out", "Oh yes I am". So Joanne, er, had a word with the nurse and said, "Look, I'm ready to come..." and they said, "Yeah alright, take it easy". And it was horrendous weren't it? You had to go back in didn't ya? She lasted, was it the last one you, can't remember, it, it...

Joanne: You on about when I got dehydrated?

Damian: No before that, there was some, there were a problem, she come out too early and she had to go back in, you know. Summat, summat happened. But she had to go back in, so, and we didn't have no back up what so ever, nothing. But er, it was very hard. She didn't know what to....you know, they just said, well if she gets any bad headaches give us a ring, if she gets any weeping from the wound take her to your

normal, you know, your normal GP and err, she'll come back in, how many weeks time to get them metal staples out. And that was <u>all</u> the back up we got.

Joanne: Yeah, I come out of hospital with all metal staples in me head round here.

As Damian describes it, Joanne was still in need of medical support when she decided to discharge herself. He positions himself and Joanne's mother as experts in this situation, advising her to stay in the hospital, but Joanne was determined to leave. This was not the only time that she had post-discharge complications and Damian gets frustrated by the expectation that he or other relatives can provide adequate nursing care. Sometimes however, it was the choice of carers to remove a patient from the hospital environment, in the belief that they could provide better support at home:

Gordon: And we decided then that er, er, she'd be better off at home, but erm, they were bringing press to bear because they were saying that they can only manage her state, er, there was nothing they could do to improve her condition RIGHT

Gordon: Erm, apparently in the hospitals, erm, it's a difference between nursing you and getting you better and managing the condition you're in, it's just er, same day in day out. RIGHT

Gordon: If they feel they're not improving, then you're better off somewhere else **Deborah:** Basically we felt as if we were just wasting one of their beds didn't we then? Gordon: Well yeah, you're occupying a bed, want to get somebody else in it

This is a similar issue to what Daniel experienced, where there was pressure to free the bed as medical improvement was no longer apparent, but Gordon initially frames Kathy's discharge as a family decision based on a series of incidents within the hospital:

Gordon: Well I had a row one night, sat round the bed and she was breathing, and when she breathed in her head were juddering, shaking like, and I said, "What's up with her?" She'd got a tube up one side of her nose, and her mouth, she couldn't even have her mouth open

Deborah: You couldn't open it, could she? No

Gordon: And you had to force it down, and as soon as you let go it'd shut. So all her breathing was through her mou..., nose, coming through. And there was this juddering, Deborah didn't know what I was talking about, and er after 10 minutes or so er, it got more exaggerated and er, so I started to look and she'd got the pipe up one nose and the other nostril was completely, congealed and blocked. I said to her, "Nose is.."

Deborah: It was blocked

Gordon: "...completely blocked, you can't get air". So I held her chin open [sharp intake of breath] and she took a breathe, breaths of air and relaxed

YEAH

Gordon: She relaxed. And I shut it, let it go and then when she were, I opened it again, she breathed, then she were completely different

YEAH

Gordon: She, she started to relax. Instead of being (sharp intake of breath), you know

YEAH

Gordon: As though she was being throttled

YEAH

Gordon: And er, I shouted at somebody, said there's something wrong here. Anyway, I stuck me finger in her nose, pulled out this mucus or whatever, it was about that long, two inches long, solid, and when the doctor came, I says that was in her nose, she couldn't breathe, she can't open her mouth, she was trying to breathe and her head's juddering. He says, "Goodness". I says, "How long is it, how long does it take for it to become as congealed as that? That's not happened in 5 minutes, it's probably been like that all day". And because we're finding things after the event, they're all just trying to hide and sort of probably go out the way and shout at each other.

YEAH

Deborah: Yeah that's it, they pass the buck

Gordon: That was when I decided that I'd had enough of this, we could do better, we can nurse better than this, er do better at home and erm, eventually when I did, I says erm,

we're gonna take her home. They says, "Oh right, that should be nice"

Deborah: Yes (laughter) Gordon: Yeah, wonderful

Deborah: Yeah, no-one said not ready, never said you're not ready, you're not

experienced, yet here we are signing the paperwork (laughter)

In this account, Gordon is seen as rescuing Kathy from a potentially fatal complication and this is one of many incidents in which he presents himself as having greater expertise than the medical staff around him. From early incidents such as these he describes how he developed a role as a carer above and beyond what he felt others were capable of offering her. He gave up his career and has devoted all of his time since to supporting and rehabilitating Kathy. At the point when she returned home she was drifting in and out of consciousness, and was still in a poor physical state. With drips still attached, it may have seemed unwise for her parents to discharge her but as they present the story, their intention was greeted with the comment:

"Oh right, that should be nice".

Perhaps this is not the exact wording that the nurse used, but the sentiment is that their desperation in taking her home was not recognised and that they were not prepared for the struggles that lay ahead. Once providing full-time care away from the protected hospital environment, reality hits home. Being a carer is a demanding and difficult task, and inevitably the roles of patient and carer will change the dynamics of previously established relationships. This aspect of care will be discussed in the next section.

5.2 Re-Establishing Roles

Roles will change after brain injury, but to what extent varies between situations. Returning to the interview with Tom and Susan, the data presented so far gives some indication of the role that Susan has taken in guiding and speaking for Tom. Theirs is a situation where there might be said to have been clear role changes, as Tom has gone from breadwinner to dependent. This interpretation is supported by the way in which Susan refers to her husband in a childlike way:

Susan: Well we try don't we? We try and give you little jobs

Susan: Which keeps him occupied don't it?

Susan: 'Cause he was no trouble, he's not no trouble anyway

These statements seem to reflect changes in status within their relationship, but this is not simply an internal issue. Susan also now expects other people to address her rather than her husband:

Susan: Well I suppose they're being polite, you know, they're talking to him instead of like to me, but er, he just doesn't grasp everything

These statements show evidence of the way in which the marital relationship has changed, with the patient being discussed in a way that reflects the new roles which he and his wife play. The patient has lost his job, and his independence. With a range of deficits he requires support. All of this means that he has lost status in the household, and we may see this expressed in the way that his wife refers to him in an almost maternal way. For some partners, the change of role and all that goes with it is an incredible burden, but patients are not always aware of this. Robert was brain injured in an accident at work and in particular he has suffered a series of emotional problems since. His wife Mary has given up her career to care for Robert but she finds spending time with him very stressful as he is now changed considerably from the man that she married. Robert and Mary were interviewed separately and comparison of their respective views of the care relationship is telling:

AND DO YOU THINK YOUR WIFE'S GETTING ENOUGH SUPPORT?

Robert: Oh yeah, she's been brilliant to me

YEAH, BUT IS SHE RECEIVING SUPPORT AS WELL? DOES SHE HAVE ...?

Robert: No cause er, she's, well she's finished work now, the missus has, to look after

me

YEAH

Robert: And she's getting, nobody comes and supports her 'cause she had breast cancer and she goes to occasionally see a doctor there and that's going back 8 or 9 years since she had that

YEAH

Robert: And she's doing better, well she seems to be doing better for it. She's, I think she's having enough support and oh, she's got enough to look after me so (laughs). As I say that's great, you know, she seems happy enough

Robert acknowledges that Mary has left work for him and that she has had health issues of her own, but as he describes it, she is happy and needs no additional support. Mary by contrast gave a very melancholy interview:

Mary: For the last year he's been on anti-depressants to keep him... we're all on antidepressants, I'm on anti-depressants

AND THIS IS ALL SINCE HIS BRAIN INJURY?

Mary: All since his brain injury, trying to cope with living, day-to-day living. I mean (showing badly scarred arms) this is all self-harm, to me, er, I've never done nothing like this in my life but, I've been ripping my skin, you know, a lot of people don't realise about what the person goes through that... you know. I had Robert crying four times a day for about six months.

Mary has been diagnosed as clinically depressed and she frequently self-harms, although she usually hides her scars under layers of clothing. Isolated by her caring role, she describes herself as having little emotional contact to share her problems. The fact that Robert is oblivious to her state adds to Mary's frustration but she feels bound by her role. In meeting social expectations though, she worries that she will eventually destroy herself. Few carers felt able to discuss the negative impact of their role in front of their loved ones, but Damian provided an exception:

Damian: Joanne's condition has changed me immensely, I'm a right, pardon the language, bastard now, I really am, you know, and I'll admit it, I've admitted it before, you know, I really am a nasty piece of work, because it's the only way I can cope. I can't, I can't cope with it at times, you know, you have got to shut it out, see, when, when things go wrong, there's two ways you can cope, either, some people throw everything, you know, and say right, I'll do anything for ya, whatever you know, that I'll be here for ya every minute of the day, I'll sit by the side of ya 25 hours a day. And that's the way they get round it. The way I get round it is to, push it away. You know, it's, I've always, that's the way I can deal with it just push it away, so I have done. Just pushed it away, pushed Joanne away to some extent, and you know, it's a case of it's happening, but you know, what can I do about it? I can't, well I'll get on. So you know, since then I've been

working seventy odd, eighty hours a week, you know, six days a week, bits and bobs like that. It's the only...,

Joanne: Seven days a weeks

Damian: It can't be seven Joanne, can't be seven it's illegal. But that's the only way I can do it, you know, and I have to have..., Joanne's probably told you about my cars, you know, and it's my get out, I've got to have to something, I've got to, to keep my mind off the fact that, if Joanne has a headache one day it could be the start of a tumour growing again and we're going to have absolute hell.

Joanne: But then again I went to the hospital, er, twentieth of May and we had some real good news, didn't we? But he can't accept that it's good news.

Damian: I can't. It is brilliant news, I'm really, I'm really, really pleased, you can't believe how pleased I am, but I just can not accept it, because I've had, how many years? Nine years? Of if Joanne has a headache, you know, it's started again and you have like six months, a year of absolute total hell when you go to hospitals, you come back, you don't know what's happening, she has operations. You see your wife lying on a table with half her head shaved with a massive great big scar with, with a drip and wondering what's gonna happen next, you know, it's so hard to get out of that routine. And er, it's changed me, you know, I'm, I'm nothing like I were, nothing at all, When I'm away from the house, you know, you know, I can't, I think, "What's she doing now?" "Is she all right?" I really, really love her but as soon as I come through the door summat changes in me. It's like an on and off switch (Clicks fingers). Because, I've, I've had quite a few years of that's how Joanne's been, been so nasty she co, she could be shouting and screaming at you as soon as you come through the door, she'll want a fight, verbal or physical, she'll want it, and you come in and you just do not know. I look at the dog, when I come in, even now I look at the dog and the dog will tell me. She'll be sitting there and she'll wag her tail and I'll know everything is all right, but if she is with her head down and her ears down, you know, the dog's picked the vibes up from Joanne, and she knows that you know, we're going to be in for a hard time, and she could ask anything she'll ask a question, so leading a question that you give an answer and that'll be it. So, you know, I could write a book on what, what's happened and what I feel and how I've got around it, but to put it in a nutshell, I've become a right, self obsessed hard, horrible, self opinionated, arrogant, shit.

Joanne: (Laughs quietly)

As has already been discussed in this chapter, Damian manages the secret that Joanne is dying. As he describes the situation, dealing with her condition and the changes in her personality and capabilities has left Damian feeling angry and frustrated. When asked about Joanne's problems, he quickly turns the conversation back to how hard his own life is. His account of their life together is very insular, and he makes hurtful comments to and about Joanne, seemingly disregarding her feelings. As he describes it, you can either throw yourself into care or you can run away from the situation and he has made a conscious decision to do the latter. We might speculate that guilt and a sense of commitment prevents him from cutting all ties but he is both physically and emotionally distant.

Joanne appears to be frustrated by her own limitations and by Damian's inability to support her. Although even-tempered in public, she lashes out at home, causing further

distance between them. In some ways, perhaps they would both be better apart, but social expectations leave Damian feeling compelled to stay, protecting his image as the caring husband. Joanne meanwhile recognises that Damian's attitude towards her has a negative impact on her emotional wellbeing, but in her sick-role status, she feels unable to move on. So they stay together and make proclamations of love, but the image that arises across the interviews is that of two people in dire circumstances, destroying each other in an attempt to protect themselves and their pre-tumour life.

Like Damian, Helen is very open about the difficulties of dealing with the change in her partner. She though takes full responsibility for care, looking after her husband Richard despite many suggestions that she should let others take that duty from her:

Helen: When he had the illness he said that it was my fault, and he said that it was because he'd got a <u>germ</u> and I'd left a <u>germ</u> around or something, you know, and that he would punish me and that's how I felt, that he was, he was trying to punish me. It probably wasn't at all, it was just that he was, he was so nasty.

YEAH

Helen: You know, it's like being married, to someone, and then someone comes and takes their place, a different, an entirely different person.

YEAH

Helen: Erm

WHAT SORT OF SUPPORT WERE YOU GETTING AT THAT TIME?

Helen: Well actually I, I had Headway

RIGHT

Helen: I mean that was for two days a week. I didn't ask for any support to be fair

YEAH

Helen: I just thought this is my burden and I've, I've got to, to do it myself

YEAH

Helen: Because you can have someone who can come and tell you what to do, but it

doesn't always work out, with someone with a brain...

YEAH

Helen: ...injury, you know

Helen's sons suggested that residential care might be more appropriate or that at least she should get additional help at home, but Helen stated several times that she was unwilling to expose carers to Richard's anger and unreasonable behaviour. She represents his care as her sole responsibility and she is also very aware that without Richard she would be alone. So Helen accepts verbal and sometimes physical abuse on the basis that it is caused by Richard's brain injury. Perhaps with help, Richard could overcome these problems, but having established the pattern of their roles in the caring relationship it is now very difficult for either he or his wife to accept outside support and so their roles are

set. Helen talks about Richard as being like an entirely different person and this was a common theme:

Mary: I couldn't cope with this person now, because he, he wasn't my husband.

YEAH

Mary: You know, he was a totally different person and I didn't know how to cope with

it

As Mary stated, it is this total change in personality that makes coping as a carer difficult, because it is as if the person she married no longer exists and she is now resigned to spending the rest of her life looking after a stranger. This feeling of difference was expressed by many carers but sometimes on a lesser scale:

Toby: She likes to get out to meet people, as long as there's somebody with her. But er, I

don't think... she's not so keen on going out on her own

Pam: No, me confidence as well

Toby: Yeah

Pam: That's another problem
Toby: Yeah, confidence has gone

YEAH

Toby: Certainly not the same person she used to be

In Pam's case the main difference is that she is less outgoing and self-sufficient. This has an effect beyond her relationship with Toby as like many patients she has to deal with the consequence of wider social structures disintegrating. For some, the existence of services like Headway goes some way to repairing this damage:

Sophie: Well erm..., Headway is very good, brilliant in fact, because right, you know when I had my first stroke, you know, I didn't have anything and erm, any communication with anybody, except my mum and dad. Mind you, they're good anyway but..., and then I had this, that second stroke and it's been like a lifeline to me, it really has, a lifeline

Sophie makes the point that without Headway, she relied on her parents as her sole source of social contact. This can create a limiting relationship and may be part of building a dependence cycle where both the carers and patients lives revolve entirely around each other. With time, this can be a difficult routine to break. Jason provides another example of the role of Headway as a social outlet:

Jason: At Headway I've learned to..., again, learn again, to socialise with people

YEAH

Jason: I mean, I knew how to do that before, so I had loads of friends, who I just don't see at all now, but erm, I learned to socialise with people a lot more, because erm, sort of like when you go into hospital you find like, that you lose some of your friends, 'cause they like move or something and yeah, I learned to socialise a lot more

RIGHT

Jason: At Headway

Jason credits Headway with his redevelopment of social skills explaining that he lost many of his friends while he was hospitalised. This is a common problem as many friendships struggle to survive the effects of brain injury. However, Jason's mother was interviewed separately and she still identifies a problem in her son's ability to socialise:

Amanda: He doesn't mingle like he used to. Erm... he won't make friends, same as at TRU he still doesn't really get along with the clients, he tends to stay with coaches, who's in charge, the staff; like he did at Headway.

It seems that Jason, who is still in his teens, only feels comfortable talking to the staff at the centres he attends. Either he struggles to relate to people of his own age or he is uncomfortable with the disability of others (as discussed in Section 4.4.1.2). Either way, this issue presents an obvious obstacle to expanding his social circle. For some, their social role is defined by their living arrangements, particularly those in residential care. This situation raises many further issues. Oliver lives in a residential home, he is in his mid-thirties, but having been injured as a child he has apparently stayed within a childlike role. A clear example of this is the way in which he complains about having to keep his room tidy:

Oliver: With..., just..., I'd like improved status..., 'cause I have to..., do my room out

once a week

AHUH, DOESN'T EVERYONE HAVE TO DO THAT?

Oliver: I don't know. It's not up to me to look after everybody else

BUT YOU JUST HAVE TO LOOK AFTER YOUR OWN ROOM DON'T YOU?

Oliver: Yeah

YEAH, DON'T YOU THINK THAT'S FAIR?

Oliver: Might be fair but it's a damn inhibited waste of time

DO YOU THINK SOMEONE ELSE SHOULD BE DOING THAT SORT OF THING

FOR YOU?
Oliver: Yeah

Oliver feels that he should not have to take responsibility for this task of managing his own personal space. This unwillingness to take responsibility extends to his comments and actions as he often acts in a highly inappropriate manner, but argues that he is

excused of any consequences due to his injury. He is able to clearly articulate boundaries, but frequently crosses them, and it is in part this problematic conduct that meant his family no longer felt able to care for him at home. Robin was also injured as a child but he still lives at home with his mother, who has apparently continued in a mothering role despite the fact that Robin is now in his mid-forties:

Patricia: We had to go to B&Q today and I said to Robin, "Are you coming?" He said, "No, I'm stopping here". I mean..., you see this is another thing, in all honesty I can go out and leave Robin, right, I'm not saying all night or anything like that, I'm, I have been known to do that when he, when he was much younger and I was much younger but I wouldn't do it now er..., whether again because I'm getting older and perhaps as you get older you get a bit more anxious about things, you probably don't think of things quite in the same..., when your younger do you as you do when you get older sort of thing? Plus the fact I think as well, I've got to be absolutely honest, er, I don't leave anything to chance that something could go wrong that I've got to come and pick the pieces up. You know, when my husband..., if anything went wrong, you'd got somebody different to share it with, but if anything goes wrong now, it's entirely on my shoulders, but oh no, I can go out erm and I mean I look after my mum now you see, my mum's eighty-eight and you see this is another thing with Robin, I know he worries about this

Patricia: Er, he says that life isn't fair to me, you know, and he'll say, "I feel sorry for you mum". I say, "Yeah, I feel sorry for myself sometimes". You know er, so I'm involved quite a lot with my mum, you know, er so I'm pretty involved sort of er, full time and I know he does worry about that er, 'cause he'll say er, I mean I've said it myself, I don't know, I'm coming up to seventy and I'm still running around.

Patricia has never felt able to give up the role of full-time mother and even though her son is now a mature adult and fully mobile, she feels unable to leave him for more than a few hours. It is as if Robin is still a child, which brings us to a selection of similar comments from parents about the hospital experience:

Rebecca: I'll tell you what it was like, it was like having a new <u>baby</u> that was able to tell you what it was experiencing, and that, can you remember me saying at the time? It was, perhaps you can't remember it, it was a good feeling

Rebecca is describing with pleasure Ben's post-operative state, where he was more responsive to his environment than previously. Her simile of him being like a new baby was used several times from this point to describe the change in him. This concept was also used by Jason's mother, but in a negative way:

YOU WERE JUST TALKING ABOUT ER, THE MOVE FROM QUEENS TO THE ROYAL,

Amanda: For physio, er, for rehab

YEAH

Amanda: Because he, he couldn't sit up or do anything, so, he was literally a baby again. Erm, his food had to be mushed up and, everything. It was hard, really hard, to watch your son have to go through all that again, and he was.

For Amanda, the image of her son's regression was seemingly difficult to cope with, having to wait for him to reach milestones that he initially passed as toddler. Regression into a childhood state could also be presented with little emotional sentiment:

Nicholas: In hospital he went back to his childhood

Lindsay: Yes he regressed

Nicholas: Right back to early childhood

Michelle: Yes

Lindsay: Yeah. He was asking me about junior school, that was when he first came

round

AND HOW LONG AFTER HIS INJURY WAS THAT?

Lindsay: About three weeks?

Michelle: Yes. About ten days he was in early childhood, eleven days. Then he was

moved onto a neurological ward, but he was still very confused

Having established this early state where James was lost in his childhood memories, his mother went on to describe arrangements where he stayed in the hospital day room so that she could continue working as a nurse. She would then collect him at the end of her shift and this provided a compromise between him being admitted to the hospital, taking up a bed, and being cared for at home full-time. She described this arrangement as childminding:

Michelle: So he'd been there since December and this was now March, but since

Christmas he'd been childminded there

HOW WAS HE COPING WITH THAT SITUATION?

Michelle: Oh he hated it. Although we thought he wouldn't go back on Sunday nights, you know. We didn't think he'd go back. He actually became quite nice then didn't he?

Well not to say quite nice, he was quite acceptable to being told what to do.

Lindsay: Yeah, he was manageable.

Michelle: Manageable is the word. He was a lot more manageable, more pleasant to be

with actually.

Beyond the issue of James's changed status, there is his family's attitude to his behaviour. He is described as being more 'manageable' which does little to suggest a future role of independence. Talking to James himself, he talks about his personal experience of emotional change:

James: Well I feel emotionally immature. Relationships are out the question I think, I don't know. I feel like a kid again you know? I mean I went on the bus yesterday and there were a couple of kids messing about on the back seat, throwing paper and that, and I joined them. Messing about with these kids, and they were about 14 or something, I dunno. And I get on really well with my nieces, whereas I don't get on so well with adults.

Since his injury, James describes himself as feeling and acting in an immature way. This is perhaps reinforced by his family and places limits on his social capabilities. In a cycle where he acts like a child, he will be treated like one. In this immature role he will always refer to others as experts to guide his way. The issue of how expertise develops and is presented will be discussed further in the next section.

5.2.1 Demonstrating Expertise

A recurrent theme is the way in which patients and carers establish themselves as experts often using medical terminology, although sometimes in the case of patients, it is used inappropriately (see Section 4.1.3). The first expression of carer expertise that could be found in the data was being the keeper of information. Carers would present detailed histories of how injuries were caused, the complications that followed, treatment that was given and value judgements on this. They would give dates, times and places, no matter how long ago that the events occurred. Frances is quite typical in this sense:

OK, FIRST OFF CAN I JUST ASK YOU WHAT THE CAUSE OF HIS INJURY WAS? Frances: Erm, Theo had had, I'll go right back to er 1962, when Theo developed erm, encephalitis, through, I was told at that stage a virus, though he has had a road traffic accident and a head injury. Several years later he started to develop epilepsy, nocturnal, which was partially controlled by medication, and during the early 1970s, he started to feel unwell in that he was suffering from some considerable pain in his head which was bound to be arthritis of the skull we was told.

Theo: Skull we were told

Frances: And early in 1980, 96, we went on holiday to Cornwall and on our last day there, Theo collapsed in the caravan, and on admittance to hospital it was found that he'd suffered a massive brain haemorrhage. He later developed complications in that the brain haemorrhage had developed the ventricles of the brain and he suffered hydrocephalus as a result of this. He had a shunt inserted when he was later transferred to the Queens Medical Centre, by private ambulance, er and unfortunately due to an infection in the menges, er, he had to have this shunt thing removed and another one placed, replaced when he'd been treated with it, by antibiotics. He was then er, sent to the Royal Infirmary for rehabilitation. He came home for some months, and then in November of 96 he went back into hospital to have a craniotomy, to treat the AVM, an anterior ventricular malformation, which he sustained and which was the cause of the brain damage. He also had to have further surgery after that because he suffered erm, a blood clot in the area between the skull and the brain and after some weeks in hospital he

returned home in mid December 96 er, unfortunately after that his epilepsy, erm, although I was told it may be cured by having this AVM treated erm, surgically removed, erm, it didn't and now I'm afraid the epilepsy has turned worse and erm he's been under treatment at the Royal Infirmary.

The power of information has already been discussed in the previous section, with the example of Damian restricting details of his wife's prognosis. However, just being the overall holder of information may give carers power. Theo decided that he would be more comfortable interviewed with his wife, rather than apart, because he was worried that he may struggle to answer questions without Frances there to remind him about the details of his past. So although Frances keeps this information for Theo, she appears to share it freely, and being the bearer of knowledge bestows her with added status. She is the expert on Theo's past and holds the memories on his behalf; without her, much of his past is arguably lost to organic brain injury.

Most carers know more about some aspects of the patients past, as most patients have at least some level of post-traumatic amnesia (PTA). Beyond this, there are also several instances where carers make reference to their role in the medical outcomes of the patient, even to a point where they are claiming to have performed tasks that would usually be expected of medical staff. Gordon for example, spent as many hours as he could in the hospital. His daughter was at this stage still comatose and he would closely monitor what was going on around her, including the medical equipment which he used to adjust himself:

Gordon: And er, so you had to keep your eye on this drip, and perhaps keep it going quick enough so that it wouldn't stop. It was a hit and miss affair, and er, you turn you back on it and then the food 'd all disappear in about a minute. So she was either getting the whole lot continuously, or, drip for a few minutes and then nothing. Hopeless really. But er, I could work it and I used to monitor it and correct it, because some of the nurses didn't know how to get it to drip continuously, and er, well in the end they used to take the rise out of me, cause when we were coming, you know, they'd say, "Ey up, here's Dr [Father's Surname]".

As was discussed in Section 5.1.1.1, the parents in this case discharged their daughter themselves and when asked why, they presented a series of incidents that led to them taking Kathy home. This was another example where they represent themselves as more able to care for their daughter than nursing staff. Following this, Gordon went on to describe how he had taught some of the nurses how to use the drip as he believed that

they found it difficult to approach senior staff for assistance. The peculiar inversion involved in this story establishes Gordon's claims to expertise. Other carers have also talked about checking equipment, for example Keith and Judy used to replace Gavin's pulse monitor when it came off his finger. Many more would monitor vital signs, desperately looking for positive change, and while they waited, some would perform basic medical tasks such as cleaning catheters:

Dennis: We felt he wasn't getting quite the care he should have done

Rebecca: Well at Queen's...

Dennis: They didn't take it quite seriously enough sometimes this...

Rebecca: No, at Queen's when we first went to book in for the operation, we were given a primary nurse. She went on holiday and we never saw her again, so we didn't know

who our nurse was. She came..., she was there all week...

Dennis: It was, it was a funny setup

Rebecca: It was a... and apparently we'd said we would do twenty-four hour care. And we can't remember actually thinking twenty-four hours we, we told them we were going to be there all the while, which we were. Erm... but having said that, we, you still went to work, and then the two days that I went to work you stood in. I didn't give up work altogether...

YEAH

Rebecca: You know to sort of... But we did, I mean we did sort of care for Ben I mean I was cleaning his catheter and everything weren't I? And... which I didn't mind. My brother said I ought to have been a nurse but I couldn't quite think I could though. But I did a lot for him like that

YEAH

Rebecca: And if we hadn't of been there sometimes we felt that he didn't, nobody would come near him...

Dennis: He wouldn't of got care

Rebecca: He wouldn't of got, there were times when he needed help and if we hadn't of been there to give him that help they wouldn't have done. But not because they, they didn't want to it was the system that, that everybody, all the parents were there I think it was er, 'cause I read about it funnily enough the other day. Somebody specifically said let the parents in. I read that in, in the 1950's, late 1950's, that the best thing for a child, their health, you know, to get better, was let the parents in. We weren't the only ones

Dennis: No we weren't the only ones

Rebecca: Every bed, had the parents sitting, all day like we were.

YEAH

Rebecca: And I mean...

Dennis: But sometimes...

Rebecca: We're still friends...

Dennis: Sometimes, we came to a thing where you really did need, need a break....

Rebecca: Yeah...

Dennis: ...and couldn't get one. Rebecca: ...and you couldn't get one

Dennis: Couldn't get one

Dennis and Rebecca were watching over their son in a paediatric ward, surrounded by other worried parents. They wanted to be there for their son, but were surprised to find that this was interpreted as wanting to provide round-the-clock care. This could be seen

primarily as a resource-saver for the hospital or as being in the best interests of the child, but either way, it left Ben's parents exhausted before he was even discharged formally into their care.

Continuing with this family, Ben needs regular doses of a drug called DDAVP to keep the fluid levels in his body balanced. Without it he will urinate constantly until his fluids are dangerously low. During their interview, his parents recounted a situation where someone broke the only bottle of DDAVP in the hospital. Ben's parents had to tell them which other hospitals stocked the medication and also had to instruct them on refrigeration as in an earlier incident it had been allowed to go off. It took several hours to locate and transport a replacement DDAVP bottle, in which time Ben became very ill and had to be put on long lines to get the fluid back in.

Rebecca: A doctor that wasn't, we knew... of him on the ward but he didn't deal with us but he came and he gave you a slip of paper didn't he? And I think he said. "There's the name of the person you want to complain to, this was all about money, not having this drug here", but we said. We just, we'd got no energy left had we?

Dennis: Well... Rebecca: And...

Dennis: They'd done a lot for us, hadn't they?

Rebecca: Yes that's right...

YEAH

Rebecca: You know...

Dennis: So...

Rebecca: Yes, we sort of thought, he's all right but they did promise to have two bottles in the fridge and let us deal with it, we said.... Cos in Queens their attitude w... there was, "You've got to do this for the rest of Ben's life, you deal with it now".

YEAH

Rebecca: But when we got to the Royal they didn't, they took responsibility for it and that's... when they broke the top off they were measuring it in a hypodermic... weren't they? Measuring it out, but we were doing it how we were taught at Queens, measuring it into a tube. I mean they measured it into the tube from the needle, but they had to break the top to put the needle in. And we said if you let us do it, not that there wasn't any, you know, not if you know... we want to do it and we want two bottles. And when we came home we had two bottles all the time, even for us, cos we knew it was very fragile stuff.

Dennis: It soon went off.

Rebecca: And it soon went off, so even we could lose...

YEAH

Dennis: But we always had a new one in the fridge...

Rebecca: Yes...

Dennis: For emergencies and stuff

Rebecca: In case...

Dennis: So if the one we were using went off...we'd always got a back up....

Dennis and Rebecca felt that they had a safer technique for measuring the drug and so offered to take over this responsibility but their claim to expertise is particularly potent in the highlighted phrases as they state that <u>even they</u> could make a mistake, therefore they always have a backup supply of Ben's drug. By emphasizing this <u>even</u>, they are making a strong claim to their knowledge and experience of administering this vital drug.

Some carers would also get heavily involved in rehabilitation, both in and out of the hospital. Most commonly this would be developing physiotherapy routines such as walking set distances or trying to get them exercising certain muscles. Some, such as Kathy's parents, would develop complex long-term strategies to improve particular skills, but the most inventive piece of carer delivered rehabilitation came from Iris:

Iris: Gradually up to Christmas she improved a lot, you know, got to sitting out of the bed and so on but they could not understand why she couldn't talk because in quite a short time she had... they gave her an alphabet card and she could point to letters of the alphabet, spell words out erm, and when we went into the room she would mouth, "Want to go home". I mean she... you didn't hear anything, she'd go (mouths, "Want to go home") see? And you could see that she was mouthing, "Want to go home". Erm, but no voice and erm, they tried all sorts, all sorts didn't they? To get that

Iris: And erm, eventually, erm, and, and it didn't... there was no, it, it was a puzzle because she did... they did send speech therapists to her pretty regularly and erm, she couldn't... they couldn't... she did have a voice 'cause if she laughed her voice was there

YEAH

Iris: And apparently when she went down to physiotherapy, she'd yell like mad because she didn't like it

YEAH

Iris: Erm, so she did have a voice and erm, I... It was after Christmas that I was, I was er, I used to... all through the summer erm, I was on holiday from the college, I used to teach at Loughborough College and I was there every day and the surgeon said that, that, that this might be helpful and erm.. he er... And I should continue with this but the sister didn't like it at all and this is in the old days of starchy sisters.

YEAH

Iris: And you'd run a mile. Erm, she was excellent with the, you know, a lot of the patients but she didn't care much about the you know, relatives, you know, they were a bloomin' nuisance, relatives, and erm, and Lucy was usually in a, in a side room on her own so, and one particular day er... Oh when term started I went back, she suggested, the sister said, 'I think you should go back to college when, when it starts.' So I did and erm... but I had Wednesday afternoons off and I used to go in the afternoons, Wednesday afternoons and one day er, she went past the ward and said, "Are you here again Mrs Smith?" And I said, "Yes I am, I'm afraid so". So I said to Lucy, "Look I've got to do something, I've been thinking about..er... you know to justify being here, I've been thinking about something. If I was to..." And she was sort of laying like half dropped off. I said, "If I lean on your chest and press you'll grunt won't you?" And so I pushed on her chest and she went, "Huuh", like that. And er she said, I said, "Well next..." I did do it a few times and of course she just laughed she didn't know what had happened. So I said, "Well next time I do it say hello". So I pressed on her chest and out came the word, "Hello". It came out, and we did that with a few other words and, for, at and so on and

then she did it. I said, "Now you do it on your own and say hello", and she did it, but ever so crudely you know...
YEAH

Iris: Very faint, and erm then she couldn't do it, she lost the trick so we left it. I said, "Well lets leave it for this evening you know, lets wait". So I felt I'd justified being there when I wasn't supposed to be. And, 'cause you had visiting times, you know, which were very limited in those days and Wednesday afternoon was not one of them. And erm... then after that the next time I went, er... well Julian and... went in the evening with [her brother] I think and there was no sign of it, you know, she didn't do it for them. But the next day I went before Julian I used to go after college on a Thursday and he would catch up with me from work, and um... er... when I went the nurse said: "She's full of herself today", laughing. So I said, "Whys that?", she said, "Oh you'll see". And she said, "Hello (faintly)", (laughs) as I went in so we practised saying, "Hello Dad", before Julian came. And erm, then, you know, it just improved she did begin to speak, but it was slow. And if I'd thought about it I would have got the tape out that I made, a little, I made a tape with the first... I'll let you borrow it if you like...

As Iris presents the story, she did something that the speech therapists could not; she got Lucy talking. Like most patients, Lucy tactfully accepts help from those around her. This acceptance may sometimes be burdensome to her, but by allowing others to carve out a helpful role, she puts them at ease in what might otherwise be a difficult situation. This pattern was also identified by Goffman (1963) and I would suggest that the dependence cycle with carers could start with tactful acceptance of help as a way forward in the relationship. Carers may not be conscious of the role they play in learned helplessness and often talk of their aspirations to support independence. The issues around this will be explored in the next section.

5.3 Encouraging (In)Dependence?

Independence is an enormous issue in disability. It is seen as the holy grail of recovery towards which all people should aim. This section will look at the role of patient-carer interactions in the development or restriction of independence, it will question the belief in independence as an ideal state and it will look at the process of planning for future shifts in agency away from the carer. In many cases, aspirations are higher than actions, as carers may actually reinforce a level of learned helplessness, but one of the exceptions to this is Andrew. He talks about his increasing worries regarding his wife Lynne and this leads him to suggest that he should retire early but he explicitly raises concerns about maintaining his wife's independence:

Andrew: I shall have to finish work really and that'll settle it

Lynne: Uh huh, yeah

Andrew: That, that's something else I think about as well 'cause, if I'm at home all the

time, then she's not going to think so much for herself

YEAH

Andrew: If I go to work, then like today, she, she thinks she's not done a lot today but she's done quite a lot of washing, she's kept herself... she's hoovered today, I know she's done that and she's also been down to the shop down the road to get... pick up some milk.

Lynne: Mmm

Andrew: But I, if I was at home, I don't think that'd happen

Lynne: No, probably wouldn't

Andrew: But because she's on her own, she's thinking things through at that moment in

time YEAH

Andrew: Even though now, if I ask her what she's done during the day, she probably

can't remember what she, what she's done

Lynne: Well nor-a-lot

Andrew sees independence as important to both his and his wife's quality of life. They have maintained a good relationship following her injury, attributed partly to the fact that Andrew has been able to continue with a life outside of caring and his wife has varied social contact which gives her interests outside of her marriage. Although Andrew monitors Lynne throughout the day with regular phone calls, they both lead separate lives which they can then share and discuss in the time they have together Many carers find their lives revolving totally around the patient's and vice-versa and although they claim aspirations of supporting independence, their actions often reinforce the cycle of dependence. Issues around this will be the focus of the next section.

5.3.1 Aspirations and Claims vs. Actions

Changing relationships produce many issues such as the difference between care and aspiration. An example being where parents talk of aspirations for their children to be independent but provide care in such a way that it can be seen to be promoting dependence. Doing too much can make a person physically and psychologically reliant on others. Kathy's family provides an example of parents who claim that they want their daughter to be as independent as possible, but their actions do not reflect this; for example, they still take her to the toilet, even though she requires no assistance when she is on her own. She was injured as an adult, so her parents have arguably gone back to a caring role; it can be even harder for those whose active parenting role has never stopped.

Ben for example developed a brain tumour as a young child, he has therefore been cared for throughout his life and has never taken on a truly adult role. Now in his mid-twenties he is facing the difficulties of transition into adulthood, with outside pressures focused on him gaining independence. Similar pressures have been reported by other families with children who were brain injured during their childhood years. Some bow down to this pressure, but the question remains whether independence is always the most positive step forward. In Ben's case, he is looked after by his parents and his relationship with them has been questioned by a Psychologist:

Ben: Because mum had labelled me disabled and this lady seen that I can walk, talk, live pretty independently, she says, "He's not disabled". She called me mum er, think, er, sort of she's er, mollycoddling me, which really annoyed me mum like. That's it, she said "I've weighed up your personality straight away, you're a fussy mother", sort of thing, and mum just went off to me like about her but, that really gets to me.

Part of the issue here, as discussed in Section 4.4.2, is the use of labels, but within the talk, Ben states that he lives 'pretty independently'. In reality, it might be said that he takes little responsibility for his own life, but perhaps if he feels independent then he gains self-esteem from that, without the risks of being left to manage his life alone. Small gestures to independence such as part-managing a bank account feed into his belief and both he and his family feel secure in his status. The Psychologist's viewpoint appeared to be that Ben was too dependent on his mother, but as he is happy in his current situation, he rejected this criticism and therefore all else that this professional said to him.

Staying with criticism of professionals, carers are sometimes concerned about the level of medication provided by hospitals, suggesting that it is used to make patients more manageable and there is an issue around whether this is acceptable. However, I spoke to one family where despite concerns over hospital use of medication, they used it themselves to manipulate their daughter's behaviour. They are very proud of their active role in helping their daughter to regain her mobility and her ability to communicate. By contrast they believe that the hospital preferred to use drugs to keep patients quiet rather than trying to meet their needs:

Gordon: I'm pleased with it, 'cause my ambition was, when she was a cabbage, was

that, I want her to be able to be mobile

YEAH

Gordon: To be able to communicate, er, to enable her to get, er, to communicate how she felt and what she needed, what her needs were, so that she would get good treatment. I felt as if she could communicate and be understood and be mobile to some extent, that's, that's as, the two basics that you require. 'Cause if you can't communicate and you're not that mobile then you'll be stuck in the corner, and drugged up, and left.

Deborah: Which she was at first, she did go on drugs

Gordon: They tried to do that, they operate er, with drugs, because they're less, less of

a problem YEAH

Gordon: Less nursing if they're drugged

He uses what could be considered a quite derogatory label by referring to his daughter as a 'cabbage', but this is used as a contrast category with her present level of recovery and his role in effecting this progress. He talks about his ambition and his wants, so the focus is very much on his own agency and achievement. He goes on to talk about the importance of his daughter being able to communicate her needs in order not to be overlooked and this brings about a suggestion that hospitals drug patients such as their daughter to reduce the nursing workload. Later in the interview however, the issue of medication is raised again. At first this is in the context of a Psychologist recommending Prozac, which again her father is resistant to:

HAS Kathy EVER VISITED A PSYCHOLOGIST OR...?

Deborah: One came, a Clinical Psychologist

YEAH

Deborah: Came once. Yeah because she went through..., this were going back a few years now, she went through a period of being depressed, quite... very depressed, you know? She wasn't coming out of it, which, she does normally, er, and all he decided, er, was, and he did when he came, I remember him saying he hadn't dealings with head injuries

RIGHT

Deborah: Which doesn't give you much confidence in him. All he suggested was you went on Prozac, that she went on Prozac and he gave her some relaxation tablets, er not tablets, er... tapes

YEAH

Deborah: So we went to the doctor, her own doctor

HER GP?

Deborah: Yeah, and he said <u>no</u>, don't go on Prozac. He didn't think she... you know, and that was that weren't it?

Gordon: Well, he didn't tell us, he asked us what our view was, and I remember telling him that I didn't want her on any drugs. So I said to Kathy, more or less, "There, you're not having any drugs, get some tapes, get your finger out, you've got no bleedin' choice but we're goin' forth". And erm, it worked (laughs)

Deborah: Yeah

Here the Psychologist is portrayed as being inferior to expectations as he admits to having little experience of head injury and he doesn't provide the service that they expect of someone in his role. His suggestion of using Prozac to control Kathy's depression was obviously considered as her parents went to their GP for advice, but Gordon again brings the focus back to his own agency in this situation. He tells his daughter that she can't have any Prozac (suggesting that perhaps she was quite receptive to the idea), and constructs her condition as needing to 'pull herself together'. The conclusion to this story however is the revelation by Gordon and Deborah that they use Diazepam to manipulate their daughter's moods:

Gordon: She hasn't been on, on drugs since. Er, she's had the odd day, erm, when

she's been that down in the mouth, that er, she's had erm, Diazepam

RIGHT

Deborah: Yeah, we've always got those in

Gordon: Er..., 'cause obviously, when you get depressed, you need help, and it can be

beneficial on a very short term basis, even if it's just to get you to sleep

YEAH

Gordon: And er, it's suprisin' what twelve hours kip'll do. The next day, you know, you can, you can be turned round, and mild depression can be turned round that quickly. So there'll be a couple of Diazeparn, or one, a good nights sleep, and then erm, we'll be alright, we'll be away then and off we go

Deborah: Because her memory's so bad as well, she would be forgotten that she was

depressed YEAH

Deborah: Wouldn't you? I mean she doesn't, not like a normal person **Gordon:** Well the circumstances can quickly bring it back to her

Deborah: Yeah, a jog of memory can

Gordon and Deborah claim that when Kathy is depressed (or rather when they perceive her to be depressed) they give her Diazepam, she then sleeps, and when she comes round she has generally forgotten the incident at the root of her negative emotions. So although the Psychologist is criticized for suggesting medication rather than dealing with the cause of Kathy's depression, her parents make use of precisely this strategy. From this we may infer that the issue is not around medication per se, but of the parents asserting their own control over its application. Control of medication can in general be a real issue for independence; the social implications have already been referred to in Chapter 2, but the impact of memory problems is also a key concern. One of the main reasons identified by Ben's family (who were accused by a Psychologist of being fussy and mollycoddling) to argue against independent living, is that they fear their son would not be able to manage

his strict tablet-taking regime, and if this is not followed precisely it could prove fatal in a very short space of time.

There is also an issue around the extent to which patients are socially active or socially protected. Some of the parents interviewed were aware that their children have very limited social lives and they oriented to a dilemma between wanting their loved ones to be happy and to have fulfilling lives, while at the same time choosing not to encourage increased social contact due to the perceived risks of exposing their children to the wider world. Lewis' parents for example cited their son's day-to-day life as consisting of television, video games and walking to the shop for beer. They are aware that he is developing a reliance on alcohol, but at the same time felt secure that they knew where he would be at all times. They make no apparent effort to encourage him to extend his lifestyle as they believe that he is safer at home. They reason that if he drinks himself into a stupor then he will fall asleep at home rather than risk going out. This belief in his vulnerability was added to when he was mugged while out walking and so he is supported in a very insular lifestyle, 'protected' from social contact.

Other carers would try to engineer 'suitable' social contact in low risk environments.

Patricia for example experimented with sending her son to a day centre for people with learning disabilities:

Patricia: The only place that was available, or that was offered, was the Fosse Day Centre and my husband and I, obviously it was all new to us, er we went down, saw it and thought that it was..., would be ok, but I'm afraid it wasn't and I fetched him away. WHAT WERE THE PROBLEMS?

Patricia: The problems were that you were dealing again with people with learning difficulties, disabilities sort of thing and I had that stupid idea, which was stupid when I look back now, I thought possibly because Robin was better, not, better isn't the word I'm trying to say. Er, I thought that Robin would probably see that he could do more than they could and he could probably help them, which it didn't work like that RIGHT

Patricia: It pulled him down

RIGHT

Patricia: And that's why I fetched him away, and when I fetched him away I hadn't a clue what, what I was going to do, just hadn't a clue and erm, he was at home

Patricia believed that exposing Robin to a group of people who were 'more disabled' would allow him to appreciate his own strengths and that he would take on a caring role

himself. What transpired instead was that he socialised with the group as equals, which Patricia felt was inappropriate, so she removed him from the centre. She in effect chose a group of social contacts for her son and then took them away from him in the belief that they were 'pulling him down'. This left him in the same position of social isolation that he had been in prior to this 'experiment'.

We may summarise these issues in the general theme of how people with brain injuries are treated. It is often taken to be the case that ideally the patient should be and is, treated as an adult (i.e. as they were before the injury). However, as we have seen, many carers take on a parental role and orient to the patient as they would to a child. This may not always be something that the carer is aware of. Helen for example, explicitly raises the issue of appropriate treatment:

Helen: See if I said to him, "You are daft Richard aren't you?" Which I'd say anytime...

Helen: ...and he'd say, "I know I've got a brain injury", and I's thinking, I, I didn't think of it like that

YEAH

Helen: Because I treat him as if there's nothing wrong with him, which I think I should do

YEAH

Helen: You know, you can't treat him differently because he's had a brain injury, we've just got to treat him exactly the same, you know

Helen here states that her husband should be and is treated just the same as before his injury. However, throughout the stories that she tells there are instances of where she does appear to be treating him differently:

Helen: I mean at one time I, I used to just let him walk round the block, because he would get lost and I used to run from, I couldn't go with him, I mean, you can't treat him like a little boy, and I used to run from one window to another to look for him to make sure (laughter) he was coming round the block

To treat Richard the same would be for him to walk when and where he likes without being supervised, but Helen talks about how she <u>let</u> him walk just a short distance while she secretly followed his progress. She also discusses how she reveals aspects of his condition to others in order that she can pre-empt his behaviour:

Helen: We went to Malta, I thought I'd pick an English speaking country because then if anything happened I'd be able to explain to them what was wrong with him

As was discussed in Section 4.4.1.3 Richard tries to hide his disabilities and it could be argued that if Helen were treating him as an adult she would respect his desire for anonymity, but instead she warms people that he may not recognise them and that he has a brain injury, therefore perhaps changing the way that he will be treated by others. Perhaps carers believe in their own aspirations, but it is important that professionals are aware that they may not always reflect reality. Caring can be an all consuming role that is difficult to look beyond but there often comes a point where other agencies or the patients themselves must take some responsibility. These shifting roles will be explored in the next section.

5.3.2 Shifting Agency in Care

There comes a point for most carers where they must consider shifting agency to others. This can mean sharing the present burden of care or it can mean planning for the future when they are no longer able to care because of their own ill health or death. Martin for example had to go into residential care when his wife developed terminal cancer. For many carers, the shift in agency is much more subtle, such as engaging the patient in day services at appropriate centres. Those who have discovered places where the patient can spend time away from home value the respite that this provides. For some it can be somewhat more serious:

IS IT BETTER FOR YOU NOW HE'S GOT MORE THINGS GOING ON IN HIS

LIFE?

Helen: (Nods)

YEAH

Helen: Yes, it is, yes, because some days, I just want to go like this (clutches head in hands) and squeeze my head, because I don't, I never shout, so I, I bottle things up you see. I 'm not a person who has a shout at somebody, you know

YEAH

Helen: Life's too short for me, you know

YEAH

Helen: And I think, and all the time you're shouting and that, you're hurting yourself aren't you. Your using that much energy as well aren't you, and so I bottle things up and sometimes I go upstairs and I just squeeze my head like that, you know, or I'll phone my daughter, and have a little chat to her

Richard regularly attends a day centre and Helen has encouraged him to join various social interest clubs. This gives her some much needed space on a reassuringly regular and secure basis. Some patients attend rehabilitation centres on a residential basis but this comes with the insecurity of regular reassessment. This can be incredibly stressful for carers who know that they were struggling to cope:

HAS IT BEEN GOOD FOR YOU TO HAVE THIS RESPITE THEN?

Amanda: When he went in for the initial sixteen-week assessment, whether, we didn't know whether he was going to be able stop or not. And we'd actually crawled down from the walls, it was hard, because we had to come to a decision and when he came home at Christmas, for them five days, you know, I don't know we coped for twenty one months. Because five days... an hours worth of it... if we'd of taken him back, it was, we'd forgot what it was like. And it was hard to get back into it, literally, but er... He's, he's your flesh and blood and it's hard for you to come to terms with it. You couldn't go back to that, no matter what. And then we have to go every twelve weeks to find out whether we've got funding again, so we never relax. When it comes to about four weeks before the meeting, things start going through my head. I don't, I don't sleep well at the best of times but I start getting less and less sleep, wondering what's gonna happen. If they revoke, withdraw the funding, what will happen? And it's hard. I wish they'd just do it for a year and get it over and done with but they don't want, don't want to commit themselves for a year.

The issue of finance leaves Jason's parents unsure of whether they will be expected to take full agency again for his care, or whether funding will last long enough for him to develop sufficient independent living skills. Their experience of him returning for only a few days has suggested to them that they would not cope with providing long-term care. They are therefore anxious about what future choices they may have to make. Finances were also an issue for those planning future residential support:

Jacob: Well for people in my situation, I can't see why people are being penalised for saving all their lives and then just because, as in Maria's condition, she cannot do any banking, she can't remember things, and so you have to look after the money, and if in consequence you are the person that's looking after the estate, but it's not your money, I mean Maria, Maria's money is Maria's, that is a pot of money so that if I die, or get ill, she has to go into a nursing home, and a nursing home is not cheap.

Maria is one of many accident victims who received compensation, but because of her brain injury the money has been placed in her husband's care. He has given up work to support Maria and is therefore seeking benefits to sustain them in their present situation, but the compensation is considered as savings, which makes him ineligible for financial assistance. Jacob is anxious to leave sufficient for Maria to access high quality residential nursing care, particularly since he has been diagnosed with cancer, but fears

that with both of them forced to use the money now, there will be little left to secure her long-term future.

Having looked briefly at professional care, it is important to recognise that many shifts in agency actually happen within the patient-carer relationship. There comes a point for many carers where they encourage the patient to take on additional responsibilities, in a move towards them managing their own life. This often means a steady hand-over of tasks and communication with agencies, which are until that point under the control of carers. One of the steps that Daniel took towards independence was filling in forms for himself, but in the early stages of his recovery, this was a difficult task for him to complete accurately:

Victoria: He'll say that he can do things that he shouldn't have done. Like when we're filling in the form for the benefit agency the other day, and his all works test YEAH

Victoria: And what was it? Can you lift 2.5 kilos and carry it round? So he wants to do it. "No you're not"

Daniel: (Laughter)
Victoria: (Laughter)

Daniel: Well it's challenge isn't it?

Victoria: Can you walk upstairs unaided? "Ooo". "No, you've got a stair-lift, leave it. You've not got to do everything, just 'cause they've asked you the question" Can you walk up K2?, "Ooo yeah, I'll do it". Oh yeah

Daniel: (Laughter) Oh dear, by the time we'd finished that form I was like, in the state I am now, I couldn't do anything for laughing

YEAH

Daniel: And Jiminy Cricket here's like, well why have you written that?

Victoria: I left the form with him as well. I come here the next day and he's put all this fiction on it (Laughter). Thinking, "Oh no"

(LAUGHTER)

Daniel: I filled it in to the best of my ability at the time, and the problem there of course is that the memory is so bad, short-term memory so bad that to me it made sense YEAH

Victoria: He'd had operations in all sorts of hospitals (Laughter), oh god. "Well what if we send away for a new one?" "No just leave it, we'll leave it, we'll cross it out...

Daniel: Oh dear

Victoria: ...they'll get the gist of what you're about, reading that" (Laughter)

By supporting Daniel to complete tasks such as this for himself, Victoria is preparing him for future situations where he will act more independently. The Benefits Agency is one of many organisations that Daniel must negotiate with and be a channel for if he wishes to take charge of his own life. At this stage, he did not appear ready to take full

responsibility, but with Victoria's help, he took an important first step, where mistakes were looked on positively as a marker of current ability.

Victoria was one of the few carers who was actively encouraging independence as an immediate concern. Most looked to the future in terms of making provision beyond their own ill health or death. Rebecca was one of those who spoke at length about preparing her son for a future without his parents:

Rebecca: At the moment we're a bit of, at a loss about Ben's future aren't we? Because we don't know ourselves...erm, what road...

Dennis: We've obviously got concerns you know, about...you know, being around, I mean obviously, you know, hopefully anyway Ben's going to outlast us but er, you know, that concerns us. I suppose it's something that concerns everybody, you know. Erm... and there's nothing much you can do about it I suppose.

She went on to talk about the preparations she has been making in terms of thinking about the future role of Ben's brother and with regard to extending Ben's independent living skills:

Rebecca: I mean we're of a situation where he's got an older brother, who... We don't even know if he'd want to take Ben on, and Ben doesn't even know if he wants to be taken on

Ben: (Laughs)

Rebecca: ...because we've had this, we've had this conversation haven't we Ben?

(Laughs)
Ben: Yeah.

Rebecca: You know he's erm, you know, he's sort of said, "Oh I don't think I could go and live with Andrew all the time". We don't know whether Andrew... Andrew knows he's got to sort Ben out, you know, I mean we will do our best to sort him out, to see where he's going to go or how's he's living and whatever, well before we go. But I mean his circumstances might change so that Andrew would have to... you know. And my main worry with Ben is, is that he's not worldly wise, and there's the money side of things, he couldn't deal with his own money. I mean he's not daft he knows... he's very good with his money...

Ben: Recently I've started getting my money out, of the bank at the beginning of the month, my erm, subs.

OH YEAH

Ben: A week and, erm...

Dennis: You have to er... dish it out, don't you?

Ben: Yeah, but see if I'm left over, got some left over from last week like, sort of budgeting for that

HOW DOES THAT GO?

Rebecca: Oh it's working out alright ain't it?

Ben: Yeah it's working okay, out okay, but mum's actually doing the, getting the money out of the bank and weighing things up for me at the minute, at the minute aren't ya?

Rebecca: Well yes, yeah I mean, it depends how many times he goes out. He's, he has to pay, I think we've worked it out it's about thirty-nine pound a month for his placements wherever he goes. And then, for most of them, he takes spending money.

It appears that Ben is actively involved in the plans for his future and that he will decide whether he would prefer to stay with family or in some form of supported accommodation. His mother is slowly trying to improve his independence skills, but looking realistically at his increasing responsibility with money, it seems currently to be a superficial gesture. The budget he manages is roughly £50.00 per month, most of which is designated for fixed activities. He is involved in sorting his money out for the different groups, but his mother still takes care of all banking and checks what he is doing. Realistically this is only a very small step towards the skills he would need if he were to choose independent living. For the present time however, Ben is happy to stay at home, citing the increasing trend for young people to stay with their parents regardless of their health:

Rebecca: As Ben says, erm, there's lots of young men his age living at home with his parents anyway that don't have to be there so...you know he's...

AND OLDER

Rebecca: ...and older that's right and he's quite happy to be here and we've always said if he comes to a time when he, he's not happy, you know, we'd have to try something. But we know, and Ben knows he couldn't be totally independent. And it's really the drug, it's, it's because it's so acute.

YEAH

Rebecca: Isn't it? That our worry is.

So Ben's parents are open to future suggestions of independence, as long as they come from Ben and are not forced by outside agencies. They are conscious however that he treads such a fine balance with medication, that he is unlikely to ever live a fully independent life. With this in mind, Rebecca is concerned that there should be others who understand her son's problems, and she is not satisfied that Ben will be able to represent himself:

Rebecca: He's a new doctor cos he's, he had to go to the adult. And I want him to know Ben's difficulties before... in the future if I'm not around to, to say this, that this is how Ben's brain is, or his memory is. But he's made a note on it.

She is happy that her job in this respect is done, not because she has completed the telling, but because she has seen the doctor write down a record of her words. This note, allows for some kind of resolution of the situation. Moving finally to another mother-son relationship where the son was injured as a child, Robin was very active following his

physical recovery from a car accident. He relied on his parents to take him to places and enjoyed a varied lifestyle. After his father died though, he withdrew and Patricia attributes this need to stay at home with a fear of what will happen when he loses her:

Patricia: Erm.. because I am constantly reminded that there's only the two of us. You know, and I think that basically, I think he has a tremendous fear of something happening to me, and yet as I've said to him, I've sort of covered every eventuality that I possibly I can.

YEAH

Patricia: Er, should anything happen to me. You know, erm... there's executors who know exactly..., and, I've made my own will, every..., it's all down in black and white erm... what I think will be best for Robin. But there again, having said that, further down the line things might change altogether. That Robin..., I would prefer Robin to go into care, erm... into good residential care. But again, as things are today, they bring people into the home. I know if he could stay here he would probably be happier. YEAH

Patricia: You know, but that's down, who knows, that's down the line and I can't answer that one, you know, but it's all there in black and white, knowing that the people the who will deal with it, I know will deal with it to the best of their abilities sort of thing. With him having no brothers and sisters or anything like that sort of thing, I've covered it as, as well as I possibly can.

The death of her partner has prompted Patricia to plan for Robin's future when she is no longer able to care for him. She knows that he would like to stay in the family home, receiving some form of care package, but he is totally dependent on his mother so part-time care may not be enough. This is perhaps in part due to the fact that Robin has, as Patricia describes it, never aimed towards any form of independence. His mother's preference therefore is for him to go into residential care. However, later in the interview a further issue came to light:

Patricia: With this giddiness that Robin's having at the moment, 'cause he's not very well as I say and the thumping heads, I wondered if... and with his state of mind, as I say, 'cause he does get over anxious, he does get frustrated, he does get depressed, do you know what I mean? And I mentioned about a neurologist and I talked it through with my doctor and he said, he would leave well alone, and he was, I'll be honest, he was quite fair. I asked him point blank, if it was his son, what would he do? And he said, "I would leave well alone".

Robin is showing symptoms of some further neurological problem. Patricia was always warned that he could have later complications and now this seems a very real possibility. Her initial reaction was that he should be diagnosed and treated but after discussions with her doctor, she has decided to let nature take its course. After the interview she discussed the possibility of Robin pre-deceasing her as possibly the best outcome, as emotionally

she is unsure how of he would cope without her. He is functioning at such a high level of dependence that she cannot see an acceptable way forward for him in life, so is therefore prepared to risk his death. This is viewed as her decision to make and so she has the highest possible level of control as a carer. This is a contentious issue and has been one that Patricia has struggled with. It could be argued that it is the doctor who has allowed her to be in this position, just as Damian was allowed to 'share the secret' of Joanne's terminal condition. This opens up questions about how carers are managed by professionals. Perhaps more concern should be taken over the way that information is shared and the responsibilities that carers are encouraged to take. These differing levels of responsibility, or agency, in care will be explored in the final section of this chapter.

5.4 Levels of Agency

As we have seen through this chapter, carers differ in the way they fulfil their role. This may be governed by many factors including their premorbid relationship with the patient, personalities, expectations and financial resources. Carers may turn over their whole lives to meeting the perceived needs of their loved ones, or they may take on a less hands-on role, overseeing general well-being but letting others, including the patient, take the main responsibility. There are many points on this continuum and we could label these as different levels of agency. In the data so far we have seen carers presenting stories of rescue, of protection, of control and of assistance. These resonate with the work of Strauss, Corbin, Fagerhaugh, Glaser, Maines, Suczek, & Wiener, (1984) who identify four distinct care agents: Rescuing Agents, who might for example save a diabetic if they slipped into a coma; Protective Agents, who might accompany an epileptic person to provide help if they have a fit; Assisting Agents, who might help a person to stay with a health regimen and finally, Control Agents, who might make a person follow a health regimen. It is perhaps more useful though to think of these as forms of agency, which carers can shift between according to the changing demands of their role.

Stories of rescue are perhaps the most dramatic, such as Gordon and Deborah who found their daughter with potentially fatal breathing difficulties (Section 5.1.1.1). They acted to

save her when medical staff had failed to notice the problem. Ben's parents also gave several stories of rescue such as their involvement in getting urgent medication (Section 5.2.1) and as will be presented, their discovery of Ben having lost a dangerous amount of fluid (Section 6.2.1). There are stories of initial diagnosis and of securing medical support, such as Helen and Richard (Section 5.1.1). Rescuing could also be extended to include the concept of rescuing from disability, in which case Iris's method of helping her daughter Lucy to speak (Section 5.2.1) would also be a representation of this level of agency.

Protective agency is common when patients are faced with new situations, such as attending a day centre for the first time. It is probably seen most clearly in the data with Patricia, who accompanies Robin when he goes out and is cautious not to leave him alone for too long (Section 5.3.2); but we have also seen her moving towards control as she cannot envisage her son surviving without her so has chosen not to seek diagnosis of potentially fatal complications (Section 5.3.2)

Control is visible in Helen and Richard's story, when Helen prevented her husband from smoking (Section 4.3.3). It has also been raised in the issue of Patrick's wife, who has chosen not to adapt the house for his wheelchair, so maintaining her own private space (Section 4.1.3). The most common form of control however, is the control of information, such as Susan avoiding mention of Tom's brain surgery (Section 4.1.2) and Damian concealing the terminal nature of his wife Joanne's condition (Section 5.1.1).

Assisting agency is perhaps best demonstrated by Andrew who has set up a range of memory aids to support his wife in independent living (Section 4.3.4). Helen also tried to provide memory aids but her less developed system did not function as well (Section 4.3.4). Assistance could also include personal care such as the help provided to Maria by Jacob (Section 4.1.2).

On the basis of the current data, I suggest that it would also be helpful to add two further forms of carer role, the Monitoring Agent and the Supporting Agent. At a monitoring level of agency, the carer is quite distant, they may no longer live with the patient but

they still take an overview of their life. Examples would include Lewis' parents who live two doors away from their son and Geoff's parents who live on the next road from him. Both families have helped their child into independent living, but in accommodation close enough that a carer role can still be maintained. This is the lowest level of agency, where they are no longer involved in active physical care, but they offer emotional support and monitor progress. One step up from this, the supporting agent is physically present but avoids interference. This is generally seen in the latter stages of a good recovery when the carer is a partner. This is the role currently occupied by Daniel's partner Victoria who has moved on from an assisting role (Section 5.3.2). It can also be seen with Rachel's husband, who starts the day as an assisting agent when he wakes Rachel and helps her to dress (Section 4.1.1) but otherwise she manages her own care.

These six levels of agency can be thought of as a continuum between high and low involvement:

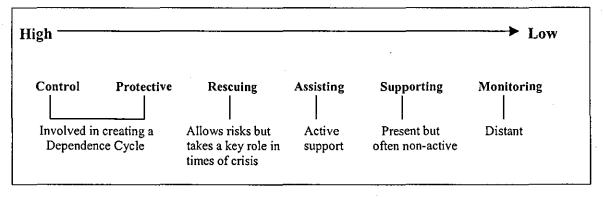


Figure 10. Levels of Agency in Care

In different situations, people may display different levels of agency but with a tendency towards either high or low involvement depending on where they are in the trajectory of care. Over time, if the patient develops greater independence then the carer's level of agency should decrease. However a consistently high level of agency may reduce the chances of a patient working towards independence and established systems of care may sometimes be difficult to change. Issues around this and interactions between levels of agency and strategies of adaptation will be explored in the concluding chapter.

In this chapter we have seen how the caring career develops from the point of injury, through critical junctures such as leaving the hospital, and shifting agency. Issues around role-taking and expertise have been explored. Independence has been raised as a key topic of concern and finally levels of agency have been identified. The next chapter will focus on issues in care delivery. It will raise practical issues such as limited time and resources and it will explore perceptions of the professional and how isolated incidents can have broader meanings for patients and carers. There will be discussion on issues around information sharing and finally there will be some initial trajectory development.

Chapter 6 – Analysis (III) Issues in Care Delivery

6.1 Enough Time in the Day?

This chapter will focus on issues in care delivery, as presented by patients and carers of which the most common concern to be raised was a lack of time and resources in the health and social care sector. On occasion, this dilemma derives from mismatched expectations between clients and providers. As an example, in the initial process of diagnosis, the doctor is expected to gather information upon which a judgement can be made. The patient will be focused on their own symptoms and beliefs and may have an extensive narrative to relate. The doctor will be conscious of limited time and will therefore need to direct the flow of information to focus on what they identify as the vital details. If interrupted and stopped from telling their complete story, the patient may feel that they have not been listened to. If they expect unlimited time then they may feel personally disadvantaged when their appointment is limited by a tight schedule. As Hurtig (1994) identifies:

It is this imbalance between the practical and the ideal that generates criticism of the doctor's professional demeanour and the charge that the medical care system is becoming increasingly an impersonal assembly line (p. 76).

This chapter will look at how patients and carers interpret these structural limitations when they conflict with their own expectations, starting with the issue of time.

6.1.1 Limited Time

Time is a commodity that often seems in short supply. As professional caseloads increase, patients must be dealt with quickly and efficiently through intensive scheduling. Comfort work is limited by pressure to meet more basic health and survival needs and mismatched expectations between patients and professionals give way to feelings of frustration as patients and carers make claims of neglect.

Emma: The people who do understand are over worked. Generally the people who were assigned to help me when I came out of hospital are very busy and don't have the time to put in to give me the help I need

Emma has expectations of how much input she should have been getting from the hospital staff, her own GP and her Social Worker, and this is beyond what they were able to provide. She understands that there is no personal blame and that the professionals were busy fulfilling other duties with other people, but this does not detract from her sense that she needed more support. Many people were less sympathetic to the wider role of professionals and the idea that they may not be considered a priority.

Sophie: Well, erm Nottingham, the doctors there were brilliant

YEAH

Sophie: The nurses weren't..., I couldn't give a toffee about the nurses because right, they weren't, erm..., well, my mum, my mum and dad helped me to get better. because right, you know, they wouldn't..., didn't feed you or anything like that

Sophie: Sometimes, so..., so I think the nurses were appalling, really

Sophie expresses a very negative attitude towards the nurses that treated her, not because they were negligent, but because they prioritised patients who did not have others to care for them. It is often the case that frequent visitors such as partners or parents will take on some of the caring responsibilities such as feeding or basic comfort work (See Section 5.2.1). Instead of recognizing that nurses may have this expectation and work around it, patients may feel that their family has been forced into a caring role by the perceived lack of professional support. However, sometimes there are real issues of negligence:

Gordon: What annoyed me the most, we used to go, we went every day

Gordon: Erm, at night, after work, and er she had a big burn mark here (points to

chest)

Deborah: Ooo yeah

Gordon: Said, "How did this happen?" Cause Kathy couldn't remember, she had

Deborah: Well she couldn't talk or anything though at this time.

Gordon: No she er, she was aware of us, and who we were, but she couldn't communicate or remember anything, and erm, apparently somebody stuck er, a dinner-plate, hot dinner-plate on her chest and told her to get on with it. Left this

massive burn on her chest.

Gordon and Deborah are the parents of Kathy. As they stated, they would visit her every day when she was in hospital, but this was before Gordon gave up work so they tended to go in the evenings. Feeding was therefore the responsibility of nursing staff, as Kathy was at this time, incapable of eating independently. Kathy suffered

quite a serious burn from the dinner plate left on her chest and none of the hospital staff were prepared to take responsibility for what happened. It seemed from talking to Gordon that the lack of response to this injury was a far greater concern than the injury itself as with no direct explanation of what happened and how it would be avoided in future, he felt that he could not trust the hospital to care for his daughter. Without the opportunity to talk to the staff member responsible, Gordon used conjecture to suggest what had happened:

Gordon: The problem with the food thing is because er, severe brain injury they come on, they er, improve so slowly, she was on, she was being drip fed, and then they go to being fed by a nurse, can't use their hands or anything, and Kathy would open her mouth and they'd spoon feed her, and I presume that one day she got some nurse that deemed that she could do this for herself. She put this plate on her chest and a spoon in her hand and left her to it, and got this big burn by it. But this is the kind of treatment you get down there.

Gordon assumes that the injury occurred because a member of the nursing staff decided that Kathy did not need assistance. It is also plausible however, that the nurse in question was suddenly needed elsewhere and so the plate may have been left in error, in part, due to time pressures on the staff rather than as an explicit drive for patient independence. Gordon's reasoning suggests that the staff were unaware of his daughter's capabilities and limitations, which as a generalised belief is far more damaging than an isolated and much regretted mistake. Whatever the chain of events, the subsequent lack of communication set up a pattern of mistrust, which led to Kathy's parents discharging her into their own care. Among the other incidents that they described was a situation where Kathy was 'lost', when a nurse apparently forgot to inform others that she had left her on the toilet before leaving at the shift changeover. If nurses do not have sufficient time for information exchange then easily avoided complications can arise. Gordon and Deborah, were also concerned about the lack of wider resources:

Deborah: Speech therapy, if you could call it that, it were very poor Gordon: Yeah, er, half hour of, twenty minutes of speech therapy a week, and um, physios were very, very good, but they were overwhelmed, so obviously she didn't

get enough, once a week

Deborah: For half an hour, that were

Many people felt that rehabilitation services were visibly overstretched. This was generally interpreted as a structural problem and professionals were often praised for the work that they did, but patients and carers often expressed frustration at their

difficulties in gaining what they perceived as adequate support. Expectations of recovery revolve partly around beliefs that there will be intensive rehabilitation, but in reality this is not available without cost and is not suitable for all. There is some inequality in service provision in this area as those who are eligible for compensation can often access early rehabilitation, paid for by the insurance of the other party. This is provided in a bid to reduce long-term disability, therefore reducing the final monetary claim and should be considered as an issue for state provision. It is financially beneficial to aid recovery as it will reduce future expenditure on health and social care services, but this requires high investment now for rewards that will be seen much later. As a structural issue this needs addressing and it would perhaps be valuable for the NHS to look to other countries such as New Zealand where focused rehabilitation seems to be used to great effect. Alex who was introduced in Section 4.3 experienced this at first hand as he was injured while living in this country. He made a remarkable recovery but both he and his parents were shocked by the difference in service provision when he returned to England. Staff who helped him here were excellent but did not have the same time available to provide consistent and intensive one-to-one support. Time issues are relevant to the whole of the professional spectrum and many patients talked about how limited time meant that relationships with professionals were often too superficial to be productive:

WHAT ABOUT YOUR SOCIAL WORKER, DO YOU THINK HE UNDERSTANDS YOU AND HOW YOU'VE BEEN AFFECTED BY YOUR BRAIN INJURY?

Oliver: No, 'cause I hardly get any time with him

YEAH, WOULD YOU LIKE MORE TIME WITH HIM?

Oliver: Well to be pro.., productive, yes

Oliver has many issues that he would like his social worker to address such as the inappropriate nature of his residential accommodation, which is aimed primarily at elderly people (he is in his mid-thirties):

HAVE THEY BEEN HELPFUL?

Oliver: No

NO? WHY NOT? Oliver: I don't know

WHAT DO YOU THINK THEY SHOULD BE DOING THAT THEY'RE NOT

DOING?

Oliver: Er..., finding me a decent place to live

He needs to live in premises where he can access a high level of support, but his current situation places him with carers who have little experience of acquired brain injury and the needs which this creates. Staff in the home have tried to develop an understanding of Oliver since they do have time to devote to him. In a hospital situation, time is far more restricted and without the knowledge that builds up through a relationship, professionals would sometimes give support that was in some way unsuitable:

Victoria: I think the exercises they gave you, they gave him early on and his eyesight we're affected

YEAH

Victoria: Real, real bad, you know, they'd written it down for him, but he'd got no memory and he'd got a list of exercises he couldn't read. He hadn't got the memory to remember he'd even been given them in the first place

Daniel: Yeah

Victoria: And if he did find it he couldn't see them, yeah, wasn't a lot of good that

was it?

Daniel: It's been fun, god it's been fun (Laughter)

As Victoria explains, without the time to train Daniel fully in the physiotherapy routines that he needed to follow, he was given written instructions. The fact that he had neither the vision to follow the list or the memory to even know that he had been given it, meant that this was inappropriate. What this displays is that the rehabilitation professionals had not planned around Daniel's needs and therefore indicates that they had not spent sufficient time evaluating these needs. In this case, the issue of restricted time is implicit in the provision of inappropriate support, but as a final example for this section, time was sometimes raised explicitly by carers as a source of frustration, with anger being directed towards the professionals who were perceived to be in control of the situation:

Helen: I don't go in with him anymore, because the last time we went to see Dr Smith, a young girl came out <u>crying</u>, and the name that she called him was, (laughter) well, and she'd been in there over an hour. Now <u>we</u> went in, Dr Smith, er, we sat down and he asked Richard the same things and then he said, "You'll have to excuse me I want to go to the toilet", <u>oh no</u>, that's a lie, he was writing down as Richard was saying and then he'd got his pen and he was yawning, and I said to him, "Did you have a late night?" "No, not particularly", he said. And he was just waving his pencil, and then he got up and he said er, "You'll have to excuse me only I want to go to the toilet". And he <u>dismissed</u> us. We were probably in there <u>five</u> minutes. YEAH

Helen: Now, if he wanted to go to the toilet so <u>badly</u>, <u>why</u> didn't he <u>go</u> before he called us in?

YEAH

Helen: I thought, "You rude man you"

YEAH

Helen: You know, and to <u>do</u> that to somebody, as I say, like Richard. We'd been sitting there all that time and it was like, "Oh well you're not worth much", you know. "I'll just ask you these questions then you can go". And it's wrong isn't it?

Helen is describing one of Richard's regular appointments with a neurologist. She starts by presenting a situation where another patient left in a distressed state after over an hour with this consultant. This sets up two suggestions for the listener: the first that the neurologist may not be good at managing people; the second that he is able to spend extensive time with patients when he chooses. The first image is then perpetuated in Helen's description of the consultant as rude and the second contrasts with Richard's brief appointment, to suggest that he was not being fairly treated. The fact that the neurologist would have had his own professional agenda is here disattended to. He may have only needed a brief time to do routine monitoring checks with Richard whereas perhaps the previous patient was still in the diagnostic stages of illness. The fact that this patient was upset may indicate that she had been given bad news and it is not necessarily a reflection on the consultant's treatment of her. A lengthy appointment may also have put the neurologist on a tighter schedule but people do not like to be thought of as low priority. Helen also seems upset by the lack of focus and this could be seen to reflect her expectations of professional behaviour but it overlooks an important issue, that a medical consultant will also experience difficult days, they will sometimes be tired or distracted, they will often be under external pressure to meet other commitments, they will have their own needs and so on.

It is also important to put this interaction into context. Patients and carers may get only a brief time with specialists such as the neurologist, with lengthy intervals between appointments. A whole day may be built around going for an assessment that lasts only minutes and expectations are developed around the experience and what the clients hope to achieve from it. For the specialist it is one of many appointments which must be dealt with quickly and efficiently, representing an imbalance between the practical and the ideal. This imbalance also extends to the availability of resources, which will be the focus of the next section.

6.1.2 Limited Resources

Not only is time a limited commodity, but resources are also stretched. Beds are in short supply and as a result operations get postponed and people stay on wards that may not be appropriate to their needs. Joanne provides an example where a beds shortage meant that she was moved from a neurology ward to a general ward populated mainly by older people:

Damian: So she, she were put up with the er, the older people and she ended up..., these were getting up at night, you know, which they was disturbing her sleep, and they were ringing the bell weren't they? And the, the nurses literally were not answering

Joanne: Oh and one coloured lady opposite, she were gabbing all the time, and I said to the nurses, is there any way you can put me somewhere more quiet it's, I've just had a brain operation and I says and, it's making me have an headache.

Damian: That wound me up.

Joanne: Just need a bit of peace and quiet.

Damian: That wound me up, and also what else wound me up was the fact that I said to Joanne, look, you know, Joanne said well I've got up and I helped 'em. I said well hang on a sec you've just had a major brain operation. She got out of bed with a drip and went and helped 'em, if she'd of tripped over in the night, she couldn't see without her glasses on, she can't even see with her glasses on in the pitch black. But if she'd of fell down and she could of smacked her head against the bit that, you know, was just operated on, she'd have died. And she were getting up and doing the nurses job, and I was so scared.

Joanne describes herself as enjoying helping others and it was perhaps helpful to the maintenance of her identity as a capable person to provide assistance to the patients around her, despite her weak post-operative state. For Damian though, it was an unacceptable risk brought about by a lack of staff – the main resource of a hospital. Transfer between hospitals was also raised as an issue of concern. Victoria describes an incident where she went to visit her partner Daniel and he had been moved without his relatives being informed. His health took a downturn although it is difficult to assess whether his transfer impacted on this:

Victoria: From a social point of view, there was, that one we um, we'd gone to visit him in the Royal, 'cause he was supposedly there. The bed where he'd been had got somebody's name over it, well they'd got his name over it and somebody else in the bed. They'd actually moved him without telling anybody. So we had to then shoot all the way over from Leicester to... and that's the night when he got really ill. I think most of the time, they, whichever hospital was getting rid of him, were ok, it was the one receiving 'cause they'd then got to get the empty bed. It was always, to a full ward, horrendous, there's no easy way of doing it apart from... you knew it was coming because, they always shove you in a chair just before they're gonna move you. If they can get you in a chair then it means you can go YEAH

Victoria: So whereas he hadn't been out of bed in all that time the next minute when you see him in a chair you know he's, hitting the road any minute

As time went on Victoria learnt to read the implicit signs of a forthcoming transfer in Daniel being moved from his bed to a chair. This strategy for keeping informed was a small comfort in an environment too stretched to share basic information. The language she uses ('whichever hospital was getting rid of him...') constructs an image where patients are an inconvenience which hospitals are glad to rid themselves of. Finding a bed means moving someone else on and this can mean transferring out-of-county patients back to their local hospital. Early transfer such as this for reasons of funding or limited resources rather than clinical need was of particular concern to carers:

Mary: Well, the first six months erm, was hell. As it would be, he was in a coma for a few weeks. He went to the Leicester Royal then went to erm, Queens Med in the ITU unit. Erm, they kept him, he was in a coma for about 4 weeks, 4, 5 weeks and the decision was made to like, turn the machine off and see that he, if he could do anything for himself, and within a day or two he opened his eyes, that was the first start. He then left there

WHICH WAS QUEENS MED?

Mary: At the Queens Med because he wasn't a Nottinghamshire patient they had to get him to a Leicestershire Health which wasn't adequately, erm, got the provision for head injured people. Erm between going from, he was still virtually comatised but kept coming round you know for a few weeks, when they moved him, as I say, he caught erm, pneumonia because he wasn't ready to go there, but because of this health business you have to be in Leicestershire, you go to Leicestershire WAS THIS BACK TO THE ROYAL THEN?

Mary: It was back to the Royal and er, I must admit, the first day there was inadequate to say the least. Erm, he nearly died, he was left for nearly 24 hours, because the doctor, it happened to be a Wednesday and there was no doctor until Thursday dinner.

WHAT WARD WAS HE MOVED ONTO?

Mary: I think it was Ward 29, it was just erm, a medical ward, but because they've got the MRAS

HE'D GOT MRSA AS WELL?

Mary: Well yeah that's it whatever it is, I know it's not, and he, erm, he had to be isolated

YEAH

Mary: And he was isolated for a month, in this room and they hadn't got the provisions so nurses didn't understand when he did come round that he was really brain damaged and was swearing and they couldn't cope with him virtually and they sort of, I think they actually shut the door on him because they thought he was going to die, but anyway. Due to persistence on my part and the kids as well, erm I ended up going to see the person in the Leicester Royal Infirmary, the Head Nurse, I don't know what her name was now, and she erm, one of the reasons being that they'd taped his buzzer up so that he could not keep constantly erm, shouting for people, and I didn't think that was right. Erm, she did say to me that they hadn't got the provisions so I said well he should never have come to Leicester, really, but anyway he spent another two months there and after I'd made the complaint, everything went a lot better. He started to come home for weekends, a day at a time, it was very frustrating 'cause every time I took him back he thought I didn't want him, you know and I didn't think he'd ever, ever be able to walk or be normal again. You know he's virtually normal now but like it's, we're in the third year now.

Mary is reporting a number of incidents within this description of her husband's early treatment. She feels that he was transferred too soon, and that this had a negative impact on his health, she talks about him contracting MRSA which delayed his recovery and she discusses the way in which staff struggled to cope, and so ended up disabling Robert's alert button, so that he could not make as many demands. This is unacceptable practice and Mary stakes a claim to improving this situation by following the complaints procedure. She suggests that prior to this, his isolation was a sign that he was expected to die and priority was therefore given to more hopeful cases. Prioritisation is a difficult issue because people affected by illness will tend to focus on their own concerns whereas hospital resources must be shared according to how clinical need is determined. People would sometimes feel that they or their loved one had been labelled a hopeless case and were therefore left to die and make space for the next person:

Rachel: I found Mr Blake, cause that was his name and I got a monumental bollocking for calling him Doctor, I think Mr Blake was very pompous. As far as he was concerned it was on a need to know basis and at the end of the day I really didn't need to know because what I was asking them to do was going to cost an awful lot of money. He'd got other patients that he could spend that money on. If I pissed off and everybody ignored me within six months I'd be dead anyway and the problem wouldn't be there and I think that was very much his view

Rachel presents an immediately negative view of her consultant because he sharply corrected her over use of his title, giving her the image that he was pompous and inapproachable. As discussed in Section 4.2.2, Rachel is keen to learn about her condition and her options so that she can make informed decisions, but feels that she has been deprived of this right. It was her decision to have surgery to clip the aneurism, but this was delayed and no medical reasons were shared to explain why she had to wait. Rachel knew that if the aneurism burst then her life was at risk so she wanted immediate action. It may be that it was not appropriate for her to have surgery at the time of diagnosis, or her doctor's assessment of the risk may have been much lower than Rachel's but without information she came to her own conclusion. Rachel appears to be convinced that she was not given details of her condition or offered prioritised surgery because she required an expensive procedure and that the consultant believed that she would die soon, therefore saving the hospital time and money. The fact that she had the surgery and survived does not seem to negate this view and perhaps it has developed simply from the conversation where Rachel was made to feel inferior due to her mistake in the way she addressed this senior member

of the hospital staff. She has constructed a representation of him and his motives that has stayed with her regardless of the events that followed. Enduring representations of health and social care professionals will be explored in the next section.

6.2 Representations of the Professional

Since the early 20th Century there has been a trend towards medical holism, but with the growth of new technology and the increasing economic complexity of medical care, some believe that doctors are once again becoming, "Blind to the personal and emotional aspects of human illness" (Hurtig, 1994, p74). After the brain injury, there is always a period of time where care is in the hands of health care professionals and this is a point where issues of blame and accountability can emerge, often from the carers who have clearer memories of this time period. They may question aspects of the care provided and how this may have impacted on health. Incidents such as this represent just a fraction of each individual's trajectory but are often remembered with great clarity and impact people's overall accounts of the care process.

With these factors in mind I will present a small selection of the concerns shared by patients and their families. I do not claim these as representative of the wider health and social care system as positive support is more easily overlooked, but they do raise very real issues that need to be addressed – and for those who told these stories, they are concerns that need to be heard. 'Atrocity stories' (Webb & Stimson, 1976) were a feature of many of the interviews conducted, particularly those that involved carers. Webb & Stimson suggest that people recounting medical situations may take the opportunity to vent thoughts that they were unable to voice at the time and that perhaps they are trying to find some redress for a real or perceived inequality between themselves and the doctors. Atrocity stories also have a function of drawing attention and provoking sympathy which may be particularly desirable for people who have found themselves very isolated either by injury or by caring. Stories of inadequate support could be used to reflect positively on how an individual coped in difficult circumstances and may therefore be meant as proof of triumph rather than complaint of failure. Sometimes however, mistakes are made and things are overlooked. The stories that follow in the next two sections will reflect these incidents, but we will also explore the context in which the understandings at the core of these narrated incidents were formed.

6.2.1 Cataloguing Mistakes

It was common in telling their story for patients and carers to present the mistakes of others and how they have impacted on their lives. Ben has already been introduced as having had a childhood tumour with the related complication of diabetes insipidus. The complexity of his health needs and the fine balance of medication that needs to be maintained has increased the likelihood of him regularly experiencing acute phases of illness. Each time this happens, his parents search for a reason, just as initial incidents require explanation (see Section 4.2.1), so do later complications and dips in recovery. For Rebecca there is an additional influence of her storytelling as she has been faced with the accusation of 'mollycoddling' her son (see Section 5.3.1). It has been suggested that she is too cautious and overprotective with the implication that this may also reflect onto Ben's beliefs and coping strategies. Rebecca is therefore keen to justify her own stance as appropriately cautious, as this next piece of talk demonstrates:

Rebecca: Yeah and then he had, I took him to our Doctor, to the GP, and erm he gave him a tonic, he told him, told me it was me. Because he had had this problem nineteen months before, I was making Ben neurotic, you know, if I was neurotic making him have my problems. But the headmistress sent a note home from school with him, cos the school's only round here and he was walking to and from school, saying that he couldn't walk straight... up the corridor could he? She was really worried about him...

Rebecca: And he'd obviously got a problem, so...

Dennis: He couldn't open doors properly

Rebecca: That's right.

Dennis: He hadn't got the strength to open doors.

Rebecca: To open doors, you know, so I took him to this same Doctor and you came with us, cos we, we didn't know whether to go to Derby or to the Doctor's because everybody round us, this was our problem, all ours friends children had got a virus, hadn't they. All of them were doing exactly what Ben was doing.

YEAH

Rebecca: Being sick and got headaches

Rebecca: So this was why I'd taken him in the first place, so, you came with me didn't you? And we went in, and explained the situation and he said... He stuck a spatula down his throat didn't he, and made Ben sick. So he said, "I'm going to send you to the, the Leicester Royal for a stomach check". And I said, "It's not his stomach it's his head, I know it's his head so we're going to take him to Derby now", and we did, we rang Derby and went straight over, didn't we? And they operated that night because his shunt had gone that's why he was sort of, you know doing all the things he was doing.

The mistake that Rebecca is cataloguing here is that her worries as a parent were overlooked and therefore accurate diagnosis was delayed. She has become an expert on Ben's condition due to her intense involvement in managing his problems, but her role as a concerned parent seems to overshadow this expertise in the eyes of some professionals. The fact that Ben was operated on the night that he was taken into hospital indicates that his condition was serious, proving that Rebecca was appropriately concerned when she followed her instincts about getting him checked properly. A further issue here is the lack of consistency as the GP's recommendations did not match with the required hospital treatment. Changes in diagnosis or treatment strategy were interpreted by carers as initial failures – raising queries about competence. As a brief example of internal inconsistency, Kathy was treated for shock immediately after her accident, for which it is standard practice to keep the patient warm:

Gordon: When she first went in, they erm, wrapped her in baking foil, keep her warm, but when the neurologist came, from Nottingham, to see her, he reversed it. He says, "Take all that off and cool her down"

The consultant ordered an immediate reversal as cooling the brain can help to limit neurological damage by reducing the blood flow. This apparent inconsistency in procedures confused Kathy's father and gave him an early impression of professionals as lacking expertise. He remains critical of hospital practices. Early problems can have a long-term influence so although we can plan improvements to present and future services, immediate uptake may still be affected by experiences from the initial phases of the care trajectory. Lucy for example had frightening experiences of physiotherapy back in the 1970s and these, she describes, created barriers to her seeking desperately needed help for over 25 years:

OUT OF ALL THE REHABILITATION THAT YOU'VE HAD, WHAT DO YOU THINK'S BEEN THE MOST USEFUL TO YOU?

Lucy: Er, well I suppose physiotherapy, <u>really</u>, but didn't think much of that for years

YEAH

Lucy: In fact in the early days, I was actually having to take erm... well I got myself in such a stew I used to be sick with fear before I went every morning. I had to take something to calm me down, just to get there, 'cause they scared the living daylights out of me. I heard it had that effect on quite a few younger people. This particular physiotherapist at Loughborough, er, she's retired now, but she used to... her tactic was to scare you into doing something

HOW DID SHE DO THAT?

Lucy: Er, well, one instance er, that really explains things I think, she... I kept falling over, obviously, in the first place, so to teach me how to fall safely, she stood me, a terrified little girl, on the mat in the middle of a gym and she used to hit me across the back of the knees so I fell. (Laughs slightly) Then I, the first time I actually went over for her I sprained my wrist doing it (laughs). But that's the sort of thing she used to do to get you to do something.

It has taken a long time for her to overcome her fear of this rehabilitation service and this may account for the extent of her physical limitations, which she has only recently started to challenge. It is easy to forget that patients often come with a history of service use that will influence their expectations and their actions. To reach these people – issues from the past may need to be explored so that damaging historical beliefs can be broken down. We also need to be aware of how single incidents can lead to a long-term change in the perceived status of professionals and therefore the relationships that follow:

WHAT HAS THE SUPPORT FROM THE GP BEEN LIKE SINCE THE SCAN?

THE INITIAL SCAN?

Joanne: My own GP?

Damian: Alright till about two months ago.

WHY'S THAT?

Joanne: I went for my er, repeat prescription of me Cipramil 10 milligram a day.

And erm, I collect em from the chemist, and erm...

Damian: You were taking em for two weeks, weren't ya? And I thought summat's

wrong here, summat's wrong. She, she were climbing up the walls.

Joanne: They'd prescribed me too many milligrams

Damian: Well she were climbing up the wall, and I thought summat's seriously wrong, I looked at her tablets. What were they? 10 times the dose weren't they?

Joanne: No...

Damian: There was something....

Joanne: I have 10 milligram a, a day and they gave me 20 milligrams.

Damian: 20 sorry, 20 milligrams. So it's an extra 10 milligrams. And it were like, she were climbing up the walls. So I rang the doctor and he said, ahh yeah, right okay, er....

Joanne: He says it shouldn't have affected her in that, now I don't think it did, but Damian said.

Damian: We all, everybody, me, your mum and my parents noticed a significant change in her attitude and, you know, oh well sorry, we're er, we're changing the system onto computer, it won't happen again, you know. I said well can you get us some more tablets, oh well you come down, I said no you bring em up here pronto, you know. And it took about two weeks for her to get back to normal again. But apart from that the doctor's been very good.

Joanne was over-prescribed her anti-depressant medication and although she was unaware of the effects, Damian saw a change in her behaviour and contacted her doctor. This was a clerical error which could have been far more serious than it was. It is interesting to notice the effect on Damian's accounts of the medical profession – as they were responsible for this mistake, he expected them to make an immediate home visit to rectify the problem ('I said no you bring em up here pronto'). The wording of this suggests a loss of respect that may perpetuate into the future.

Returning to Ben and his family, I would like to conclude this section with Rebecca's description of one of their 'worst...bad times'. Ben was not being closely observed and he urinated constantly until his body was drained of fluid. He lost his sight temporarily and suffered a brain haemorrhage. It was not until many hours later that his parents discovered evidence of the fluid loss that had caused this crisis, so the mistake could be viewed as a lack of monitoring, but there is also a separate 'incident' in-between:

Rebecca: He wasn't being..., he wasn't in front of the main bay. He sort of moved down cos they were more sort of really poorly people. And he wasn't watched was he? And in the morning I went in and he said, "Mum turn the light on". And it was bright, hospital bright lights and I said, "Ben the lights are on", and he said, "They're not, it's dark". And we realised he couldn't see, he'd actually gone blind. So we fetched the Doctor, we fetched his brother, and erm... it turned out that Ben had weed all night. Now we did, it was one of our bad times wasn't it? One of our worst... bad times in hospital. Erm... they scanned him through the day, we had tests all day, they told us he'd had a brain haemorrhage and they sent us to the Christmas party. We lived in a very, very surreal world, not kidding didn't we? Put him in a wheelchair...

Dennis: That was a most peculiar weekend...

Rebecca: It was the, the most peculiar weekend that was. Three or four days of odd, and we came back from the party, we had to take things with us because he was weeing a lot, cos that was out of control (laughs). I remember wheeling him as, as Santa's coming to say hello and I mean he's just so ill, you know, it was like... And you're trying to smile cos by... we'd been there about five weeks by then hadn't we? So we knew everybody that was on our ward. When I was getting ready for bed that night, I don't know what I did but we discovered that the mattress was sodden... Dennis: Absolutely sodden...

Rebecca: Absolutely sodden, so when we took it off the bed, the bed was... like that (making u shape with hand), shaped... full. It was full of urine. And we said no wonder he's poorly we didn't know he'd lost this much fluid, nobody did and it wasn't being put back in. So, nurses and doctors came again and it was a real emergency wasn't it

In a state of crisis with an upsetting diagnosis, Ben and his family were 'sent' to the Christmas party. Expectations of Ben's need to fulfil his role of 'being a child' alongside attempts at a pretence of normalcy put his family in an incredibly uncomfortable position in which the ability of others to enjoy festive celebrations highlighted the dire nature of their own situation. This shows how events which may be interpreted as positive by professionals may be viewed negatively by clients. In some cases this can be due to misinterpretation or unmet expectations; this will be explored in the next section.

6.2.2 Missing the Point

Sometimes patients and carers would interpret situations or procedures in ways which were at odds with how medical professionals would describe them, resulting in negative feelings about the capability of professionals. We cannot be sure of the original circumstances because we are judging from the stories of service users only but we can begin to question the basis of some of their ideas. Simon for example believes that doctors did not understand the effects of his head injury, citing an example where he was asked to remember a phone number:

Simon: Yeah, I don't think they were up on it because they sometimes asked the impossible. Oh you know, remember this phone number for me it's only a mobile. Yeah and you know, you're stuck on the second number. And like, but, and things like that...

AND YOU DON'T THINK THAT, THAT WAS PERHAPS TESTING YOU? SEEING WHAT YOUR MEMORY WAS LIKE?

Simon: Mmmm, not, cause sometimes it happens, like the Simon Jones man is a master of the unexpected gesture. It's alright, I'm just thinking (looking at tape recorder)

People are generally not expected to remember phone numbers without writing them down. It is possible that this shows some overestimation on the part of the professional, but it could also be an informal testing procedure looking at Simon's short-term memory – as it is a method I have seen used by Psychologists before. Suggesting this caused Simon to lose his focus; perhaps he felt uncomfortable with his reasoning not being accepted at face value. Testing may not always be explained fully and sometimes people would feel frustrated by its repetitive nature as with Richard's annual neurology appointment:

Helen: Richard absolutely hates him, he can't stand him

YEAH

Helen: And that is because every time he goes to see him, he will ask him the same thing, who is, who's erm, what's the Queen's na..., er what is the Queen

VEATI

YEAH

Helen: Who is the Prime Minister, erm what year were you born, and it is, it's aggravating, he should, I mean he's got enough intelligence and Mr Smith must know that

YEAH

Helen: And he'll, I'll say to him, "Have you practised what day it is, what month it is", because I mean he knows all of that

YEAH

Helen: You know, and I mean each year he goes, and Dr Smith asks him exactly the same questions

YEAH

Helen: And he'll go to see him this, in this September, two years on, and he'll ask him again, and I think that is belittling somebody, to do that

Helen interprets these questions as a 'belittling' test of her husband's intelligence, but he has a severe memory deficit and in cases such as this it is common to do orientation and amnesia tests at regular intervals. These help to measure the return of function and if Richard is being asked to repeat this task then it suggests that he is not performing as well as Helen imagines. It seems that without a full explanation of the purpose of these tests, Helen has misinterpreted their use and therefore formed a low opinion of the neurology input. Perhaps the real issue for her is that her expectations have not been met, but maybe they have never been explored and challenged. Similarly Jason went to see a Psychologist who performed tests rather than offering answers:

Jason: There's one guy, I can't remember where he was from, can't even remember his name, erm, Doctor..., he was my Psychologist anyway. Anyway I can't remember his name but he doesn't understand head injuries at all. And er, they sent me to him and it was just pointless 'cause we went there once and my mum and dad said they were never going to go there again, she was absolutely no help at all

It is interesting to note that Damian is inconsistent with the gender of the Psychologist. He remembers the experience as pointless but cannot describe details of who he saw or what happened. This may be seen as an example of incomplete reconstructed memory, where perhaps Jason's parents expressed dissatisfaction and this is all Damian can remember, so he trusts and incorporates their values without really understanding why. Talking to them however, it was the lack of answers that made them feel negatively about this support, although it is usual for initial appointments to be used for assessment. It is likely that Jason's family felt unable to express their needs and if the Psychologist did not ask directly what they hoped to gain from the visit then their expectations may simply have not been apparent and therefore were not addressed. Sometimes people interpret professionals as being deliberately unhelpful, but this is not always the case. Emma expresses a belief that doctors want to help her but are simply unequipped to do so:

Emma: I think that the doctors in the hospital would have wanted to help me 'cause they're doctors and that's what doctors do. I think they just didn't know how to help. I don't think my doctor or social worker know enough about brain injury. People take me very literally when I say things and when I get stressed I have a little panic and I cry and they take it all very seriously and very personally and it scares them in a way. I think it would be important for them to know, well one of the important things would be what not to say to a brain injured person. I don't have a lot of confidence anymore, I need to feel like people want me to be there and want me to go there and my doctor said to me a couple of weeks ago, "I'd rather you didn't come to

the surgery as often", which was a real dash in confidence for me. He was my doctor and I trusted him and now I feel like I can't turn to him anymore because he doesn't think that there's really anything wrong with me. I had a very good doctor before, he sent me to all the right places. I think my previous doctor took more time.

The main incident that Emma is relating here involves her doctor suggesting that she made fewer appointments to see him. Emma describes herself as a very anxious person and as needing avenues in which she can explore these anxieties. The GP felt that it was inappropriate for her to be making weekly appointments with him but Emma interpreted this as rejection and misunderstanding of her condition. Perhaps what she needed was a formal introduction to another service that would better suit her needs, such as counselling, but without setting this in place, Emma has been left feeling stranded. She identifies herself as a 'brain injured person' and thinks that it is this which people cannot deal with rather than looking at her behaviour patterns and individual responses. If things do not work for her she tends to represent this as resulting from the generic brain injury and peoples' reactions to it rather than questioning her own role and beliefs. Emma now feels that her GP service has been restricted and therefore no longer feels able to turn to her doctor for advice. For many people, it was not just services that seemed inaccessible, but information. This will be discussed in the next section.

6.3 Manipulation and Restriction of Information

Information seeking is a primary coping strategy for people with head injuries (Frank, Haut, Smick, Haut, & Chaney, 1990). It is also of inestimable importance to carers and many feel that they are not adequately informed of either the neuropsychological sequelae that patients may experience or of resources and agencies that are available to support them (Bowen, Tennant, Neumann, & Chamberlain, 2001). Data has already been presented on information restriction in Section 4.2.2 with discussion of Rachel's case, where she was not able to give informed consent regarding a cooling procedure that was used during her operation. Much of the difficulty obtaining information though, occurs in the acute stages of illness when doctors are cautious about giving details as accurate predictions are difficult to make and this is usually what carers want. Iris recounted the early stages of her daughter's illness when she could not get the hospital to give her any details of Lucy's condition. She even asked

her GP to find out, despite a now poor relationship between them. Iris particularly wanted to see the consultant and tried every day:

Iris: He wouldn't see us would he?

Julian: No

Iris: They just, erm... the message came back that he would see us when he had something to tell us, and after she'd have been admitted the following day when she was in the coma and we asked to see him. We were sent or a, a Doctor was sent to talk to us, who was sort of on the team erm, and he was a Spaniard and he really couldn't speak English, he really could not speak. And I think he was... there would always... a big team of people walking round with them, the surgeons...

YEAH

Iris: On the morning rounds, and several of them were there learning... and erm... we believed that he was one of them. And he, he said, in his broken English erm... "Your daughter is very sick and she will not recover". You know that was it.

YEAH

Iris: But we could not get to speak to the man she was under.

YEAH

Iris: And we really resented that and I still resent it

Iris was unhappy that she could only access a less senior member of staff and the information he gave her was both blunt and later proven wrong. It was just such an early prediction that doctors had been trying to avoid giving and by eventually meeting Iris's need for information, they again failed her expectations with inaccuracy. Perhaps this is to be blamed on the lower status of this professional, but the net effect was that Iris felt let down that she could not see someone more senior until her daughter began to show signs of recovery. As she put it, they resented it then, and she still resents it now. It seems that there is an expectation that medical staff will be available and should have detailed knowledge of likely future events. It is also implied that this information should be provided openly and perhaps even without request, but many felt that they had to fight to learn the truth:

Andrew: In the end they were pretty good at explaining that, erm, obviously we've had the information from him in the end, it took... we had to fight for the information though

YEAH

Andrew: And she never seemed to have the same doctor much more than two weeks, before you were seeing somebody different again. There didn't seem to be much continuity

Lynne: Yes, there weren't a lot of that, so there's your problem I think (laughs)

A further issue is identified here, it can take time to build a relationship where information can be freely exchanged, but the hospital system means that the staff responsible to a patient may change regularly and without a consistent link it can be difficult to keep well informed, especially as each doctor may be new to her

condition. Andrew talks here about gaining information as a joint concern with his wife, but in some cases the patient was overlooked. This will be explored in the next section.

6.3.1 Overlooking the Patient

In the last chapter (Section 5.1.1), data was presented from Damian and Joanne in which he revealed that doctors had told him far more about his wife's condition than they had told her. He chooses to conceal this information while at the same time telling Joanne that he has some additional knowledge. Most carers however felt that the patient was entitled to know about the hurdles and barriers that they will face:

Rebecca: Erm... when he was, he had the tumour removed when he was eleven, and he had his birthday in the hospital. When he was discharged he went to Ashfield Special School and he used to see Dr Hughes at the General and this one particular day.... Now Ben's never, even from when he was four, been sent out of the room to be told be told anything he's known all along

Dennis: Yeah

Rebecca: Hasn't he? Excuse me

Dennis: That's alright

Rebecca: As much as he's needed to know at the time what's happening. But Dr Hughes sent him out of the room because he'd done a bone grown test on him and we'd gone back for the result. And he said to Ben, "Would you like to go and make your next appointment? Go with the nurse". And off he went. When I got outside (laughs) he's sitting out there, "Well what's he told you?" What he did tell me was, Ben was five foot one and a half, he wasn't going to grow any more, because all the growth, growth hormones had gone. So I said to him, "You're not going to grow any more", that's what I said. And he said, "Well I'm bigger than me Grandma". Everybody's bigger than... (laughs), my mum's quite tiny. And that was it, that was as much as he bothered

Ben was a child at this time and perhaps the doctor was unsure of whether and how to tell him that he would have restricted growth, preferring to pass agency in this information sharing to his parents. It was obvious to Ben though that something important had been discussed and he demanded to know what had been discovered. With a brain tumour there is always the risk of re-growth so it may have been a relief to discover that the discussion was not about future expectations of illness. Without access to full information, worrying assumptions such as this can easily be made. When told that he would not grow any taller, Ben took this on board with apparently little concern. As it transpired however, Ben defied medical convention and continued to grow for many years without evidence of the required hormones in his system. He is still smaller than average but has happily breached expectations.

Adult patients could also be overlooked particularly in terms of their rights of access to information about their condition. Rachel for example, claims to have had excellent support from her GP:

Rachel: My own GP, she was brilliant. She would answer anything she could, <u>but</u> there were things that she couldn't answer but she would tell you truthfully....

YEAH

Rachel: "I don't know...

YEAH

Rachel: I can try to find out but I don't know". She also got pictures to show me exactly where things were. You know medical books that she'd photocopied to show me where things were. She was brilliant.

However, she wanted more detailed information than this professional was able to offer, but found that hospital specialists were less forthcoming:

Rachel: I'm not a bloody cabbage I'm a person I want to know what's happening, but, that's right. I decided, okay none of these people, my GP can't help me anymore, they won't help me so I go find out on my own. So I look on the Internet but there's very little information. So then I thought, right I'll go to the library, I went to the general library and I did learn quite a lot. For one I learnt that it could never have been hemiplegic migraine, because as the doctor had said, it is not selective, it does not always appear on the left hand side, it is not predictable. Migraine is down to an electrical going on in the brain that causes a spasm and it doesn't come back in the same place all the time.

YEAH

Rachel: Now I couldn't find anything more so I thought right if I go to the hospital library, they wouldn't let me. You're not allowed. I think that I had a <u>right</u> to that information...

YEAH

Rachel: So why was I not allowed to get it. Why couldn't the hospital library of said 'you're not a member of the medical profession, however, if you tell us what you're looking for we'll point you in the right direction and if you get stuck, go and ask somebody'....

YEAH

Rachel: Why can't I...? Why is it a secret? It's me.

Rachel had originally been misdiagnosed as having hemiplegic migraine, and by accessing information on this condition, she proved to herself that this was not the case. She wanted to find out about aneurisms as well, but found the local library of little use so she asked to use the medical library. This would seem a very sensible next step, but it was only available as a resource for hospital staff. This may be an arrangement of practicality, to allow medics quick access to urgently required texts but Rachel interpreted it as a veil of secrecy over medical information where only the appropriately trained are allowed to know the truth:

Rachel: I... think they think, you don't need to know, but I do. YEAH

Rachel: I want to know, I want to understand. I don't want you to give me bullshit, I want to know what's what because then; for example before I went for my operation, because I knew that it was highly possible that I wasn't coming out of the theatre, I had time to go, write a will, talk to my children.

YEAH

Rachel: Sort out, ask my children, you know, okay if the worst comes to the worst

what personal thing of mine do you want?

YEAH

Rachel: I had time to sort all those things out.

YEAH

Rachel: But that was no thanks to them.

Rachel does not describe herself as looking for miracle cures or unrealistic hopes. She simply wants to understand her condition and its associated risks. Rachel wants to plan for the future and she wants her family to know the challenges they may face. When professionals lack the time to share this information, perhaps resources such as the medical library should be made available to patients and carers, with appropriately trained staff to offer guidance. However many people are less self-motivated in gaining information and only realise later that perhaps they are under-informed because they did not ask appropriate questions when opportunities arose. This will be considered in the next section.

6.3.2 Passive Support

Information may not always be actively restricted, but if patients or carers do not ask the right questions of the right people, then they can still feel that they have been kept in the dark. Back in 1957, Pratt, Seligmann & Reader reported that doctors seem to assume too high an ability in patients to initiate discussion and this is still true today. Consultations can be stressful events and it is often only afterwards that people have the emotional space to consider what they wanted to know but did not ask:

Edward: Erm, I would have, er, loved to speak to somebody who had er, dealings with head injured people and could sort of erm, stress the problems I'm gonna have, like the memory, mood swings, stuff like that

YEAH

Edward: Erm, just so I didn't feel so freakish, like you know, why me? Why am I behaving so irrationally?

YOU MEAN YOU WERE NOT GIVEN ANY INFORMATION ABOUT THE POSSIBLE EFFECTS THEN?

Edward: Nothing at all, nothing at all, so erm, it is hard coming to terms with what you are

Edward expresses frustration at his own lack of understanding but early on he did not ask questions. As mentioned above, this can be partly due to the stress of consultation

but it can also be that people do not know what to ask or do not feel that they have the opportunity. The dynamic of a consultation tends to focus around the professional as they will tend to lead such sessions, trying to quickly extract information (as discussed in Section 6.1). When their task is completed they may signal that the consultation is over either explicitly or through body language, and a patient may have left the room before they remember what they wanted to ask. People also feel that they are overlooked for help if they generally do not 'make enough noise':

Jenny: The thing with being disabled is that like, it's not just trying to get help, it's really struggling to get help. You've got to literally be at deaths door before anybody asks you.

The key phrase here is 'before anybody asks you'. Jenny assumes that people will come to her offering information and support and that if this is not offered it is because she is not ill enough to be visible in the system. She relates this to being disabled, as her status means she is overlooked. Some people however took personal responsibility for not being approached by agencies:

Helen: If I didn't get any help from anybody, it's only my fault. I couldn't turn round and say, "Government should be doing something about this" (laughter), and I mean if they don't know you exist, all these people, and people come and go from jobs, and if someone new comes in, they're not aware of Mrs Smith sitting, at home, are they? And erm, and if I haven't approached the people before them, then you know, I've only myself to blame, if there is any blame, but er, I've got nothing to grumble about...

Helen has consistently rejected suggestions of seeking support on the basis that she feels responsible for her husband and worries that his sometimes irrational behaviour could mean that he would be taken away from her. She reiterates the issue here that when someone is aware of her husbands needs, they may not stay involved in his case, and she makes no effort to inform new staff of their situation. As a final note to this section, returning to the issue of out-of county support, this too can have implications for information sharing:

Rebecca: We couldn't go to Leicester to start the chemotherapy because Dr Lawson, we didn't know her then but she was off with the flu and the whole unit was down. Erm... Queen's didn't do it then, I think they do now, but they didn't do chemotherapy then, so we'd got to have a doctor from the City Hospital.

Dennis: From the City Hospital in Nottingham

Rebecca: But don't ask questions, just you know, you'll be told in Leicester what's happening cos you're not going to be a patient at Nottingham, and the doctor's going to come over and start his chemotherapy. But, you know, so we couldn't ask

questions, we were left some books, to read, but, I don't know we just took it all in our stride that really we just, we'd gone through so many things...

Dennis: Absolutely we just, we just went with the flow. **Rebecca:** That's right, that's right, we went with the flow.

Ben's family were in a confusing situation. They had originally been informed that his tumour was benign and so after its removal they expected gradual long-term improvement. No clinical need was seen for radiotherapy but without it, the tumour redeveloped. It was only in hindsight that this treatment decision was questioned but now Ben was sent for chemotherapy to treat the more serious diagnosis. This was a new experience but as he had to be sent out-of-county for the initial treatments, his family were unable to access the expected level of support. This seems to be an issue that needs to be addressed at a structural level. Where resources are not available locally, treatment will be sought elsewhere; in these cases, patients and carers should not be made to feel that they are intruding on the territory of others and therefore unable to demand the same rights. Cross-county medical care is reciprocal and perhaps if hospitals were less concerned with boundaries, support could be greatly improved.

6.3.3 Talking Another Language

In 1965, Ley & Spelman conducted a study of how well patients remembered what their doctors said. They reported evidence of selective recall, where patients tended to forget instructions and advice but recall diagnostic statements. Wadsworth, (1976) suggests that this indicates a desire for understanding. This claim is supported by Balint (1957), who drawing from many years of clinical experience, observed that, "The need to understand is so compelling that it may actually outdo the desire to be cured" (p. 280). Sometimes however, professionals talked in a 'medical language' that patients and carers were unable to understand. Helen for example, felt able to speak to her GP and gain useful information as he talked on her level, but found hospital consultants less helpful:

Helen: He was talking to me like <u>you</u> are talking to me, you see because in the <u>hospitals</u> they, of course, as I say it's their profession and they go into all these <u>names</u> and things, you know, "What the hell they talking about?" You know.

Helen claims to have found herself struggling with medical terminology and this puts her off trying to talk to people at this level. It was discussed in Section 6.2.2 how

Helen was dissatisfied with support from the neurologist as he always asked her husband the same questions. I queried whether she had ever shared her concerns with this particular specialist:

YEAH, YEAH, AND HAVE YOU SORT OF EVER, SAID TO HIM HOW YOU

FEEL ABOUT THE QUESTIONING OR ...?

Helen: No I haven't

YEAH

Helen: Because he's the professional

YEAH

Helen: Isn't he?

YEAH

Helen: So he could come out with something and \underline{I} wouldn't understand and I would take him at his word, because \underline{he} is the professional, and I mean he, he's actually the one who was \underline{there} at the hospital, when Richard was there, so, he probably helped to

save his life RIGHT

Helen: So I can't, you know, can't really say anything, I just think it

Two key issues are raised here, the first is status. The neurologist is apparently perceived as unapproachable and beyond direct questioning because of his role. The second returns us to language ('He could come out with something and I wouldn't understand'). Rather than ask for explanation, thereby showing herself to be lacking in expertise, Helen would rather hide her concerns and dwell upon them privately. The use of appropriate language by professionals is key to their relationship with patients and carers. Assumed understanding can be the root of later conflict as people claim that they were not kept informed. Returning to Rebecca and Dennis, we can see how different people may interpret the same information:

Rebecca: And they said something that we didn't at the time, they said the tissue had grown up into it, didn't they?

Dennis: Yeah, there was comments you know, that we got, was that the tissue had grown into the part so there was obviously something growing <u>and</u> we were told that there was a grey area, which is a doctors way of saying he's a bit concerned about things, you know. So we knew that the doctors had got a concern

Rebecca repeats what was said by the doctor ('The tissue had grown up into it'), and Dennis provides the interpretation that this is a doctor's way of showing concern, it seems that Rebecca did not take this notion forward though as she expresses surprise at the later diagnosis of a tumour:

Rebecca: Anyway we went in, and we'd had the appointment for the whole body scan which was gonna be in January, the 17^{th} , it's alright, I know all the dates. And we sat there and \underline{I} said to him, we said he's still being poorly and whatever and \underline{I} said, what did I say? Something about, "If I didn't know better I'd say he'd gone into

puberty". And he said <u>straight out</u>, "He's got a tumour on his pituitary gland". Just like that, didn't he? And like this word was going...bouncing off the walls, but <u>you</u> weren't shocked were you? I was...

Dennis: Well because I'd heard that comment I remember that comment they told us that there was something growing and he'd got a grey area, something was growing that shouldn't be growing. So I, I prepared myself. You know, at the time.

The implicit understanding of abnormal tissue growth was taken by Dennis but not by his wife. If questioned separately, we might expect Dennis to express a feeling of being kept well informed, while Rebecca may feel less involved in information sharing, simply because she was not familiar with the 'medical language'. The message then is that people want to know about their situation, but they need to be told in a language they will understand. Also, conjecture may be interpreted as fact, which if proved wrong, can damage relationships between professionals and clients. The difficulty is to find a balance between waiting for irrefutable information and meeting the needs of patients and carers who feel lost without the knowledge to explain the events unfolding around them. In the next section this will be explored further in terms of the changing needs that develop through time.

6.3.4 Signposting and Monitoring

Signposting and monitoring was a much repeated theme throughout the interviews. Patients and carers wanted to know what help was available and where, and they wanted someone to be aware of their shifting needs through the passage of time. Many people only gained information about available services by chance through friends and relatives:

HAS IT BEEN QUITE EASY TO GET ALL OF THESE SERVICES SET UP? Laura: Well it's been you know, I've heard about them through the grapevine

With personal contacts having a large role in service access, some people felt that they missed out due to a lack of information:

ARE THERE ANY OTHER SERVICES THAT YOU FEEL YOU NEED NOW OR YOU PERHAPS NEEDED A BIT EARLIER IN YOUR RECOVERY?

Edward: Yeah, somebody who knew, erm, what I was entitled to, either payment wise or erm, medical help. You know, where could I go for like movement, to help my movement, and erm, mood swings and stuff like that. Just the basics, you know, you're gonna have these problems going on for a while, so they deal with it

Edward would have liked someone assigned to him who could have signposted services and resources throughout his recovery, appropriate to his needs at any one time. Without this people may not realise that services even exist and therefore fall through the net without appropriate provision. Others felt that information was not enough and that they also needed encouragement to take up opportunities:

Simon: I felt that my head was cracking up like it is now, but a lot worse, so erm, but I do not, oh another thing, this is erm, I would like to see some momentum, some movement to propel people to move into something. I mean you know, its alright you saying to someone, "There's a college down the road", and they're "Oh is there? Yeah well I'll have a look" And like then they won't. Or I think that some people need help with having there minds made up because thinking is quite hard when you've got a head injury and like you can think and you see all the negative aspects, well I do, and like so it makes me say no when I should be saying yes.

Simon was offered support to regain skills and therefore improve his future prospects of independence. As he constructs it, afraid of the unknown and struggling with motivation he did not pursue this support and now regrets it. Perhaps then, if there were professionals to guide people towards services, they should also be available to give advice, and practical support, maybe even accompanying patients to investigate available resources first-hand. For many though, it is still a battle just to find out what their options are. Problems also arose when information was not shared between professionals or not used by those who received it. Rebecca discusses an incident where Ben went to see a Psychologist who told her son that he should have taken GCSEs:

Rebecca: So I said, "I'm sorry but he just can't cope". And she was really, she went, went for me, and in the end I said to her, "Have you read his notes?" And she said, "No, I don't need to read anybody's notes". Now Ben's got two, erm... clip files, well you know, the lever arch files

YEAH

Rebecca: ...full of notes, from 1982 we're talking. She says, "I don't believe in writing notes"

Ben: Yeah

Rebecca: She says, "I can spend an hour with somebody and get their... you know, and I've got the measure of you", this is me, and she told me I was interfering and whatever

Dennis: Bossy mother

Rebecca went on to describe how the Psychologist later apologised, as she set Ben tests that he was unable to do and thus caused him considerable upset. She was unaware of issues such as his visual problems – as she had not read the notes – and therefore set unsuitable tasks that he was bound to fail. When information sharing systems are set in place it is crucial that professionals take advantage of the

knowledge of others. This case shows how failing to take account of collective knowledge can lead to wasted time and unnecessary upset.

Finally, people wanted to know what the future might hold. There is a common myth as discussed in Chapter 2, that recovery is time limited and it seems that this is still being conveyed to some patients and carers:

Victoria: They told me that when he got to six months, that would be what he'd be

like, pretty much, for the rest of his life

WHO TOLD YOU THAT?

Victoria: Erm, Dr Smith at the Queens ONE OF THE NEUROLOGISTS?

Victoria: He was a consultant something...

Daniel: Who was that? Victoria: ...on that ward

YEAH

Daniel: I think if you're not careful there's a, there's a lot of false information flying

around, I've learnt...

Victoria: I found there wasn't any

Daniel: ...you know

Victoria: ... I don't think anybody had a clue really

YEAH

Victoria: All they could do was go on past scenarios, there was nothing specific.

YEAH

Victoria: But as I say, with Daniel, typical, nothing happened until six months, and

then it all happened

YEAH

Victoria: So if I'd have gone on that, I did when it got to bang on six months, you do, you think, well that's it. How the hell's he going to go home in that state?

YEAH

Victoria: I mean, what's going to happen now? He's going to have to go into care. I mean he couldn't do anything for six months, I'm telling you, and then, then the physio completely changed

Daniel was assessed as being severely brain injured with little hope of recovering his mobility or even full awareness of his situation. He was in a dire state when his partner was told that at six months, 'that would be it'. This future date became fixed in Victoria's mind and when this point arrived Daniel was still totally dependent. Victoria had resigned herself to the fact that Daniel would need residential care and would never regain any more of his former self, but then a change in treatment proved a catalyst for significant improvement. Many relationships fail when a rewarding future cannot be envisaged and the information given to Victoria might have pushed others to end their partnership. When the doctor told Victoria what he did, not only was he misinformed, but he risked damaging one of the few things Daniel had left, a stable partnership. In the final part of this chapter I will present initial thoughts about

HOW COULD THEY IMPROVE THEIR SERVICE THEN DO YOU THINK, WHAT SORT OF THINGS WOULD HAVE BEEN USEFUL FOR THEM TO UNDERSTAND?

Aaron: Erm, that it basically, each and every need is different right and, each person is different and, just to take out more time I suppose rather than just seeing a person once in 6 months and just putting them down on a pile and then, well I dunno, if they actually forget about a person for the next 6 months but whatever, but rather than that, just try and spend a bit more time with the person involved.

Time and resource constraints restrict opportunities for professionals such as nurses, doctors and therapists, to build relationships with their patients. Aaron describes how this has had a negative effect on his experience of service provision as the lack of relationship has made him feel unimportant as a patient and makes it more difficult for professionals to understand his needs. However, illness is ultimately unsharable as for the patient it is a personal and subjective experience that disrupts their life and causes anxiety; for the doctor it is a case, that is part of the ordinary working day and that exists to be dissected, understood and where appropriate healed – all in a detached and professional manner. These contrasting perspectives make it impossible for the experience to be truly shared (Toombs, 1992). Oliver was one of the patients who identified the difficulty of creating shared understandings; he stated that others didn't know what was going on with him, prompting the question of who he was referring to:

WHO DO YOU THINK MIGHT HAVE PROBLEMS UNDERSTANDING HOW A BRAIN INJURY AFFECTS YOU?

Oliver: Everybody, 'cause they're not me are they?

Oliver has already been introduced as having had a childhood injury, a result of which, he tends to express ideas in quite simple and childlike terms. This can however have the benefit of being very direct and poignant. He is quite right to state that only he can truly understand his own experiences and what they mean to him. Others will however try to understand the problems of people who have been injured, and will often extend these assumptions to predictions around the future trajectories of illness and care. As an example, Rebecca identifies what she feels is her son's main problem and discusses its future impact:

Rebecca: The one thing that is his, is a $\underline{\text{main}}$ problem and \underline{I} think it's going to get worse, is the memory problem. I don't mean his memory is going to get any worse, but as life gets, he's like moving into the adult world and he's perhaps got to remember more for himself. That's when he'll get more confused.

the developing trajectory and how we can look to future events in terms of changing relationships and the impact that these have on care, support and recovery.

6.4 Taking Account of the Trajectory

Through the thesis to this point I have presented a series of events sorted into themes and categories. These events are not however isolated, for each person they are part of a complex trajectory from the time when brain injury first affected their life through to the present day and into the future. Within this trajectory are changing perceptions of what has occurred and what is yet to come. One way of understanding this is in terms of Heidegger's (1962) concept of the 'projectful' character of our experience, eloquently explained by Slife (1995):

All meanings of the 'now' necessarily involve meanings of the past and future. In contrast to conventional concepts of time, the past, for example, is not dead and gone, nor is this supposedly immutable entity stored for later retrieval. The past is a constant and dynamic presence in the present. Meanings of the past are changeable meanings rather than stored pieces of information or aggregates of various past experiences (p543)

If we accept Heidegger's notion that our perspective on both past and future is conditioned by the needs of the present, then through the stories people told during their interviews, they actively reconstructed the past (see also Ashcroft, 1989). This telling will have been influenced by their present situation and by future objectives of that time. This story will then also become part of the past and affect future retellings. In other words, for the patient, their sense of their own trajectory is constantly fluctuating as it unfolds in time.

We should however not forget that recounting the trajectory is not simply affected by changing priorities and perceptions. Following a brain injury there is also the issue of memory loss, as explored in Chapter 4. For those who do remember the events they have experienced, there are many issues to address and often a feeling that they are not being heard. Although there are commonalities between trajectories each person has individual experiences. Frustration can come when patients feel that this individuality is not recognized and taken into account:

Rebecca highlights the transition to adulthood as a critical juncture in the trajectory of those who have had a childhood injury. Organically based problems may be the same but their impact may change as expectations and support systems alter. Staying with childhood injury, Lucy raised further trajectory issues related to the point in life at which brain damage occurs:

Lucy: I'm still behind in age, I haven't caught up with that and of course because it happened then, when I was so young, my education, formal education was knocked back quite considerably. I can't pick that up, can't even imagine picking that up. I did go to college after I came out of hospital and tried to get some education but not at the same level as I should be by any means.

YEAH

Lucy: Yeah, and that sort of thing, you know that's something I'll never be able to really pick up

Lucy has made the transition into the 'adult world' and now lives independently, but she still feels the loss heavily of having had an injury during childhood. As she describes it, she feels that she has never been able to reach her full potential due to the timing of her injury and in particular, how this affected her learning experience. As Strauss (1970) identifies, status has a temporal dimension. For people who were injured as children this may be reflected in differences in the way that childhood and adult disabilities are perceived and provided for. It is acceptable for a child to be dependent but if this continues into adulthood they may experience a downward shift in status (Glaser & Strauss, 1971).

Carers also appear to experience shifts in self perceived status and experience across time. Being a carer may seem manageable in the early months, but if recovery does not occur at the level or rate that is hoped for then the long-term nature of the caring task becomes apparent. A shift is made between temporarily caring for someone and being a carer as with Andrew:

AND HOW HAVE THINGS BEEN FOR YOU?

Lynne: Driving him up the tree (laughs)

Andrew: Alright in the first few months I'd, I, well the first year, that bit I were okay but I seem to get more stressed out now, than what I did in, you know, in the first twelve month. Whether it's because it's all so ongoing all the time I don't know.

Andrew has found being a carer increasingly difficult and hypothesises that perhaps this is because 'it's all so ongoing all the time'. He now has to accept the change in his life role and this is a stressful period within the trajectory. Critical junctures such as this will be explored in the next section.

6.4.1 The Emerging Trajectories of Acquired Brain Injury

Many people chart their progress through reaching milestones. Following a traumatic brain injury, the first milestone is often to regain consciousness. This can be a steady process with the patient drifting between different states of awareness, but there is often still a key moment that marks this important milestone for waiting loved ones:

RIGHT, AND WHAT WERE THE EFFECTS THAT YOU FIRST BECAME

AWARE OF AS KATHY CAME ROUND

Deborah: (Laughter) Do you want me to say that? (Laughter) I remember it, do

you? She passed wind didn't she!

Gordon: Yeah Kathy: (Laughter)

Gordon: Yeah, and smiled

Deborah: That was the first we knew, we bought her, when she was really...they tried to encourage us to bring her home; that was in June I think, July. They encouraged us to bring her home so we put a bed in the lounge and er, she was all piped up you know, catheters and feeding tubes and everything, and Gordon was just doing something to her tubes and, she passed wind, believe it and then she said, he said, "Ooo Kathy" and she smiled and that's the very first reaction. We knew that she

could hear us all, that she was with us weren't you Kathy

Gordon: Yeah Deborah: Yeah

Stories such as this present a positive step forward, but are also the start of many trials to come. Waking from a coma can be interpreted as a sign that 'everything will now be ok' but it actually marks one of the most difficult periods, when the extent of injuries are first indicated; the patient may struggle to communicate, they may show signs of paralysis and perhaps most upsetting, they may not recognise their family. In the months following a coma, many milestones are expected, simple improvements in function including the patients regaining memories, talking, feeding themselves, looking after their own personal care and in Daniel's case, dressing:

Daniel: Just saying, I remember the first time I actually got my own shoes and socks on, a big cheer went up from the nurses you know and I said, "Well what's up with you?" and she goes, "Well don't you realise you've just done it yourself for the first time"

YEAH

Daniel: And I didn't realise that up to then I'd actually been having help, getting dressed, cause I wasn't capable of doing it, I couldn't bend properly and I couldn't get me legs properly, I couldn't get the sock on because I couldn't reach the floor YEAH

Daniel: And of course that's all history now, but at the time it was like "Ooo Daniel's got his own shoes and socks on" Big cheer, you know think "Ooh"

Victoria: I think it's one of the, one of the yardsticks they've got

Daniel: Beg your pardon?

Victoria: It's one of the yardsticks, once you get over that one, you can move

forward

Milestones such as these can be represented as critical junctures. They are times of change when relationships must be re-evaluated. These critical junctures can be charted across time to form a trajectory or model of likely events around which medical support and family care should be monitored.

6.4.1.1 The Medical Trajectory

The medical trajectory starts at the point of injury and follows the individual through formal health and social care settings, from admission to discharge. As such it can be linked to both Bellaby's (1991) traumatic brain injury model and Strauss' (1998) chronic illness model, as discussed in Chapter 3. The main focus of this trajectory is the differing experiences of people with traumatic injuries and people with organic damage. Although many of the same issues are faced and the same physical, cognitive and emotional effects may be experienced, the medical trajectory is quite different for each group.

A serious traumatic injury is likely to occur as a sudden crisis incident and as a result, the patient is usually rushed to hospital, where due to the prioritisation of head injuries, they should receive immediate attention. Where injuries are classed as severe, there is often some question over whether the patient will survive and preserving life is the focus of all early treatment. It is likely that they will be taken to an Emergency Medical Unit (EMU) and once stable, moved to an Intensive Care Unit (ICU), both of which have high staff to patient ratios and a lot of visible care work takes place.

This series of crises events will impact on the way the injury is viewed and on attitudes towards medical care. As discussed in Chapter 4, with traumatic injuries there is often an issue of blame that forms part of the coping process. Readjustment is forced suddenly on the patient and carers, but acceptance is often delayed by the formation of unrealistic expectations of recovery. The initial joy felt by carers at the

survival of their loved one, can turn to grief if the months pass with little improvement.

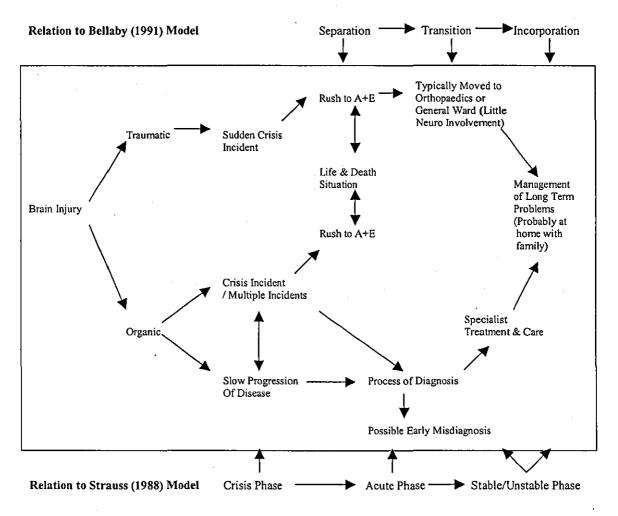


Figure 11. The Medical Trajectory

Beds on high dependency wards are in great demand and as others in greater need are prioritised, the patient will be moved to an alternative ward. They may be placed with other patients who have suffered neurological damage, although these are often older people recovering from strokes. It is often the case however that they will stay on an orthopaedics ward to deal with other less critical injuries, or on a general ward where their progress will be monitored and some rehabilitation may be offered.

Families are often shocked by the reduction of care as they have come to expect the time and attention received during the acute stages. As a result, they will often praise the early life saving work, but be quite critical of later, less intensive support. It is also a difficult time emotionally, as without the threat of death, life must now be

faced. Deficits are realised and monitored, with carers often struggling on behalf of the patient.

As recovery reached a plateau, or demand for beds increases, the immediate future must be planned and the responsibility of care is either taken or forced upon loved ones. Although residential care may be an option, it is usually dismissed in these early stages, and so the patient goes 'home', although where the carers are their parents, it may be a home that they have not stayed in for many years. Once outside of the hospital setting, further adjustment and acceptance work is required as the reality of any deficits is heightened once in the home environment. Damaged expectations bring frustration and strain on relationships and it is the work done around this that forms the second trajectory presented in this thesis.

Those whose injury is organic in nature are less likely to suffer a sudden crisis incident without warning, although haemorrhages provide the obvious exception to this. There are often many symptoms leading up to any crisis point, although recognition and understanding of them may only be found later. An initial crisis incident may also not be the lowest point in the trajectory, medically speaking, as it may be the start of a chain of such incidents, e.g. epileptic fits, loss of consciousness, loss of proprioception. Coping strategies are therefore different as an upwards recovery curve cannot always be expected.

Organic damage is less visible than a traumatic injury and diagnosis may be a lengthy process. Symptoms can be frightening but may be dismissed or misdiagnosed by professionals. However, when the real cause is identified, specialist treatment and care is often available. This produces a reverse mirror image of the traumatic patients' experience of care, where instead we see negative representations of early support, as clinicians are unable to give immediate answers, but far more positive reflections on later specialist care.

Increasing support from loved ones is often a more subtle process where each party has some time to adjust and prepare. The experience of loss may be different because it does not usually have the immediacy that follows a traumatic injury. There may be sudden changes however following a crisis incident or neurosurgery. In general though, adjustments to lifestyle are easier to cope with because they happen slowly

and in small steps. In the long term however, uncertainty around future developments can lead to chronic 'stress' as the hope of permanent improvement is less palpable.

6.4.1.2 The Care Trajectory

The medical trajectory is focused around support provided by health and social care professionals. The patient's life is also shaped to a great extent by the support they receive from their family, particularly at the point of discharge and beyond. This period in time forms the care trajectory. This trajectory can be seen as an expansion of Bellaby's (1991) Incorporation Phase and Strauss' (1988) Stable/Unstable Phases. As such it can be overlaid onto the medical trajectory to extend the picture.

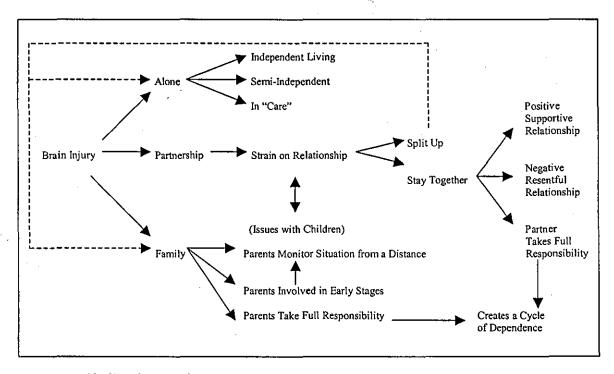


Figure 12. The Care Trajectory

We may think of the patient as in one of three basic situations following their injury; they may be supported by their partner, they may be cared for by their parents, or they may be without emotional ties (possibly as a result of the injury). To start with the latter situation, the patient may have been living a fairly solitary life prior to their injury and must therefore deal with its consequences primarily alone or with professional support. They may in contrast have been in a partnership and/or had close family relations but the changes brought about by the injury can put immense strain on relationships, so post-injury support cannot always be assumed.

It is not only the direct roles between patients and carers that change, but also wider relationships. We have already touched on the issue of decreasing social circles but there is also the often forgotten issue around children with brain injuries of siblings and how their relationships change. For a young child it can be difficult to understand the changed family dynamics and the difficulties that one or both parents may have in supporting them.

For adults in relationships, their partners must deal with wider issues associated with role changes, losing their main source of support when they need it most. Where patients are aware of these changing dynamics, this seems often to prompt a struggle against the effects of injury (see Chapter 4 – Strategies of Adaptation) which often puts partners into an assisting role (see Chapter 5 – Levels of Agency). They may also have children who have to cope with changes that are often beyond their understanding. For ethical reasons, no children were involved in the interviews but discussions with their parents revealed the additional strain that a young family can have on the caring relationship. Unaffected partners would sometimes refer to the patient as being like another child, and this status makes it difficult to maintain a parental identity. Some children were involved in care, necessitating an early development of maturity and responsibility, whereas others found the loss of secure expectations incredibly difficult to adjust to. One father in particular complained of the verbal abuse that he suffered from his children as they struggled to come to terms with his disability. Having heard others mock him, they joined in, maintaining common ground with their peers and separating themselves from the perceived stigma of his condition.

By contrast, where a person is cared for by their parents, this can involve a turning back of the clock to re-experience former roles. As both parties experience a corresponding change in status, parents seem more likely than partners to demonstrate a consistently high level of agency; this in turn reflects back into the patients strategies of adaptation, with acceptance of dependence seemingly easier in a relationship that was dependent once before. This reinforces the parents controlling or protective agency and makes it difficult to move beyond the dependence cycle. This will be explored further in Chapter 8.

In this chapter we have looked at limited time and resources, perceptions of professionals and where these may be misinterpretations and issues around information sharing and restriction. Finally we have explored some initial trajectory work around the medical and the care experience. In the last data chapter I will present a detailed case study following a couple through a trajectory of care from symptoms of a brain tumour to the final terminal stages of illness. This will include interview data and detailed personal diary extracts. It will be structured in terms of Strauss' trajectory of dying (1988) but additional themes raised through the rest of this thesis will be interwoven to show how they are temporally connected experiences and not simply isolated incidents.

Chapter 7 - Detailed Case Study

7.1 Living With a Brain Tumour

Throughout this thesis we have seen accounts of people's lives, their representations and their shared memories, but these snapshots, although valuable, do not give a sense of the full trajectories of care in which they exist. For each person there is a point in time where their life changed and with it their relationships, their expectations and often their own sense of self. This point marks the start of their trajectory and it may have been a traumatic accident, a critical health incident or a neurological diagnosis. With moderate to severe ABI, the trajectory rarely ends with full recovery, although it may reach a steady plateau. For some it is a downhill struggle and the trajectory shifts from one of care to one of dying.

Within this chapter, I will attempt to illustrate critical junctures across a complete trajectory, from the first symptoms of a brain tumour, through increasing disability, to death 5½ years later. This is possible thanks to the openness and cooperation of Rod and his wife Ann, who shared their personal diaries, their private correspondence and their thoughts. Rod first experienced the symptoms of a brain tumour in July 1997, when he had a seizure whilst on holiday. His wife made a written record of the day's events on a piece of A5 paper – for her own and the GP's information:

I awoke to strange (choking?) noises and the caravan shaking. My first thought was severe cramp then maybe a nightmare (neither a normal occurrence) as I could only see him from the chest down – but what I saw was so unnatural I got up immediately. My husband was rigid and shaking from head to foot – I noticed spittle at the side of his mouth. I pulled a pillow out of the way (he has three) as his head was pushed hard against his shoulder and his breathing very noisy and laboured.

I was speaking to him all the time but getting no response – ran to get help – returned – still rigid, shaking less severe – placed my arm under his neck to try and straighten windpipe. Spoke to helper – looked back when I felt moisture on my arm – saw blood from his mouth. Tried to open jaws with other hand – impossible. Now 'still' but awful bubbling when breathing – coming round? Tries to swallow – tell him to spit – no response – calming down – breathing still noisy – semi conscious.

Amb. arrives. Medics check him over – transfer him to amb. Give oxygen etc. Semi conscious but still unaware. Fights off oxygen mask – medic insists I tell him off – we win. Hos. Rec. Room regains consciousness – puzzled. Staff remove sleeping bag, discover patient has urinated some time during fit.

Form filling Tests & X Rays Driving ban Slung out (Not lit) Guess at time for rigid shakes 2-3 min. Total lost time approx 1hr.

At the start of this note, Ann records her thoughts on what may be happening when Rod was having his first seizure, even though a medical explanation is now available. She is letting the reader share in her role in the story by representing her internal beliefs as well as her actions. Her use of the term 'my husband' confirms that this record was not written for Rod; she also uses the term 'patient' rather than his name when she notes his uncontrolled urination. This impersonal statement perhaps allows distance from the event, but it may be asked why this detail is included at all. Ann also includes quite incidental information by noting that Rod usually has three pillows. It is this sort of detail that makes it feel more like a verbal record, perhaps even one half of a conversation.

In the second paragraph we see a move from sentences to brief statements; this reflects the increasingly frantic mood of the time. Ann notes that she spoke to a 'helper' but they are never identified or mentioned again. She also stakes a claim for her own role in providing assistance, as she seems to act as a rescuing agent. The third paragraph includes a move towards abbreviation as responsibility/agency shifts to the hospital. There is a particularly interesting statement on role taking ('Fights off oxygen mask – medic insists I tell him off – we win'). Finally, Ann gives an inventory of the post-crisis events, perhaps reflecting the list-ticking and form-filling involved in discharge. She also makes an estimate of the seizure length for medical purposes, using the term 'lost time' to reflect Rod's level of consciousness and PTA. An interesting term as it suggests that some of the past simply does not exist for Rod. Ann also made another (shorter) note after the second attack:

1st attack Wed 9 July. 7.30am-8.30am+ 2nd attack Fri 18 July, 12.10am-12.48am

Not quite as severe or as long lasting attack but basically the same reactions as before but without the urination.

Post attack behaviour very different, throughout the day actions less sure pos. as result of straining left arm and other muscles during fit. Although not a 'noisy' person his whole demeanour has bee slow & quiet.

Pain to upper left arm
Pain in both sides of jaw + tongue

This time Ann does not record her own feelings so this note seems more medically oriented. She mentions that Rod's post attack behaviour is different and justifies this as a potential result of muscle strain, we might ask whether this is her own diagnosis? As she assisted the medical team following the first attack, perhaps she has already started to take on a feeling of clinical expertise, often demonstrated by carers. There is also the inclusion of personally known facts when she states that he is, "Not a 'noisy' person". This again suggests that the note is written for others who do not know Rod so well.

7.1.1 Interview Data

Rod and his wife Ann were interviewed together in July 2002. This was one of the last interviews conducted for this thesis. At that time, Rod was living at home, with Ann as his carer. Ann was dealing with all of his basic needs, including food, medication and personal hygiene. However as his condition worsened, it became increasingly difficult for them to manage. Two months after the interview, Rod decided that he would move into full time residential care. In December, he sadly passed away. It seems appropriate to look at the start of this interview as it briefly explores the illness trajectory from its first acute phase to the present time.

OK, FIRST OF ALL, CAN YOU JUST GO BACK OVER THE CAUSE OF ROD'S INJURY

Ann: The recent injury?

THE INITIAL BRAIN INJURY

Ann: Well it wasn't an injury, erm, we were on holiday when he had his first seizure, erm and was taken to the local hospital at Hexham, and then er, when we came home, er, the doctor was informed, Rod's work was informed, and then because Rod kept having seizures, erm, the doctor decided to apply and have a scan done which was about 4 to 6 months after the initial seizure and the scan showed, erm, a tumour, which they call glioma, erm, on the left side of his brain, quite deep in his brain and erm, an operation wasn't recommended because of the depth of the seizure and the possible..., it could have caused more damage than the seizures themselves were causing at the time. So, we decided to leave it at that till a future date when the problems outweighed the risks of an operation, er, and things have been gradually deteriorating, very slowly over the next four and a half years or so, erm, and then last October time roughly, erm, Rod became slightly more incapacitated, his movements became slower, erm, and, I think, just before that he was diagnosed with erm, diabetes as well, you've been diabetic for a year now haven't you? Erm, and the combined problems, plus all the medication, erm, has really made quite a mess of him, slowed down, really tired aren't you a lot of the time? Confusion, lack of concentration, mobility's a pain, erm...

Rod: Basically I can't do anything

Ann: (Laughter) You can talk, (under breath) when you've a mind, erm, so the immediate situation is we're waiting for an appointment, erm, the Queens, to have a biopsy done on the tumour, erm, he had a second scan earlier this year and erm, decided that the way the situations were, we'd go ahead with the biopsy and probable treatment, either or radiotherapy, chemotherapy, depending what they

decide at the time. We don't know the sort of, pros and cons of all this, whether it's best to leave alone and carry on with the downward spiral, or see if we can halt it. But er, actually whether you have your biopsy or..., well we're hoping to get in on Tuesday, erm, won't know until Tuesday morning when I phone in as to whether there's a bed available, erm, if there isn't, erm, well as I've said many times, it's because some poor sod's in a worse situation than Rod is.

YEAH

Ann: But erm, hopefully we'll, we'll get in, see from there

It is quite typical of the joint patient-carer interviews that the carer (at least initially) takes control of the conversation. In this interview, I specifically directed the first question to Ann as it was agreed with Rod that he would find it easier to join in as and when he felt comfortable. There had already been some informal off-tape discussion, hence Ann was asked to, "Go back over the cause of Rod's injury". We see an immediate classification issue as a tumour does not fit into Ann's injury category. I came across this in other interviews, where patients or carers do not identify organic brain damage with traumatic injuries, even when there has been neurosurgery. Symptomatology may be very similar, but there is a natural division in trajectories and experiences, and therefore, in conceptions and labelling.

Ann demonstrates expertise (Section 5.2.1) by using medical terms such as 'glioma', but clarifies that this is a name used by doctors rather than herself (Section 6.3.3); ownership of the condition is conferred by the use of personally chosen terms. There is also subtle use of the word 'we', projecting a joint experience and therefore decision making process e.g., "We decided to leave it at that".

Without prompting, Ann continues by highlighting some of Rod's many problems. This leads Rod to make his first contribution to the interview, "Basically I can't do anything". There are many ways in which this could be interpreted, a true internal belief, a joke, a reflection of what he believes Ann is thinking/trying to say, or even a tactical move to end this part of the discussion. Ann takes the comment in humour and responds, "You can talk, when you've a mind". There is an implication that Rod does have at least one untouched skill, but may choose not to use it. It is the first time that we see a hint of Rod's personality beyond the illness.

Ann continues to refer to herself and Rod as a combined unit, stating, "We're waiting for an appointment", and, "We'd go ahead with the biopsy". This shows how Rod's life is so intrinsically reflected in her own. She also points to the fact that Rod's

condition is in a downward spiral; this could be seen to equate with a downward trajectory. However, Ann places Rod on an imagined severity scale, seeing that he is not at the bottom, that other people are in an even worse situation (Section 4.4.2.2). This conceptual work is important for Ann's understanding of Rod's condition; it allows her the positive feedback that Rod is better than he could be, but also prepares her for future possibilities. As Ann had raised the issue of treatment, I asked Rod how he felt about his choice in the situation. I wanted to give Rod the opportunity to talk and to see whether he discussed the decision making process as being personal or shared:

HAVE YOU GOT ANY FEELINGS Rod ABOUT WHETHER YOU'D LIKE TO

HAVE SOME TREATMENTS? ...IF IT'S SUITABLE

Rod: Yeah

Ann: Well it was your decision wasn't it this time?

YEAH?

Rod: Yeah, yeah

YEAH

Rod: Definitely going to...

YEAH

Rod: ...go in now.

YEAH

Rod: Yeah, he's er, talked me into it.

WHO'S TALKED YOU INTO IT?

Rod: Dr. Smith

YEAH

Rod: And er, obviously, he's the consultant, so he's the one that we've gotta

trust, and he's er...

Ann: He thinks it's time doesn't he?

Rod: Yeah

Ann: To have a look at the situation

Rod: So... and the trouble is, its not, he's not doing it, its being done by er, a

surgeon at Queens

YEAH

Ann: Yeah but Dr. Smith's recommended

Rod: Oh yes, he's recommended him, he's said go ahead

YEAH

Rod: We actually had the bloke come over Queens to look at me... scan. He was

quite keen for me to go, so... that's it!

By stating that the doctor has talked him into an operation, Rod is making two important claims; the first is one of the authority and persuasiveness of the doctor, but the second is that it was Rod's decision to be made. He is highlighting his own control over the situation and therefore claiming a high level of agency.

Rod's decision to have surgery is noteworthy as this not only highlights a critical juncture in his trajectory, but also Rod's continued need to assert his autonomy despite his increasing dependence.

Ann: Because he'd already got an appointment to see Dr Smith, and the last visit that we had with Dr Smith, up until the point of actually seeing him, he didn't want an operation or anything else, you know, quite happy with the way things were going, erm, until this last spell, and even, until we got in to see Dr Smith in the room, he didn't want. Erm, but then Dr Smith had read the notes and we'd gone in, and he said, he said, he leant right forward on the chair and looked at Rod, because that's the way to get the information across to him, he says, "Think we need to look at this a bit further now, don't you?" And Rod said, complete turnaround, "Yes, alright, lets get on with it then.

Rod: I decided I was gonna do it

Ann: One side of the door, "No", inside the door, "Yes"

Rod: Decided, going through the door, that I, I was gonna have it and that was it

WHAT DO YOU THINK PROMPTED YOU TO DECIDE THAT?

Ann: Dr Smith's attitude possibly?

Rod: Yeah, I think it was, yeah, er, you've gotta go in, you've gotta have it done,

so...

Ann: He's always given you the option hasn't he?

Rod: Yeah

Ann: And he's, yeah he's given you the option, but said that the way things are at the

moment, you know, but it's your choice at the end of the day

Rod: Yes

Ann: And er, that day you decided it was time

Rod: Yeah, decided that I'd have, (pointing to head) hole

Ann: And he asked me how I felt about it and erm, I said well it's Rod's decision,

whatever decision he makes, I will support him in

YEAH

Ann: If he changes his mind at the last minute, which Dr Smith says he's every right

to do if he wishes, erm, I shall support him in that as well

YEAH

Ann: Because what other option is there really?

Imagine for a moment that you are slowly dying and as time passes, so your discomfort and dependence increases. Now reconsider Ann's opening comment that Rod was, "Quite happy with the way things were going". If we think of this in terms of strategies of adaptation, perhaps Ann is saying that Rod has accepted his illness, building his life around it.

Breaking down the issue of whose decision it was to have the surgery, Ann attributes the decision to the neurologists persuasiveness ('He says, "Think we need to look at this a bit further now, don't you?" And Rod said, complete turnaround, "Yes, alright, lets get on with it then'). Whereas Rod asserts his own agency in making the decision ('I decided I was gonna do it'). By deciding to have surgery, we may say that his strategy of adaptation has shifted from acceptance to struggling. Ann however uses the circumstances of this shift to demonstrate inconsistency and ease of persuasion ('One side of the door, "No", inside the door, "Yes'"). Rod quickly reframes this as a positive if somewhat speedy, independent decision ('Decided, going through the door, that I, I was gonna have it and that was it').

The next question is directed to Rod ('WHAT DO YOU THINK PROMPTED YOU TO DECIDE THAT?') but the answer is suggested by Ann as she reinforces the role of the neurologist in Rod's decision making ('Dr Smith's attitude possibly?') To which Rod responds by portraying quite a forceful image of the consultant telling him what to do ('Yeah, I think it was, yeah, er, you've gotta go in, you've gotta have it done, so...'). Ann goes on to refute this, backtracking to the operation being offered simply as an option that Rod has the power to refuse and so it once again becomes Rod's decision. At the end of this conversation, Ann makes a move towards making her own agency a central topic, as verbally she gives Rod total control of the situation ('Well it's Rod's decision, whatever decision he makes, I will support him'). She portrays herself as a supporting agent, following the only available course of action — to comply with Rod's wishes.

Later in the interview, Ann talks of the increasing difficulty involved in <u>maintaining</u> her role as Rod's carer (as also expressed by Andrew in Section 6.4). Her comments highlight the fact that the care trajectory is at an unstable juncture. Although Ann's care is consistent, Rod's needs are changing. The support needed is not only ongoing, but it is increasing and there is the sense that Ann is beginning to recognise her own limits in providing for these needs. However she goes on to express a personal sense of responsibility for Rod's emotional state and suggests that he needs her to, "Sort him out". It is interesting how she makes the move from her own responsibilities to a more generalised, "But nobody's actually doing anything".

Ann: And, I can only give and do so much and after five years my resources, you know, are <u>really</u> low now. I'm finding it difficult, so we have the odd serious chat about different things.

Rod: Yeah

Ann: (Laughs) Err and try and sort him out mentally to get a better outlook and give him suggestions. "Oh yes I'll try this, oh yes I'll do that". Well it doesn't materialise because nobody's actually doing anything.

YEAH, WHAT SORT OF THINGS DO YOU ENJOY DOING?

Rod: [Sighs] Don't really know. I mean I've got paint books that I could do. Errm... I could go out and work on an engine or something like that, I could, I don't say I would but...

Ann: On a practical note, could you?

Rod: Well, I don't know. I mean I don't know whether I could swing on the chandeliers.

Ann: He's just had a job putting half a dozen screws and getting...

Rod: Yes...precisely

Ann: Those two bits of wood, two bits of wood in the right order.

Rod: Yes

Ann: So on a practical level.

Rod: I'm not doing anything.

Ann: I mean it's, it's good that you've got an idea that you would like to try.

Rod: Yes.

HOW DO YOU FILL YOUR TIME THEN?

Rod: Basically I sit in this chair, with a book or, not even a book. I just literally sit in the chair. Can't do anything.

Ann: Occasionally I take you out to, highlight of the week, Tesco's for dinner.

Rod: Yes.

Ann: Ermm, because mobility is a problem. I can just about make it from the car park, on a good day, from the car park to the café, and the most important thing is there are toilet facilities, which is an absolute essential because Rod has got very little control. When he needs to go to the toilet he needs to go, no messing about looking for somewhere, or waiting for somewhere. It's got to be there. Therefore even a car ride round the countryside, for a couple of hours is fraught, erm, for both of us to some extend, but me especially, I mean if he just needs a pee, I can clear up. But any another problem we are both absolutely, you know, it's beyond our control. I can't cope with it, and he can't control it. Erm, so you know, lifestyle is...

Rod: Non existent.

I asked Rod what he enjoys and his responses initially show that he feels it is his choice not to be involved in activities. Ann questions this belief, to which Rod responds that he does not know the limits of his capabilities. He uses a quite flippant perhaps defensive, remark, "I mean I don't know whether I could swing on the chandeliers" (This is reminiscent of the comments made by Daniel and Victoria regarding Daniel's unrealistic self belief – as shown through the Benefits Forms he completed – Section 5.3.2 – Rod also filled in Benefits Forms suggesting a much higher lever of ability than he had at that time). Ann tries to ground Rod with the reality of his situation, pointing out that he was 'unable' to complete a simple practical task. Rod admits at this point, "I'm not doing anything" – which is a personal reflection on Ann's earlier 'nobody' statement. When asked then how he fills his time, Rod paints a very bleak picture of total inactivity. With a sense of irony, Ann points to their weekly meal at a supermarket and uses this as an opportunity to discuss how Rod's incontinence impacts on both of their lives ('It's beyond our control. I can't cope with it, and he can't control it')

Ann finds herself reflecting on her actions during the interview, realising that perhaps it would have been beneficial for her to seek outside support earlier on. By getting a wheelchair, maybe the last years of Rod's life would have been more fulfilling, but it would also have meant the admission and acceptance of Rod's position on a downward trajectory. Each adaptation highlights his decline and points towards the terminal nature of his condition. Emotional survival can rely on maintaining a positive outlook and it could be argued that seeking help means applying labels

(Section 4.4.2) and makes the problems of disability more visible than if support needs are ignored.

Ann: I mean, we've had to stop a lot of things, I mean we used to love going round museums, didn't we? Country houses, parks all things like that. But because Rod was so unpredictable with his falls, you know, ermm.. there's a lot of expensive stuff in those places and we couldn't afford him smashing it all up (laughs). So erm, that all... fell by the by...

Rod: We'll go... Ann: Didn't it?

Rod: Slowly round things. Now we just don't go anywhere.

Ann: And now you haven't got the mobility to do it anyway have you?

Rod: No

Ann: I mean, actually, I suppose looking back, had we looked into getting you a <u>chair</u>, we could have continued doing a lot of those things that we wanted to do.

Rod: Yeah

Ann: But it just never occurred, never thought and we didn't have the, I hadn't gone looking for the help that we needed.

YEAH

Ann: Er, because we were coping, erm, it didn't occur to me, that if. You know, it's only looking back right at this minute, when Rod did have better control that we could have gone out with a chair and gone round these places because they do accommodate these days with ramps and etcetera. Erm, so in that respect, I'm sorry I missed out on a few things for ya.

Looking at the language, Ann is emphasizing the implications for both Rod and herself. Rod's restricted lifestyle impacts heavily on Ann – it is almost as if she is disabled by association. As the breadth of his life has decreased so has hers. We can see through this discussion though, that there is a clear shift in representation between the limitations belonging to Rod and being the result of absent resources. Ann takes personal responsibility for this (as does Richard's wife – Section 5.2), but perhaps outside agencies should have offered support without the need for a direct request.

7.2 A Recorded Life

During the interview, Ann mentioned that she and Rod had kept diaries since the first incident and she began to quote from them. She offered to lend me this valuable data source and agreed to me making copies. My visit and the arrangement for me to borrow the diaries were noted in that day's entry:

5th July 2002 [A] RED CROSS TO COLLECT ITEMS PHONE 9.30 for info of COLLECT TIME

Collected mid-day.

Liz Dodson (Headway) visited this afternoon, doing research and interview for college work. relaxed, friendly personality and very interesting. Rod & I agree to lend the diaries to give an insight into the realities of our lives and how we cope. This has made an enjoyable distraction.

From this point, Ann knew that I would be reading the diaries – this may have had some small effect on the later content (the final six months) but no clear change in her writing is apparent – perhaps as Ann seemingly always intended the information to have an audience.

It was Rod who initiated the diary keeping after his first fit in July 1997. At first it was a functional record of appointments and seizures. It was a slim-line book and contained at most a short summary of each day. Rod's 1998 diary started off much the same, but he decided after a month to change to a larger A5 book and wrote a longer summary of each day. By 1999 the diary was A4 but as Rod's problems increased he went back to a more simple short summary format. However he added lists of meals from 15th May, exercise 21st-30th September and toileting from 5th October. In the year 2000, Rod continued to write a short summary of each day, also writing notes on toileting and meals. This was sustained through to 2001. The lists tailed off though, he wrote notes on meals to 27th April, toileting to 23rd June and snacks to 15th July. On Ann's suggestion, he began a health routines checklist from 16th October, this was designed to help him remember whether he had completed various tasks such as taking medication and caring for his feet (due to diabetes related problems). The 2002 journal shows increasingly repetitive short summaries but these entries were extended substantially when Ann took over for good. Rod stopped keeping the health routines checklist after 26th March when Ann realised that he had been copying earlier entries rather than using the checklist as a memory aid. Ann used the diaries as a record of crises, care interventions, and daily struggles; with time she also incorporated personal feelings. In the latter months, the diary became a minimal record of Rod's condition following the handover of his care to a nursing home. The diary was concluded following Rod's funeral.

The existence of the diaries was first introduced during the interview when Ann used them as a reference point to find out when Rod started at Headway and even before she is asked about the diaries, Ann is justifying her decision to take over the responsibility of completing them:

Ann: I'm just trying to find out where all this started (leafing through old diary)
April... Well Rod used to keep this diary, but it's very repetitious, like, (very monotonous slow tone) "Up at 7:45 came downstairs had pills and tablets, washed and dried and greased had breakfast...had wash... and had a wash and a shave... had a seizure early in the morning, came down stairs and did the diary bring it up to date", sort of thing. And that's the same day after day after day...
YEAH

Ann: Till he gave up. (Sighs) Ohhh... A lot of confusion over tablets and medication so I took over, took over all that and the diary in March, I'm just trying to find out when and where. Oh yeah, your first day at erm, Headway was in March.

Ann emphasizes the lack of value in Rod's entries by using a monotonous tone as she reads his words. His diary writings had become repetitive, where the same was written almost every day, regardless of what had actually happened. Ann had hoped that he would use the diaries to keep a tally of when he had taken medications and completed other healthcare tasks, but instead of using the current diary as an immediate record, he just copied the previous day's entry each night (This is reminiscent of the tick-list based memory strategies used by others - Section 4.3.4, which were also unreliable if operated without backup). Ann's first step was to take over the medication as Rod was putting himself at risk. Later she also took over the diaries; at this point their function changed again as Ann tried to keep detailed records of their day to day life and the struggle of dealing with Rod's condition:

Ann: Actually I've started writing so much down that it's difficult to find out exactly what and where

WHAT SORT OF THINGS ARE YOU KEEPING DETAILS OF? Ann: Erm, Rod and his condition, erm... such as "He had a seizure at 6:30 and another at 8:15, he went to bed after seizure, and I took mother", cos his mum was staying with us I took her home. Err.. "When I got back Rod was still resting in bed. 8:10 I called up to see if he was awake. He answered so I told him it was time to take his pills. I then went and did the washing up. Rod didn't come down so I went up to check. All the lights were still out, I put the lights on and found him lying in bed, shaking locked in one position. I dealt with him, dealt with the medications, did a blood test and everything was okay. So I gave him his snack and helped him into bed" and then because he would have had a bath, erm but I took, took him, took his mum home. Erm... it said "Getting out of the bath is getting more diffi, difficult and exhausting. A rest af, on the toilet seat is needed before getting dried. I wrapped him in a towel so that he didn't get chilled. I am now having to help Rod to sit down into the water at the start of his bath as he is no longer able to get beyond a crouched position". You know, these sort of things I'm writing, I mean, if ever you want to have come, if you've got the time to come and have a look at that them you are very welcome.

THAT WOULD BE VERY USEFUL.

Ann: Erm, "Climbing stairs to rest after, to erm rest on the bed after a seizure is very laborious task. Both rails are used to haul the body up the stairs. He's not really aware of anything. He's working on automatic pilot. He stayed in bed so I gave him his 8 o'clock pills, a snack and a drink and a blood test as he said he was cold and was shaking un-controllably. This also happened about 10 days ago but I forgot to make a note of it". Errm, oh there's, there's so many bits in there. Erm, have you got time for this?

The fact that the diaries are no longer useful as quick factual references shows how their purpose has changed. As the depth of recorded thoughts increases, clarity reduces, but they now fulfil the role of telling a story. When Ann was asked what she wrote about, she started to quote directly from her own diary entries, picking an extract that she felt would say something more about Rod's condition. Reading this quote gives some idea of the minutiae that was included. Instead of the seemingly insignificant details being left out, as would be expected in later verbal recall, all time is accounted for around the event described. Examples of this are her mention of doing the washing up while waiting for Rod and taking his mother home once he was in bed.

Ann gives the impression that she is in control of the situation as she 'dealt' with Rod, made an assessment and provided appropriate care. It suggests that although Rod has many problems, Ann is able to cope with them. She has routines that are followed almost automatically and a balance is maintained. However, she goes straight on to discuss the increasing difficulty she has experienced in physically supporting Rod while he has a bath; so boundaries are becoming apparent. It is at this point in the conversation that Ann offered full access to the diaries for this research. She then went on to quote from a different entry that also discusses the increasing physical demands of caring for Rod. Ann's use of the phrase, "Haul the body" is reminiscent of the way others have talked about the person they care for in an inanimate way (e.g. Gordon & Deborah – 'sack of potatoes' – Section 4.4.1.1). It allows distance from the failing body and could be interpreted as making the claim that the patient is less of a 'person'. Ann states that in this instance Rod is, "Not really aware of anything" and that he is, "Working on automatic pilot". She is referring to his post-seizure state but it is difficult to truly state that another person is without any awareness. In some cases though, it is an easier assumption to make than considering the possibility that an active mind may be trapped in a failing body.

Ann was asked why the diary was started and perhaps because the word 'you' was used in the question, she again responded in terms of why she had taken over the diary from Rod, "Because he was writing a load of bloody nonsense". She then expands her answer to explain that the diaries were kept from Rod's first seizures and that they were previously written solely by him:

WHAT PROMPTED YOU TO START THE DIARY?

Ann: Because he was writing a load of bloody nonsense. Erm, Rod, we've got the diaries right from the start of his seizures basically.

Ann: And Rod had always, I didn't always, check what Rod was writing, and I found eventually that he was writing the same things about having his pills doing The daily routine, because he cannot think, and then I was having to start take over his medication, and there were things. My memory's not that clever. And I was having to remember, what was going on so as I could tell the doctor or whoever.

Ann: His medications were changing, erm, and I were forgetting things and missing things out. And to be quite honest his mum, well not just Rod's mum but, when you tell people, erm, how he is or what, you know, you can only tell them so much. Errm. and you can't really express feelings and to be honest a lot of people when they say, "How's things?", "How are you?", they don't really want to know. They've got their own problems, I can't blame em, I can't say as I blame em at all, you know.

It is interesting that she states, "I didn't always, check what Rod was writing". This tells us that it is not simply a personal document, an outlet for thoughts and feelings. If it is important that what Rod writes is significant and accurate that it must be seen as an active reminder of events or as a record for other people. This view is backed up by Ann's extended explanation about Rod failing to use the diary to keep track of his daily routines and she suggests that she needed to use them for this purpose when she took over the responsibility of his medication. Ann also talks about her lack of outlets to discuss fully the day-to-day problems faced by herself and Rod. The diaries serve as an alternative outlet and also as a way, at some indefinable time in the future, to tell people who may not want, or be able, to listen now.

7.2.1 Significant Incidents

In this section a range of significant incidents will be presented as markers of Rod's downward trajectory. This will follow the established Strauss (1988) model, relating also into issues raised by this thesis. It should be noted that all diary excerpts are copied exactly with spelling and punctuation unchanged; the only exception being that names have been altered to protect the identities of those involved.

Starting with his initial seizure:

9th July 1997

[R] 7.30 to 8.30 Hexham Hos. Blood Test X Ray Discharged

This is Rod's first diary entry, all pages prior to this date are blank. This indicates that the purpose of the diary is to record appointments and events around Rod's as yet undiagnosed illness. Although the tumour must have existed for some time, it is the first symptoms and related actions that mark the trajectory onset. Over the next six months, entries were consistently sparse, comprising of brief notes of seizures, visits to the doctor and places that Rod walked to. The next year Rod acquired a larger diary and in line with this, the length of his entries increased. Although the trajectory of illness had begun, Rod continued to go about his life. It was six months after the first seizure that Rod entered what could be defined as a crisis phase - as the cause of his symptoms was identified as a tumour. Rod noted in January that he attended hospital for a brain scan:

15th January 1998

[R] Up just after 9.00

Took prescription into Docs Back via chemist's & Buzzie Bee Had bath & shave. Waited for Ann to come Home to take me to LRI for scan. Arrived at LRI 2·30 Long Queue for Car Park Got in for scan at 3·15 approx

Weird. Relaxed Keeped Eyes Shut

Had Dye Injection. Missed the first 1. 2nd OK

Went to see Mother then Home

He is now using his diary to record wider events although they are all related to his illness – sorting his prescription, going to the chemists, reporting to his mother. The illness is a part of his life but not yet his whole life. There is also a small move towards recording feelings in that Rod described the scanning experience as weird. It was another month before Rod got the results from his scan and the brain tumour was diagnosed:

12th February 1998

[R] Pills at 9.00 up by 9.15

Breakfast then into Lough.

Saw Doc. Have got Tumor on R/H side of brain Epilepsy is the way to control it, nothing to be done until prity regular pain in head. Up Pills to 1500mg N&M

Had dinner in Café then went over to Mothers to tell her.

Attack about 7.00pm.

The wording of this entry is a little confused but it is meant as a straightforward account of the facts. Rod mentions that he went to tell his mother about the diagnosis but there is no discussion of the conversation they had or feelings of the day. In the following months, Rod's life settled into a stable pattern (or phase) where he had regular fits but went about his daily life as best as he could. No longer able to work, his days centred around relaxing at home and walking in the local area. With his changed status from breadwinner, to disabled, the dynamics of his relationship with Ann shifted and his life seemed increasingly controlled by his condition. The following entries are from three consecutive days in August that were significant to Rod, in that he regained a feeling of control and autonomy from the events that occurred. On the 16th, Rod highlights feelings of nausea and problems going to sleep, this has been ongoing for several days. The key difference is that Rod identifies his medication as a possible source of this malaise and makes a list of what he believes is going wrong:

16th August 1998

[R] Woke 8.30 Pills at 9.00 Up 9.05

Breakfast refilled pill boxes

Feel a little bit queasy. Ann Replaced doors made out list of things that are going wrong with the new pill. Made some errors with Ann. She needed some space and I <u>didnot</u> realize it. I'm trying to remember everything but unfortunately I have a short term memory problem. Watched

Grand Prix. Had tea. Ann had a bath at about 8.00. Have had a sickish feeling for most of the day nothing serious just a faint background sickness. Went to bed 10.30. Ann made another coffee. gone 12.00 before I lay down to go to sleep I think it was nearly 1.30 before I slept

getting tingling in R/Hand palm

The next day, he is active and motivated. He does some work around the house and then goes to see his doctor. They negotiate a dosage change on which he writes, "We would go back on the dose" and, "We could build it up that way". This highlights his own agency in this process.

17th August 1998

[R] Pills 9.05 Up 9-10 Breakfast

Cleared shelves over sink. moved mugs at other end to shelves above the oppersite wall where chimmny breast has been removed. Put ca'ving on shelves. Arrows up cross tray Tools in a box. blocks of wood. Ann to help me bring down. Had dinner Shaved. went down to see Doc D. had a chat. Decided that we would go back on the dose as his book sais & see if we could build it up that way. should be at full dose just before next meeting with Doc C.

Pills are deffinatly the cause of the change in my sleep patterns. now back to patter of pre epilepsy ddays

went bed 10·15 did get to sleep till gone 1. Woke at 7·15.

Although the events of the previous two days may not strike the reader as in any way striking or unusual they bear great significance to Rod, as illustrates in his next entry:

18th August 1998

[R] Woke 7.15 Up at 8.15 Pill 9.00

Breakfast. going into Loughborough to get boots reheeled, coat cleaned & othe weeks coat should be ready on Thursday.

Boots split across sole. needs new sole unit Be ready in about a fortnight. Went to Boots. They have to order Small & Ex Large Hopefully by the end of the week. Had a McDonalds shake then had a look at the recliner up by the taxi rank. Caught bus home. Got of in village and picked up bunnie bits plus looe rolls, and other bits. Still a struggle comming up the hill. Fire engines dousing the field at the top of Holmfield Rd. Did one-or-two bits but was quite worn out by 2-30. Up until 5-30 no attack.

Ann didnot arrive home till 7·15, but dinner was ok. Bit of chaos at work. Had dinner watched TV till 10·00. Ann feed Bunnies whilst I did washing up.

We had a bit of a chat and I told her what I had decided, over the last 2 days. I don't what has happened, I only know that somewhere in the last 2 days My life has been returned whowever temperorally to MY control, and that's where its going to to to stay.

Went to bed and having read the paper went almost straight to sleep.

Rod's entry on the 18th really shows how the diary has developed since its initial beginnings. It started as a record of medical facts, but now reports on much wider events – as such it is now a record of Rod's life. The question is – does this merely reflect an expansion of Rod's biographical interests or is it more of an indicator that his tumour now affects all aspects of his life? To record that he has independently been into town and completed various tasks is to record that he is still capable of these things. They become markers of his ability and his current state of health. The fact that he reports on Ann's separate day also shows an awareness and interest outside of his personal experiences, although it is recorded in relation to the way that Ann's problems impacted on his day, i.e. the lateness of his tea!

Just taking Rod's piece on the impact of the past couple of days:

We had a bit of a chat and I told her what I had decided, over the last 2 days. I don't what has happened, I only know that somewhere in the last 2 days My life has been returned whowever temperorally to MY control, and that's where its going to to stay.

We can see that something has changed for him. He now feels in control of his life, so what has brought this about? It seems that by taking some control over the dosage of his medication, and perhaps by doing more independent tasks, he feels an autonomy that has been missing from his life. Of course the existence of the brain tumour and its degenerative effects means that Rod does not have as much power over his life as most people. The control he feels is that of self-determination on a day-today basis. He recognises that this state of being may be temporary, but at the same time makes the powerful statement that his life is going to stay in his control.

Over the next year, life continues at a stable pace, but then on 6th September 1999, Rod enters an acute phase:

6th September 1999

[R] Up at 8.00 Pills Breakfast

8.15 Attack Feel in Kitchen ([A] corrects to FELL IN KITCHEN) Wet pants at same time. Just had rollicking to give ups safe flow to give up us tieghter guaititaire a lighg tergegton to score across the the board to give use foppratre zero

[A] Just to put the record straight:-

attack approx 8.15am in kitchen. fell. wet pants. confused and unsteady on feet. 10.00am go to Loughborough. wet pants in car. (you) go J.S.H. have coffee - sandwich - I get you incontinence pants & pads and new joggers. (you) go to disabled toilet to change - have another attack - come out looking lost, disheveled and unsteady. I get you to a seat. you return to toilet, fast: return home. no bladder controll at all. continuous "visits" to toilet all day. I Phone doctor & take urine sample (bloody). inform her of all the symptoms, conclusion:- bladder infection - anti-biotics prescribed.

Above mentioned rollicking was because as you went to go to the toilet (again), I told you not to put the 'pad' down the toilet but to bring it down stairs with you and dispose of it in the dust bin. As you came down the stairs I went into the bathroom& found that you had done the very thing I had said not to do, I had even explained why - but you 'forgot'____.

Got you to have another go at a crossword puzzle - your responses are slow and confused, even with a

lot of help your thought processes are not rational.

Go to bed at 8.00 pm. - still ^ getting up at intervals to go to the toilet. - see what to-morrow brings!

Rod's entry here is somewhat confused as it was made soon after he had a seizure. Ann therefore decided to 'put the record straight' and for the first time she took charge of the diary for several days – perhaps reflecting her increasing role as a control agent in caring for Rod. In this piece of text, she emphasizes how she takes charge of the situation when Rod wets himself. She portrays Rod as having little

agency as she organizes everything around him and gives him a 'rollicking' for not following her instructions. In his confused state, she is the stabilising influence with an element in their relationship of what might be seen as parent-child dynamics. Over the next few days, Rod is hit hard by his bladder infection and Ann finds herself providing almost 24 hour care as she continually gets up to help him in the night.

By the 11th September, Rod is much improved and again takes control of the diary.

He appears to be entering another stable phase but then has a crisis incident just over a fortnight later when he collapses into the pond and has to be rescued by his neighbour:

27th September 1999

[R] Up at 8.20 Pills Breakfast Went out to part time look about. MAM & ANN went of to the town. Went for meal & then upstairs for Art Class. Ann came in at 2.00 to let me know that they'd be be backby 3.30. Came home and had coffee. Took Mother home and then cam home ourselves. Did 12 trips down the garden after todue I collapsed into the pond. Jessica heard dogs making a noise and came to investigate. She found me with apprently my head under water and about ¼ of my body also under water. Pulled me out and took me up the garden. Don't remember anything until the next morning.

[A] 12 TRIPS DOWN GARDEN AND A 'SWIM' IN THE POND!!

Approx 6pm. JESSICA'S dogs began barking FURIOUSLY

she went to investigate and found you in the pond <u>head and shoulders under the water</u>. She helped you to pull yourself out and helped you up the garden. You are <u>very</u> lucky, you nearly drowned yourself because you <u>just don't think!</u>

10.40? Called emergency doctor because you were shaking uncontrollably and breathing fast and shallow. Told to call Para-Medics to check you over. — probable shock from falling in pond — given the all clear.

Rod made a note of the incident but Ann felt the need to also add her own comments. This event was of sufficient importance for Ann to make this response because it put Rod's life at risk. She blames him for this because he did not avoid walking near the pond ('you just don't think'), but this means that she expects him to restrict his lifestyle to maintain his life. Paramedics were called and Rod was 'given the all clear'. Attached to this diary page was a copy of a letter that Ann sent to thank their neighbour for helping Rod. This copy was handwritten, and Ann obviously thought it a sufficiently important record to be preserved:

Letter regarding the incident on 27th September:

Dear Jessica

We both owe you so much that 'thank you' hardly seems adequate.

I think this has come as quite a shock to Rod, realising just how close he came to drowning himself.

Over the past two years I have asked then told him time & time again – don't go near fire – don't go near water – don't overfill your bath and don't take boiling water of the stove, but of course I don't know what I'm talking about and he knows it all!

Well, he's just had such a talking to plus the upset of what has happened that I think he is feeling quite sorry for himself. He's definitely got a lot to think about. He owes you his life – he couldn't have got out on his own. I've made him very aware of this fact.

and all we can say

is

THANK YOU

so very much.

Ann.

This turns quickly from a letter of thanks to an expression of despair over the dangers that Rod places himself in. Perhaps this was saved to reinforce to Rod, Ann's concerns about him ignoring (or forgetting) her advice. This letter again gives insight into their changing relationship ('He's just had such a talking to') and also the reasons for Ann taking an increasingly control oriented role.

Life settles down again into another stable phase and over the next few months Rod begins to regain a sense of agency. This is illustrated in entries such as the following:

23rd March 2000

[R] Up at 8.00 Medication Breakfast Wash and shaved ready to go to see Dr Smith. Went down to Buzzie Bee's for a paper. Went to Hospital Saw a new Doctor. Had nearly 1hr with her. Have decided that I will increase the phenobarbiton to 3 tablets at night. Try it for 3 · 4 weeks, if it lowers attacks, carry on; if not discontinue. Patches on my legs are probably dry skin suggested I use E45 Cream. If it doesn't clear in a month see Doctor of a short course of steroid cream. Left at 1.25 and came home. I felt that this was a good meeting, probably because I was listening to what she said. Next appointment in 4 months.

Came home and had coffee & biscuits.

Relaxed during last part of afternoon. Had tea & watched Pet Rescue. Watched TV from 8.00 till 10.20. Bed Coffee.

Looe Visits

Visits have been tight up till 3.00 Was still a little tight up till evening

Breakfast

Branflakes Coffee

Dinner

Toast & Marmalade (2) Coffee

Tea

Pizza Baked Beans, Rice & Banna + Ice Cream. flavoured Water.

Apple Orange Pear

Rod's wording suggests that he was involved in his medical consultation rather than simply present ('Have decided that I will increase the phenobarbiton'). He notes that

this 'was a good meeting' as he was 'listening to what she said'. He felt involved in dealing with his needs and this was a positive experience. This excerpt also shows how the purpose of the diary has extended to include toilet visits and food intake. Perhaps as Rod's life becomes more insular this demonstrates his changing focus towards elements of the day that most would overlook.

Disability and the demands of caring can put a strain on a relationship, and after brain injury, many relationships fail. Visiting the Relate counsellors a month later, is a sign that Rod and Ann have had some difficulties adjusting to the changes in their partnership, but that they are finding constructive ways to address this:

5th April 2000

[R] Up at 8.00 Medication Breakfast

Went down into Village at 9.00. Took prescription in. Picked up paper. Came back towards home. Got 3/4 way up Park Rd Had a seizure. 2 people helped me up. Carried on home. Had dinner Went to Mothers. Ann came home whilst I stopped there. Had tea then caught bus to meeting. Arranged Walk details. Ann picked Jane & I up at 9.30

Dropped Jane of then came home. Bed Coffee.

Pills not taken till 10·15pm, but felt no ill effects.

Went to JSH to see Relate Counsellors (2)

Spent 2hrs with them and got a good start in clearing up my stress problem. Was very good because we were the only 2 people there and so had both the counsellors to ourselves although they were there mainly for me.

Breakfast

Branflakes Bannana Coffee

Dinner

Tea

2 Eggs. Bread. Jelly fruit Ice Cream Coffee

Apple Orange Pear, Not eaten

It is particularly interesting to note the way in which Rod represents this meeting with phrases such as, "Got a good start in clearing up my stress problem" and, "Had both the counsellors to ourselves although they were there mainly for me". It is difficult to identify the root of this perception but perhaps as Rod's problems are more visible (and indeed socially acceptable) than Ann's, he will become the natural target of any joint intervention.

The needs of the carer are often overlooked as they are expected to cope with their situation. The patient may be assumed to be the one who is struggling and in need while the carer is 'lucky' not to be in their situation. However it may well be that the carer has a far greater awareness of the changes that have taken place than the patient, as brain injury often reduces insight. Coping with these changes is in itself difficult, but there is also the added stress of choice. It is classically assumed to be psychologically favourable to have some control over a situation, but when carers consider the options in which they would no longer have to fulfil the caring role, they are confronted with feelings of guilt and even despair. Partners can leave, parents can put their child into residential care, maybe the patient will die; but to entertain these thoughts can add to the stress and strain of being a carer.

Also to be noted from this diary excerpt, seizures are now reported as part of everyday life, creating only minor interruptions in otherwise uneventful days. Not only is food intake recorded but now Rod is mentioning things he hasn't eaten. As the scope of Rod's life slowly closes inwards, anything like food, which breaks up the day, takes on increasing importance.

A few days later Rod made two diary entries that are particularly interesting because they cover the same day. It seems that Rod recorded nothing on the 9th April and so seeing the blank page took that as the next day when making his entry for the 10th. When he realised what he had done, he wrote a note that this should be moved to 10th April, but wrote a subtly different record of the same events on the following page.

9th April 2000

[R] Up at 8.00 Medication Breakfast Move to page 10/04/2000

WASHED up. Ann ran me into Loughborough to the College to sort out my enrolment. Papers not correct but I may get a reduction because I don't pay Council tax

Onto JSH for dinner & then Art Class. Went into Town. Picked up money & fruit. Collapsed into Townsends Window. Had ambulance but declined a trip into LRI. Came out of ambulance and saw the damage I done to the window. Spoke to one of the girls but she said they would deal with it. Went into the Carrilon Centre but neither shop had any plaster. Came home getting in at 5.00. had teas then watched TV. Ann ran me into Browns Lane for 8.00. Had an interesting evening. Going swimming on Sunday. Came home at 10.20 Bed and Coffee

Looe Visits

Feaces still hardish but Visits to the toilet were down

today

Breakfast

Branflakes Bannana Coffee

Dinner	Steak & Kidney Pie Potatoes Veg Spotted Dick & Custard
Tea	Chicken Curry Rich Peas
Pear	

Rod had a grand-mal seizure in which he collapsed into a window. The ambulance was called but as fits were by now commonplace, he sent them away. In both diary entries, Rod places this incident within his normal daily routine as if it is simply another hour of his life:

10th April 2000

[R] Up at 8.00 Medication Breakfast

Got ready to go into Loughborough. Visit college No rebate but as I dont pay Poll TAX they could only charge Reg fee. Onto J.S.H. Had dinner then went to Art Class. Came out at 3·20 Walked into town. Picked up money from the Bank then fruit from just round the corner. Started to walk to the Carillon when I had a seizure. Out for a few minutes. Ambulance sent for and I recovered quite rapidly. They wanted to take me to LRI, but I pointed out there was nothing they could do for me so it was pointless. Carried on shopping and then caught the 4·10 home. Got home at 5·00 Had tea and the watched Farscape. Watched other programes latter on. Went to Foxes at 7·30 Stayed till 10·15 then came home. Went to bed Coffee

Looe Visits

Still tight but no pain

Breakfast

Branflakes Coffee Steak & Kidney Pie

Steak &

Dinner Chicken Potatoes Veg Sponge

Pudding & Custard

Tea

Chicken Curry Rice

Pear

In the second entry, Rod makes no mention of damaging the shop window or of Ann's involvement in the day. This recollection seems to portray him as more independent and the day's major incident as less serious. Bearing in mind that seizures are reported as commonplace events, his statement, "Started to walk to the Carillon when I had a seizure", is less striking than his first recollection, when he writes, "Collapsed into Townsends Window". The differences between these two versions perhaps indicate that the second account is managing Rod's accountability for the events described. The second entry demonstrates that Rod does not always complete the diary as events happen, or even on the same day. The following excerpt further highlights the retrospective nature of the diary:

20th June 2000

[R] Up at 8.00 Medication Breakfast

Went to looe before going into Leicester No Feaces Played Table Tennis at YMCA then went to the Granby for dinner Walked back to ST Margarets and waited for a bus. At this point in time I felt no need to use the looe. Caught the bus home and got of at 1.57. Walked Home. As I got within 30 yards of the house my bowels began to let go and there was nothing I could do to stop them. By the time I reached the looe, all the feaces had left my body

I'm not really sure how I feel about my lack of control, but obviersly I have got to start taking stock of this problem. I am going to have to go to the looe more often and hopefully this will remove the stress on my bowels. I'm also concerned that I could have an attack away from home in a shop or in the town centre where I might have a real problem dealing with it. I am going to have to use looes whenever I see them \checkmark .

Breakfast

Oat crunch Coffee

Dinner

Bangers & Mash Cake (3)

Tea

Sandwiches Cake

Apple Orange Pear

Rod shows insight and concern about the very sensitive issue of incontinence, but at the end of his private monologue there is a tick, suggesting that this writing was actually a record of a discussion he had with his wife and that she probably asked him to record his thoughts. This became a routine between them, that when Ann felt important issues had been raised, that Rod needed to understand and remember, she would ask him to make a record of it in the diary or she would write a note herself.

It was in June that Rod was diagnosed as having diabetes, an added complication that further increased his dependence on Ann. Like Ben, he now had a complex health routine to follow that was difficult for him to manage independently (Section 5.3.2) Related to this, Rod became very ill, entering an unstable phase of illness through the second half of July, during which Ann again took control of the diary. He was unable to manage his insulin and Ann performed her first injection on 21st July, giving her a new medical role. Rod did try to take responsibility for his medication again from 1st August on the condition that he was monitored by his wife. He was never again truly independent in this.

Three weeks later it was Rod's birthday. This is the only entry that mentions a private event such as this:

21st August 2001

[R] Up a 7.45 Medication

Came downstairs. Had Insulin Injection. Washed feet. Had Breakfast. Rang Mother to thank her for my Birthday Card. Also thanked Ann. Caught the 9.45 to Leics 3 days of a dry throat combined with 3 days of the coughing. Dry throught. Played Table Tennies till 12.00 then went to the Granby Had Dinner then came home. Went to Tesco's at 5.00. Went shopping Had siezure st about 5.15 lasted normal length of time. Had tea then came home. Put groceries away then watched Video + TV.

[A] you had just picked up a tray of 12 eggs and was inspecting them – this always bothers me – for obvious reasons. I took them from you and said "for goodness sake use some common sense". I put them into the trolly then turned round to see where you were ———— you were still in the same spot – in front of the egg shelf – with a glazed look on your face. I managed to get between you and the eggs and steady your fall to the floor.

IF YOU HAD BEEN ON YOUR OWN, AND AT THE CASH DISPENCER – HAVING JUST TAKEN OUT £??? THE MONEY AND YOU CARD COULD EASILY HAVE BEEN LOST OR STOLEN!

THINK ABOUT IT

This is a fairly standard entry, but Ann adds details of the seizure that Rod mentioned. Again we see another instance of Rod being scolded as if he were a child ('for goodness sake use some common sense') — which Ann would argue is the only way to get through to him when he puts himself in potentially damaging or dangerous situations. She relates Rod's lack of control around the time of a seizure to the potential consequences of using a cash machine — suggesting that he should further restrict his independence in order to reduce the risks that he faces.

Over the next couple of months, Rod suffers from what Ann terms 'extreme lethargy'. He has further medication problems due to forgetting and Ann also found that he was not recording all seizures after finding unexplained bruises in October. The following month, Rod reflected back over the previous weeks:

9th November 2001

[R] Had talk with Ann regarding various problems. Decided that the problems I have got all stem from the idea that because I got One more problem, I thrown the whole system into a "Mess". Needed to talk to Ann about the problem and then to decide what I'm going to do about them I've decided that I'm going to go back a month or two, and start from there, when I had no real problems and forget the last 2 months, and start again today. So as from today, everything is back to normal.

[A] Not been able to wash feet all week untill today, due to aches & pains from two falls last week

[R] Seizure 3.45

T | F/T B/T R V | | | | | | | | | |

As can be seen, Rod is now completing the checklist suggested by Ann with six regular tasks to remember, tablets, insulin, foot-care, blood test, regulon and vaseline. He states in this entry that he is, "Going to go back a month or two, and start from there, when I had no real problems and forget the last 2 months, and start again today. So as from today, everything is back to normal". To say that he had no real problems two months ago is a comparative measure, as is 'back to normal'. Life is measured on a new scale that relates to Rod's illness, showing that he has accepted the tumour and its effects (Section 4.4.4).

Four days later Rod is actually told to make a diary entry regarding his behaviour and a lecture that he received:

Ann is deeply concerned that Rod is risking the level of health that he has by not controlling his diabetes. An example has already been presented of Ann ticking an entry that Rod made. This gives further evidence of the diary acting as a log of agreements made between Rod and his wife. As his memory becomes increasingly

erratic, the diary provides a concrete external record of his past (as seen with Lynne – Section 4.3.4). He revealed however that reading it meant little as he had no internal memory to relate to it and without recognition he felt quite detached from these documents (reminiscent of Rachel's comments – Section 4.3.2). This again raises the issue of purpose – as it seems that for Rod the diaries have become more of a routine than a personally driven need to write. This does not mean however that Rod is without insight, as this next excerpt demonstrates:

26th November 2001

[R] Up at 7.45. Injec and Pills at breakfast at 8.45. Rang doctors at 9.00 for blood test. Rering for an appointment with a Doctor. Booked an appintment at Wed at 9.00. Went into Loughborough at 11.00. Went to aTesco. Picked up groceries then went up to Art class. Left at 3.30 & came home. Got in at 4.00. had a conversatation with Ann, which was against my grain but was in a way, the way I'm feeling at the moment. I feel as though I have lots of things going on for me, that I don't know exactly what I'm doing, or where I'm going.

Had dinner & washed up. I went to bed about 6.00. Woke at 8.00 to go to the looe. Back to bed and slept till 9.30. Had cereal and spent some time talking to Ann. I think Ive finally sorted out my general life but will need time to sort out the little things

Slept through till 7.45am.

T	1	F	B/T	R	V
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Following a conversation with Ann, Rod writes of his confusion ('I feel as though I have lots of things going on for me, that I don't know exactly what I'm doing, or where I'm going'). He talks again about his life being sorted but it is difficult to define what he means by this. Perhaps he feels the need to re-evaluate his position as he travels along the trajectory, taking time to understand his changed self through a steadily shifting pattern of illness and care.

In Chapter 4 we saw the issue of memory discussed at length, including cases of false memory. Rod too would forget what happened in the past and so in his diaries he would sometimes fill the gaps with what he believed to be true. Ann however sometimes challenges these records, as below:

[A] I don't think so 8.00 as I remember it!

18th March 2001

[R] Up at 8.00. Pills Breakfast

Went down to Buzzie Bee's at 11.00. Picked up paper biscuits yoghurts. Walked home Ann got up about 12.00 Made Dinner. Had dinner and washed up. Had steady afternoon. Had tea Watched TV till 8 25 Coffee Bed.

28th February 2002

[R] Up at 7.45. Came down for Pills & Injection. Washed dried & greased feet. Had breakfast then washed & dried pots.

Had dinner at 12.30, the washed up at 1.30. [A]?

[R] Had Tea at 5.30 and washed up at 6.30

Went to bed at 10.00pm

[A]? dinner at J.S.H. with Tom. I gave you a lift into town then picked you up at 1.30

These could be seen simply as markers of Rod's confusion, but when his memory is stored externally, reconstructed 'facts' become his past. Ann seems concerned that this past should be truthful and therefore she corrects his mistakes. These entries provide further examples of Ann checking what Rod writes and showing more elements of the control level of agency by using Rod's private resource to make shared understandings. Ann also wrote in Rod's diary when he forgot to make entries:

12th March 2002

[R] Up at 7.45. Pills & Injection. Came downstairs and washed feet. Dried them & greased them. Had breakfast and washed pots & dried them. Washed & shaved & got ready to go to Leics. Wash ready to go at 9.45. Taxi arrived at 9.50, took me and another person to Headway House. Was met at Headwouse and shown around. Meet staff then started on a clay job. Had dinner at 12.30 then started playing a card game. Came home he about 3.00 & got in at 3.30. Had a good day out. Had Injection at 5.00 & tea at 5.30.

[A] you had a good and interesting day – your first at the day centre
a Taxi to pick you up. friendly helpful people to greet you, a morning doing some clay work, lunch, a
card game in the afternoon. new faces, enjoyable atmosphere, and another taxi to bring you home.
You said that you thoroughly enjoyed it. And what have you writen about it? a big fat ZERO!

[A] (10.45pm 13.3.02) 'R' has written the above notes on Thursday after reading my comments.

[R] Had Mini Seizure 1 at 8:00

T I B/T F/T R V

As this extract explains, Rod made a diary entry based on what Ann had already written. This is perhaps a personal response to Ann's complaint – as he is now expected to make entries as part of his daily 'work'. Less than three weeks later however, Ann took over the responsibility of the diaries for good. During the interim time, Rod had further medication problems and then between April and May 2002 he was hospitalised for a month. On 7th May his doctor phoned Ann, "To confirm our request that no CPR is to be carried out". This marks recognition of the downward trajectory ahead. All hope however, was not yet lost.

Interview extracts have already been presented, referring to Rod's decision to have a biopsy of the brain tumour done, with a view to having treatment. This diary piece covers the same decision, but was obviously recorded at the time. The tone of this closely matches Ann's viewpoint as expressed in the interview. Again she emphasizes a rapid change in Rod's opinion from not wanting surgery to arranging an appointment as a result of the consultant's influence.

9th May 2002

[A] Appointment with DR Smith as arranged = taken to & from appt. by ambulance. Advised that <u>now</u> would be a good time to have another scan and then proceed with appropriate action chemo/radio therapy and pos. an op to reduce the tumor. Appointments to be received via post.

Disability parking badge arrived in morning post.

Red cross delivered toilet seat/frame combination. 2.30pm-

Phoned Lex garage & fitted new fuel injector – problem not solved possibly fuel pump which is situated in the tank. phone again tomorrow for update.

Up to the time when we saw DR Smith, Rod was sure that he didn't want any treatment other than pills.* We had spoken quite often over the years – the pro's & con's – and the answer was always the same. Less than five mins with Doc. C. and Rod did a complete turnabout. His comment being "lets get on with it." when asked how I felt about it my reply was that I would support Rod whatever his decision.

* to controll the epilepsy

Having reiterated her impressions of Rod's decision to have treatment, Ann also demonstrates a further use of the diary by noting non-medical events. Perhaps this is a reminder to share with Rod. Two months later I conducted the interview and plans were still in place for future medical intervention. A few weeks later however, Rod's health became unstable again. He had another period in hospital and then a fall within

2½ hours of returning home. Ann describes the physical steps involved in getting Rod up after this fall and his reaction to a similar incident the following day, "I don't understand it – what is happening to me?"

Moving into August, Ann makes and entry about her agency in Rod's care and his fluctuating levels of ability:

6th August 2002

[A] Rod admits to being shamed into doing some exercises. During Mothers visit yesterday I told her that I was fed up asking and trying to help and encourage 'R' to do some physio. Ever since he started having problems related to the diabetes — no — right from day ONE, at the onset of his medical problems, I have tried to guide, help, support, encourage, push, nag, talk and show him how to get the best out of the years ahead, and, basicaly, he has chosen to ignore all my efforts. He will take what I give, he will accept what I do provided he doesn't have to make a contribution or effort, with help he actually did a series of step and walking exercises and even managed to walk down the garden. What I find unexplainable is that, having found it necessary to use the walking frame — even for a few paces, or require my assistance to get down the patio steps and walk the garden, he suddenly found "power" to negotiate the back step, pick up the rubbish bag, back up the step, through the house through the awkward front door and porch door, down another step and deposit said rubbish bag outside for the dust man, and then return to his chair — unaided? About half an hour later — bed time — he used the frame to get from chair to bed — half a dozen or so steps — He just don't make sense! This little escapade was performed without my knowledge — I was in the garden at the time. There have been odd attempts at co-operation, but they have been very short lived.

Ann presents Rod as having made an active decision to ignore her efforts to, "Guide, help, support, encourage, push, nag, talk and show him how to get the best out of the years ahead". We may interpret this as Ann indicating different levels of agency from support to control, with Rod taking a strategy of acceptance that does not require him to push beyond his illness. Rod has spoken of an increasing lack of motivation and this is likely to have a neurological basis, but Ann sees him as unwilling rather than unable to cooperate. As evidence she cites sudden shifts in apparent ability where he will independently complete a task which for him is physically demanding, but then slip back into a dependent role less than an hour later. Is it possible that sometimes Rod forgets his own limitations? This would explain many incidents where Ann accuses him of not thinking about the potential consequences of his actions, such as trying to get out of the car unaided, walking close to the pond and holding breakables when out shopping. Sometimes, forgetting can put him into dangerous situations, but it seems that it can also break down a psychological barrier as to his level of capability. By August 2002 however, Rod's limitations were greatly increased. With decreased mobility and double incontinence he was increasingly restricted to the house. Attempts to bath him became less frequent as paramedics would inevitably be called to help get him out. Early on, Rod had been determined to

get on with his life as much as possible but now his time was built around illness and therefore Ann's days were built around supporting him. On a constant day-in day-out basis this became an emotionally draining experience for Ann and she began to express feelings of not coping and thoughts about Rod going into residential care:

15th August 2002

[A] Quiet day? Rod bed rest most of afternoon – check him at about 5pm for insulin injection – double incont. takes nearly an hour to clean and clean up.

My body and my mind are having difficulty adjusting to _____ everything! Over the years, and especially since October last year, I have taken each incident as it comes, dealt with it and carried on – a minor, temperary problem. Even with decreasing mobility it was "nothing we can't handle." But now I have to face the fact that I can't, and that is scarey and worrying, the thought of leaving him in someone elses care – It isn't some one though, is it? It is a team a group of people. I feel so mixed up with for and against each situation.

I feel unsettled at the thought of letting Rod go into a home and I can't cope much longer with the alternative – Guess I'll be 'guilty' either way! If, as predicted, Rod lives another fifteen years, I will be 75 – (if I survive that long) what happens then? 'Smokey' my big furry tranquilizer, has kept me sane, but even she can't help with the physical efforts required. – That's enough personal stuff!

The thought that she cannot cope is 'scary'. Rod is her much loved husband and she does not want him to be looked after by others, but she knows that despite earlier beliefs, she can no longer be his carer. Physically, as he becomes less mobile, she struggles to support his weight and emotionally she is running out of the resources to both help Rod and to care for herself. She expresses feelings of guilt, but having provided five years of care, she cannot face a predicted fifteen more, especially if age weakens her own body. She refers to her one escape, a pet rabbit from whom she gets emotional comfort, but as she states, this does not make her any more able to cope with the increasing physical exertion of looking after her husband. That evening Ann managed to take some time out to go shopping, leaving Rod in the care of a neighbour. It seems that this acted as a catalyst for Rod to begin talking and issues that he had bottled up in Ann's presence, were now shared:

16th August 2002

[A] [Tracey] – neighbour, sat with Rod yesterday evening whilst I did some shopping, then stayed on for another hour talking with him – I stayed out of the way as I picked up on the fact that Rod was better able to communicate if I was not present. As a direct result, this morning Rod was able to tell me some of his problems, for the first time ever.

After Rod seemingly rediscovered his own agency, talking at length about his problems, he then felt able to approach Ann with his concerns. Ann's strategy to this point had reflected the early instructions of the paramedic, where she gave orders and took control in order to ensure that Rod listened and responded. In this dominant-

passive dynamic, Rod became less able to communicate and may see that it was only outside of this relationship that he 'found his voice'. Ann was surprised to discover that Rod's communication abilities were much greater than she had thought.

Assumptions that he was unable to manage conversation were shattered by the realisation that he had simply felt unable to share his feelings. This realisation and its consequences extended into the following day:

17th August 2002

[A] Lots more talking

Seizure 8.45pm

The floodgates had opened and now Rod and Ann had regained some element of their pre-trajectory relationship as they were now talking on a level – as partners rather than as patient and carer. Three days later, Rod announced his decision that Ann should no longer be responsible for providing full-time care:

20th August 2002

[A] Doctor Clarke very supportive given us advice and direction for us to consider. Rod has made the incredibly brave decision that going into an appropriate care-home is the way forward, whilst social services have been very helpful the direction of the help is no longer suitable to Rod's requirements and a different approach is now needed.

All unimportant appointments are to be cancelled. others to be re-dated, as Radiotherapy treatment takes priority.

After lots of talking between Rod and his wife, Rod announced that he would prefer to be residential care. Plans were underway for extending and adapting their house to accommodate Rod's increasing needs, but although the physical environment would have been much improved, the burden of care would still have fallen mainly on Ann. She writes that, "Rod has made the incredibly brave decision that going into an appropriate care-home is the way forward". He is depicted as having all of the agency in this decision. Less than two months later, entry into a downward phase was marked by the discontinuation of treatment:

16th October 2002

[A] Rod in new 'jama trousers and T.Shirt. looks quite smart. for a change! pleased with news that he is going back to Willows tomorrow.

Treatment is discontinued. because of Rod's continued inability further radiotherapy will be of no benefit and he is not fit enough state to cope with the discomforts of side effects, nor all the waiting about for ambulance transport etc.

After another spell in hospital, Ann writes that Rod is pleased to be returning to the residential home (this could be interpreted as her being pleased – but clarified through discussion). Regarding the end of treatment, Ann appears to be retelling the medical story with no emotional commentary. With the last hope of arresting the effects of his tumour gone, Rod and Ann must now face expectations of continued decline.

19th October 2002

[A] Willows phoned. Rod undid lapstrap – tried to get out of chair and fell: DR did physical check – O.K. – he tried to do the same thing yesterday but I was with him at the time and persuaded him that it was not a good idea – obviously the message didn't get through – surprise, surprise!

Ann continues to tell stories of Rod's falls. She visits regularly and is still involved in providing verbal assistance, but believes that the messages are not getting through. She is still presenting her own role in preventing incidents and securing Rod's wellbeing. Rod is no longer able to stand safely without help, and so he is confined to his chair by a lap-strap. When he undoes this, perhaps he has forgotten his limitations, but maybe this strap is simply one restriction too many. Two days later, Ann reports another fall:

21st October 2002

[A] Visit Rod – slipped/fell out of chair again in dining room. I arrived just as staff began the struggle to 'sort him out' he appears to treat it as a big joke – seems completely unconcerned about the whole procedure of being hoisted back onto his chair and then being transferred to his bed once the corridors have been negotiated. This little 'do' needed four members of staff to get him up off the floor – and three of them to transfer him from chair to bed.

Ann's description of the incident highlights the number of staff needed to assist Rod. Perhaps this is a reflection on her own personal struggle and in some ways a justification of Rod's move into residential care – for although it was Rod's decision, Ann privately expressed feelings of guilt that she was no longer able to cope. Ann feels that Rod treated the above incident as, "A big joke". It is difficult to interpret whether she is annoyed at this or is perhaps making a comment on Rod's current state

of mind and levels of awareness. As Rod settles into residential care, Ann's level of agency shifts more and more towards a monitoring role. Within this, she checks and comments on the beliefs of Rod's new carers:

24th October 2002

[A] [Janice] from Willows phoned to tell me not to worry, Rod is much better than yesterday. Will visit him later.

Stayed 1¼ hrs, not that much better

She is displaying her own expertise and knowledge of Rod as compared to the professional carers now responsible for him. In Rod's continued decline, he signed a power of attorney form the next day, letting go of another aspect of his independence. His communicative phase appears to have been brief as now he has returned to his former quiet self:

28th October 2002

[A] Rod sitting – propped up in bed – much better in himself than for quite a while. Jim sorted T.V. on Sat. maybe this interest/stimulous has helped. – still not very talkative, but I guess there isn't really much to talk about

Ann provides an interesting observation on the relationship between context and behaviour as we may comment that a person is uncommunicative, but what if they have nothing to say? When time passes without incident, few memories are recorded – hence we see large temporal gaps in recalled trajectories. In the present we may also see a reduction in active behaviour if there is little environmental stimulus or feedback. Rod is still interacting but Ann highlights the limitations to this:

30th October 2002

[A] Rod seems more alert now T.V. available - thanks to Mum & Jim

Rod used mobile to "chat" with Mother, ie yes ___ yes ___ no ___ yes etc to whatever questions Mother put to him.

Lucie – a member of staff (with helpers) got Rod into his wheelchair for a couple of hours yesterday, apparently enjoyed the 'outing' but got very tired and had to return to his bed.

Gave Rods feet a massage with moisturiser cream as his skin is very dry. Also asked for chiropodist to visit on his next rounds (two wks time?)

Looked at some cars - need advice?

Rod appears to be demonstrating classic response – if a sentence is pitched as a question then respond yes, regardless of understanding. This masks cognitive deficits

to those who are unaware of the strategy. Ann has written, "Apparently enjoyed the 'outing'" referring to a short period of aided mobility in his wheelchair; the inverted commas on outing, again pointing to limitations. We might also ask - according to whom did he enjoy this? Ann is still recording her own role in Rod's care — her own agency in this situation and her relationship with other agencies. Also her comments on the need for advice on cars reflect the fact that this was previously Rod's responsibility — highlighting the knock-on effect of changing roles.

Diary entries by this point were generally brief, as Ann was no longer involved in the personal struggle of providing constant care and incidents tended to be second-hand reports rather than first-hand experiences. Small improvements in Rod's condition are noted:

1st November 2002

[A] Visit Rod – so much better since steroids increased – appetite not diminished – eats any & every thing.

As Ann highlights these positive steps, we might ask, "But towards what?" The next day she takes one of her much loved rabbits on her visit to see Rod:

2nd November 2002

[A] Took Cirrus in for a quick visit. Rod seemed quite pleased but, as usual, his attention span was minimal, however that doesn't matter – what matters is the fact that he is happy.

Ann is still monitoring Rod's capabilities but her focus appears to have shifted from deficits to emotional well-being, perhaps signalling acceptance of what is to come. As time passes she shows increasing distance from the situation and from day-to-day events in Rod's life:

7th November 2002

[A] Visit Rod. Also visited Monday, or was it Tuesday – can't remember which – not that it really matters.

The time of her visit is presented as unimportant, suggesting that Ann no longer sees her role in Rod's life with the same level of importance. Also perhaps in his declining state, he is less aware of the time between visits. Less than a week later, Ann announces that the file is closed:

13th November 2002

[A] Meet Julie Jones at Willows 3pm re assessment everything fine. Rod happy to stay - staff happy to keep him - file closed.

Perhaps Ann means that Rod's future is now settled and the trajectory is now predictable in events if not time. The decision has been made that Rod will stay where he is and that he and the nursing home staff are 'happy' with this outcome. Ann's role in care has not however ended:

29th November 2002

[A] Difficult morning, Rod needed hoist (as usual) to lift from bed to stretcher but because the bed has a lot of metal fixtures underneath it is almost impossible to position the hoist for transfer. At Glenfield it was discovered that they were not prepared for Rod's immobility so he was put into a consulting room — with bench — Rod was heaved onto this by four of us to await consultation by which time he was tired — cold and upset though I must say that everybody was very kind and helpful.

Rod has now been discharged as full care and attention are being received at Willows nursing home.

Rod'S LAST 'OUTING'

Ann refers to this as a, "Difficult morning" which seems to be a relative assessment in terms of Rod's point on the trajectory (Charmaz, 1991). She reinforces the physical struggle as Rod is 'heaved' onto the bench and although there is a note of unhappiness about the lack of preparation, Ann feels the need to be supportive of the individual staff who do their best to provide care. Problems are therefore presented as structural, environmental and resource based. The term, "Full care and attention", seems to acknowledge the personal change in responsibility for Ann – although she still takes a supportive/monitoring role, she is no longer in charge. The final comment again puts the word outing in inverted commas. This must have been added after Rod's final decline – showing the diary to be more than a day to day record.

There are less and less diary entries after Ann relinquishes responsibility as Rod's primary carer, but she still monitors his condition and the support he is receiving:

2nd December 2002

[A] Catheter fitted 5th Sep. needs changing!? Have brought this to the attention of staff

After making this medical note, there are no entries again until 19th December, and this was the last entry prior to Rod's death. It is the first mention of Christmas in five

years of diary keeping. It records a final gesture of care but it is tinged with the sadness that Rod was unable to respond:

19th December 2002

[A] Decorate Rod's room with Christmas trimmings - looks pretty - but I don't think he is aware

Ann knew that death was inevitable and Rod was on a downward trajectory, as indicated by his lack of awareness, but she was still shocked by the suddenness of his passing two days later. This is not surprising when only a few months before she wrote of a predicted 15 years ahead.

21st December 2002

[A] Rod died in the early hours of this morning. He is at rest – he is peaceful – he is <u>free</u>, dignity restored.

(PASSPORT PHOTO INSERTED)

21.AUG '46 - 21.DEC'02 56years 4months

Although in recent times, Rod had no input into the diaries, they were always about him and often written for him. After his death, the diaries came to a natural end. For the first time, they contain other media as Ann inserted a photo of Rod to mark his passing and a cutting from his wreath on the day of the funeral. These artefacts provide a stamp of reality to this written record of a life lived and lost.

7.3 A Five Year Snapshot

Having presented a snapshot of the lives of Rod and Ann through interview and diary data, it is interesting to point to some of the additional records provided as further evidence of their trajectory. Ann tried to keep a note of many related occurrences and these would sometimes be slipped into the diary at relevant points. For instance, Ann started to log breakages around the home that were caused by Rod's seizures (Appendix II). This highlights the impact of regular falls on the home environment and also the additional responsibility that Ann had for maintaining household repairs.

Like many people Ann also had to negotiate the benefits system, and after Rod completed a form incorrectly she found that their income was severely reduced. To rectify this she asked both Rod's neurologist and his GP to provide evidence of the

extent of his condition (Appendices III-VII). The benefits agency were under the impression that Rod had only two seizures per month when Ann had recorded him as having over 120 each year (and perhaps many more unrecorded). It is interesting that status seems to affect the letters Ann writes as the GP received a brief note accompanied by a copy of the letter to the neurologist. Also, Ann wrote a second time to the specialist, seemingly placing more weight on his reply.

Ann did however write to their GP in 2001 to ensure that someone other than her was aware of Rod's care needs (Appendix VIII). Like many carers (see also Section 5.3.2) she felt the need to prepare for the eventuality of her own ill health or death. Reading this letter, again highlights the changed dynamics in Rod and Ann's relationship and its tone suggests a need within Ann to share the difficulties of caring, with someone who might understand. This is perhaps the clearest indication that for her, the diaries were as much a tool for communication as a record of events.

This case study has demonstrated a full trajectory, highlighting critical junctures at which new phases begin. It has also shown how brain injury can affect relationships, with Ann steadily becoming a control agent as Rod's acceptance of his condition increased. It has then illustrated the emotional difficulties of managing the transition into a nursing home, where agency shifts to professionals from an all consuming relationship of care.

The diary entries give a valuable day-to-day insight into the realities of illness and care, and show how interpersonal dynamics affect actions and beliefs (such as Rod's lack of communication). This temporally recorded change brings something beyond the retrospective interview data recorded in a single instance. It is not a memory reconstructed to fit with present beliefs, but it is of the time in which events occurred.

In the final chapter of this thesis, all the threads of data analysis will be woven together to consider three key issues, the changing relationships experienced by patients and carers, the implications of identified care delivery issues and the trajectory of care, within which there is an ongoing ecology of factors. Finally, the research itself will be evaluated, reflections will be made on the data collection process and suggestions for future expansion of this thesis will be presented.

Chapter 8 - Discussion

8.1 Changing Relationships

The first key issue to be taken from this thesis is that of the changing relationships experienced by those whose lives are affected by brain injury. Parents and partners take on new roles as carers and their relationship with the patient changes accordingly – affecting personal and shared identities. Their agency in the care process may shift along a scale between high and low involvement (Chapter 5). In conjunction with this, the patient's relationship with others is greatly affected by the way in which they deal with their injury. This has been considered in terms of Charmaz's (1991) levels of acceptance model, which have been treated as strategies of adaptation (Chapter 4) and redefined as a changing pattern of beliefs and behaviour influenced by time and context. The carers' level of agency can affect the patient's strategy of adaptation and vice-versa. The opposing trends of these can be seen in the figure below:

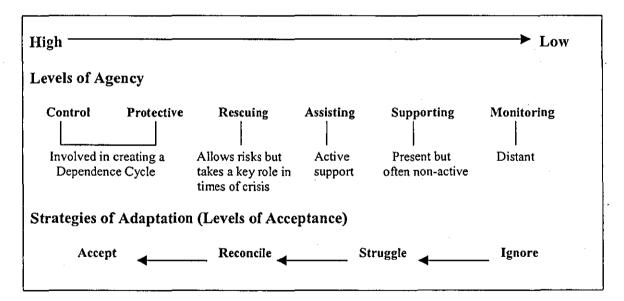


Figure 13. Levels of Agency in Relation to Strategies of Adaptation

Data has been presented illustrating each of these levels and strategies, and questions have been raised about functionality. We may have preconceived ideas about the right ways to deal with illness and disability but in real life, there are multiple factors that

make different support dynamics work for different people. Control may be looked upon negatively, but in a situation where it helps to preserve life, perhaps it is the most appropriate level of care. Struggling against personal boundaries may be idealised and for some this struggle is important to maintaining their identity, but others may find that struggling makes adaptation to insurmountable deficits a more difficult and lengthy process. Awareness of the strategies people employ is an important step but an understanding of how and why these strategies develop and of whether they serve a positive function, is crucial if services are to be successfully targeted.

At critical junctures on their trajectory, strategies of adaptation and levels of agency may shift and support needs will change alongside this. With an ongoing awareness of the trajectory and the work that these roles and relationships perform, perhaps we can meet needs that are often unspoken. To illustrate, in a situation where carers take control and the patient accepts their condition, there may be a high level of counter-dependence and if this does not have positive outcomes for those involved then services should be targeted early to offer external support, relieving the burden of care and giving the patient space to explore their own potential. In a situation where the patient ignores their symptoms while their family simply monitors their condition, the patient may benefit from external help, but be overlooked because distant carers may be unaware of day-today problems and the patient may be unable to accept the changes brought about by their injury. By overlooking their limitations and not seeking strategies to overcome them, they may place themselves in physically or emotionally dangerous situations, such as an early return to work. The damage of failure can be long-lasting, but again, early intervention can help people to renegotiate their world and access appropriate support, giving better long-term outcomes. This would require patients and carers to be identified at the point of diagnosis or hospital admission with available help explained clearly at this time and again at future critical junctures, monitored by an appropriate professional.

8.1.1 Recommendations for Patients

You have potential but this will be influenced by more than your injury

It is important that patients recognise their own agency in the recovery process. Some appear to believe that their level of recovery is determined only by the extent of their

injury and this can limit the amount of work they do to regain what has been lost (e.g. Patrick 4.1.3 and Gary 4.3.1). They should understand that they play an important role in any progress made and that the nature of their relationship with those who care for them can also have a large impact on their later outcomes. They should be encouraged to accept help only when they need it, otherwise they are laying a path towards learned helplessness where both they and their carers may become trapped in a cycle of mutual dependency.

Success is something that you can define

There are a range of formal measures of a successful recovery, many of which are oriented around independence and return to work. Whether or not patients meet the goals of others though, should not determine their 'success' or 'failure'. People can live happy and fulfilling lives without meeting standard recovery criteria and they should not feel pressured to conform to the expectations of others (e.g. Edward 4.1.1 and Ben 4.3.3). They should be encouraged to celebrate their personal achievements rather than being pushed unnecessarily to leave a loving family or to start full-time employment. Whether or not they take these steps should be based on the extent to which independence will improve or degrade their personally defined quality of life.

8.1.2. Recommendations for Carers

Be aware of your own agency in the patient's recovery

Carers should be helped to develop appropriate coping strategies as over-zealous caring can foster dependence in the patient, negatively affecting the recovery process (Livingstone, 1987). As explored in Chapter 5, carers should be made aware of their role in encouraging or limiting recovery. They should also receive advice on using available support to prevent themselves from becoming trapped in a full-time, long term caring role where each day, choice becomes less visible. When caring becomes a career beyond which families can see no alternative, relationships may disintegrate and opportunities to promote recovery may be missed.

There are no accurate ways to make exact predictions as there is such a complex web of contributing factors

Brain injury is not a single predictable disability; both the premorbid personality of an individual and the precise damage caused will contribute to how that person will be affected and how they will react to any physical, cognitive and social deficits (Golden, Smith & Golden, 1993; Walsh, 1991). It must also be remembered that deficits following brain injury are not generally found in isolation, but occur in various combinations which can further limit a person's recovery (Newton & Johnson, 1985). As an example, someone who suffers both attention and memory deficits may lack both the attention needed to learn new memory strategies and the memory needed to recall ways of increasing their attention span. A premorbid tendency to lack patience and become easily frustrated, will add further difficulties. With combined factors such as these, doctors cannot be expected to give carers clear and accurate predictions of future possibilities. With some understanding of this, carers may be less likely to pressure medical staff for potentially inaccurate information, which in itself may be enough to permanently harm relationships of trust with other health and social care professionals.

Six months is not the end of recovery

Until recent years, it was believed that recovery from head injury takes place exclusively in the first 6 months (Evans, 1994) but research now shows that the processes of recovery can last for many years (Kolb & Whishaw, 1996). It has been suggested that social and rehabilitation services are necessary for 30-40 years following head injury, with support being needed in the home, the community and the workplace (Roessler, Schriner & Price, 1992). People with acquired brain injuries and their families therefore need lifelong access to a range of services provided by professionals who are well informed about neurological damage and its long term effects. People are still being told that six months is a critical juncture (e.g. Victoria 6.3.4), and this can be a frightening milestone if there is little recovery at that point. Professionals should therefore be wary of giving time-limited predictions and carers should be encouraged to look for ongoing signs of recovery.

Caring may become harder over time if you do not demand adequate support

It is perhaps an automatic response to bring a loved one home after an injury and to offer care and support. At first this is a loving bond, supported and strengthened by hope of

recovery. Loss or weakness of physical ability is often temporary and to an extent, some return to health can usually be expected (Bond, 1975), but cognitive and emotional changes are more likely to cause permanent disability. Work capacity and leisure pursuits are the main areas of daily life affected by brain injury and if the patient stays predominantly at home, then they may become increasingly isolated, relying on their family to provide for all of their cognitive, social and emotional needs. Family cohesion was shown by Bond (1975) to be resistant to physical disability but much more greatly affected by cognitive changes, especially memory impairment and differences in personality. Over time, it can become harder to maintain the energy that caring requires, particularly when damage caused by the injury has changed the person being cared for into someone barely recognisable from their former self. As time passes, if steady improvement is not shown then carers may become increasingly weary. If they have not had support from the beginning then it may be difficult to introduce it at a later stage once routines are in place and expectations of constant family care have been created. It is therefore advisable to arrange some external support early on to protect the long term interests of the patient and their family.

8.2 Reviewing Care Delivery

In Chapter 6 we have looked at attitudes towards professional health and social care support and we have seen how these form in response to the trajectory of care as it is experienced. Particular attention was paid to three issues, limited time and resources, cataloguing mistakes and the manipulation and restriction of information. Within this I have explored the effects of contrasting expectations between service users and service providers, suggesting that it is often unchallenged beliefs that cause conflict and the development of negative attitudes towards certain aspects of professional care. The root of many complaints was actually a lack of appropriate information sharing particularly in cases where people are looking for reasons but offered only limited facts. There was also the important issue of patient involvement in this information sharing process, with implications for control based role taking when carers are given the responsibility of knowledge to the exclusion of their loved ones.

The main implication of this thesis for care delivery however is the importance of understanding trajectories of care (Figures 13 & 14) and their tendency to shift across different contexts. This is particularly relevant in terms of assessment and decisions on service provision. In assessment, the professional must be aware of the effects of context and how this may influence both behaviour and information sharing. A person who is quite animated in a short interview may then be exhausted and withdrawn for the rest of the day. Someone who tells a professional that they are able to complete certain tasks may be eager to present a positive image of themselves and to fulfil their obligation as a recovering patient; their reality may be somewhat different. Carers who depict a person as dependant may never have stretched their capabilities as they may be settled in their established roles, not realising that in different contexts the patient displays much higher levels of capability. For their part, the patient may allow carers to take a dominant role in order to maintain a comfortable relationship where all feel able to contribute in some acceptable way.

Looking at the medical trajectory (Figure 12) and the care trajectory (Figure 13) these fit together to provide a superficial overview of some of the critical junctures that may be experienced by patients and carers – linked into the models designed by Bellaby (1991) and Strauss (1989). It is impossible however to express the full complexity of a single trajectory in a diagram, as it is attempts to summarise human experience that bring dangers of misinterpretation as with the checklist assessments presented in Chapter 2. A far more compelling example comes from detailed explorations such as the case study that forms the basis of Chapter 7. My aim in this thesis is not to offer some minimized model or scale that 'produce(s) the illusion of a frozen present' (Brown, 1997, p185) but to raise issues that encourage professionals to look deeper into the lives of the people they hope to assist and to be aware of the constantly shifting influences experienced within the trajectory.

Using memory as an example of an expected post-brain injury deficit, I have also tried to explore psychological aspects of beliefs and claims about capability. A problem that could be viewed as a purely neurological phenomenon has been revisited in terms of the work that is done by and around deficits. The loss of memory can be functional in terms of emotional protection and levels to which it is regained may be influenced by

relationships as well as the limitations of brain damage. Where it is not regained, strategies are available to compensate, but their effectiveness may be poor unless framed within an appropriately supported system. These concepts can be transferred to other deficits such as reduced mobility as recovery is not an isolated journey from injury to a return of self, it is part of a complex life with social, emotional, historical, biographical, structural and contextual influences (see also work by Dreier, 1999 - on personal social practice).

8.2.1 Recommendation for Professionals

Be honest, open and upfront

Information seeking (gaining knowledge and advice on brain injury and its treatment) is a primary coping strategy amongst patients and carers and having information on deficits (e.g. memory) can provide improvement and enable patients to compensate better for their injuries (Frank, Haut, Smick, Haut & Chaney,1990). In the case of more severe brain injuries, it is at first only possible for doctors to give an uncertain guess about what outcomes to expect. They can indicate how severe an injury is and based on probabilities, they may be able to say how likely it is that a person will survive and whether to expect lasting disability (Gronwall, Wrightson & Waddell, 1998). Families are often desperate for information but may be told very little. Some professionals may simply be cautious about saying too much, too soon. It is also possible though, that without the specialists' experience or knowledge of head injury, they are unable to prepare patients and their carers for the range of possibilities.

Professionals face an often paradoxical task of encouraging families to support rehabilitation and to remain goal oriented, whilst simultaneously communicating often negative expectations with regards to prognosis (McLaughlin & Carey, 1993). Families in turn often perceive these professionals as pessimistic; they often feel that others have given up on their relative and may believe that they are receiving very mixed messages. The rehabilitation team must instil a sense of hope in both the patient and the family. This should be realistic rather than naïve, but should reflect the human ability to fight adversity (Prigatano, 1986b). Typically, people with traumatic brain injuries believe that with time they will be able to function at pre-injury levels and often they do not readily

accept their limitations (Zuger & Boehm, 1993). Prigatano (1986b) emphasizes that patients and carers should be made aware that although recovery may not be complete, significant progress can be expected, with an aim that patients will eventually regain independence.

It is important also to clarify that recovery may be a slow process. Sbordone, Liter & Pettler-Jennings (1995) monitored the recovery of 20 patients who had sustained a severe traumatic brain injury. Their data suggests that recovery still continues 10 years postinjury. They recommend that clinicians should refrain from telling patients and their carers that all recovery should occur within two years, or even six months (a common claim), as this may create a loss of hope and exacerbate depression when goals are not met within a strict time limit. In order to deal with the long-term deficits caused by brain injury, we need adequately trained and informed professionals within the patients' local communities (Rosen & Gerring, 1986). There should also be a range of resources offering psychosocial, medical, educational and vocational support.

Do not fall into the trap of trying to give answers that you cannot be confident in

The Department of Health, (1997) reports that carers want more information about the types and characteristics of brain injury, prognosis, available services, benefits and legal matters. They found however that most Local Authority practitioners were unable to supply all of this information and a significant number of patients and carers have never seen the leaflets produced by voluntary organisations. This finding was explored in Chapter 6 of the thesis, particularly Section 6.3 on the manipulation and restriction of information, and Section 6.3.4 on signposting other services and monitoring progress.

Families caring for brain-injured members are often ill prepared to face the long-term rehabilitation process (Man, 1999). Those who are provided with information may mistrust it if early communication with professionals was seen as misleading.

McLaughlin & Carey (1993) highlight the negative effect that 'proving the experts wrong' can have. If carers are told to expect the worst and 'the worst' does not happen then they may develop scepticism about the knowledge and opinions of all related professionals. Distrust of hospital staff can in turn lead to open hostility and aggression.

Tzidkiahu, Sazbon & Solzi (1994) claim that in a few cases, carers may express this pent-

up aggression physically e.g. hitting a nurse. This behaviour is unacceptable, and may be avoidable if carers feel better informed and more in control. Perceptions of the professional have been explored in Section 6.2, including details of how certain incidents in particular contexts can set up a career of medical avoidance, where doctors are no longer consulted and carers take on additional responsibilities of monitoring and diagnosis.

Explain diversity and be aware of wider issues

This is where knowledge of trajectories of care becomes so important. A professional may be well informed about neurological aspects of brain injury and they may know about a range of possible effects, as highlighted in Section 2.4, but this may not equip them to give appropriate support. Living with brain injury is about much more than an individual coping with acquired deficits. It is about a multitude of interactions across a wide range of contexts. It is about beliefs, expectations and attitudes. It is about the roles people play and the conflicts between them. These things together form an individual trajectory. If the professional can gain access to this, then care can be planned in a way that thinks beyond neurology, that remembers that people are not isolated medical entities, but are people with complex needs that must be adequately addressed.

Many people express dissatisfaction with care and much of this is based on limited time and resources

Only a small proportion of head injured people are actually admitted to hospital and although they may come into contact with a bewildering number of staff, they are not likely to be seen in a specialist neurosurgical unit (Van den Broek, Schady & Coyne, 1995). Those who are admitted tend to be treated on general medical wards, but the vast majority who seek medical support, will be seen by their GP. The Royal College of Surgeons (1999) recognises that general practitioners need to be made aware of the potential sequelae of mild, moderate and severe head injuries. It is stated that they must also be informed of the agreed local referral protocols for the follow-up of patients with head injuries. Traditionally patients with minor head injuries receive no follow up but they may suffer deficits for many years. Therefore general practitioners should arrange further contact with these patients and possibly refer them to a specialist in rehabilitation medicine or a clinical neuropsychologist.

Patients who are taken to hospital having sustained a traumatic brain injury (e.g. from a road accident) often have other more visible injuries and may therefore be dealt with in orthopaedic or general surgical wards. In this situation, their brain injuries and the resulting deficits may be missed or given insufficient attention (NHS Health Advisory Service, 1997). In the case of mild or moderate head injury, most people are given no follow-up after they visit casualty (Powell, 1994). Many will suffer post-concussive syndrome (dizziness, headache, impaired concentration, irritability, insomnia etc.) and significantly, most people experiencing this do not understand what is happening to them (Vogenthaler, 1987a). Many patients could benefit from receiving basic advice about the possible consequences of their injury and how these can be managed (Powell, 1994), and we can expect them to face many problems when they realize that their whole lives have changed and that any future plans must be adapted (Haglin, 1996).

More thought needs to be put into the long term benefits of rehabilitation for patients and their families – but also for the state as minimizing damage reduces the need for lifetime support

Levin et al. (1982) reported on a treatment program in Israel where the primary goal identified was to assist patients in developing skills that are indirectly related to the ability to work. These include, maintaining a positive attitude to life, enhancing self-esteem, increasing cognitive efficiency and developing adaptive behaviour such as requesting assistance at appropriate times. They also aimed to help their patients to accept the consequences of their disabilities and to pursue activities which emphasize the abilities that were spared by the injury. It is only in more recent years that rehabilitation centres in the UK have started to set similar patient goals after research highlighted the inadequacy of British services (Bigler, 1987; Bond, 1975), with the tendency of professionals to concentrate on obvious physical disabilities whilst serious emotional and intellectual deficits may be overlooked (Johnson & Newton, 1987). It has been recommended that professionals focus significantly more of their energy and resources on the psychological health of clients with traumatic brain injuries (Morton & Wehman, 1995). Staff should be trained to detect the signals that patients may be sending, as psychosocial factors are one of the main obstacles that prevent community adjustment.

Most patients however will never have the opportunity to access these costly services and will receive only hospital based rehabilitation, aimed at restoring physical functions.

8.3 An Ecology of Care

Returning to the overall theme of this chapter, perhaps instead of thinking purely in terms of trajectories, we should consider the experience of brain injury as being within a finely balanced ecology of care. This concept of an ecology has been applied to mental health and substance abuse treatment (CIGNA Behavioural Health, 1999) and is a useful way of representing multiple factors that affect and are affected by a central concern. So taking the superficial representations of a trajectory, as presented in Figures 12 and 13, we can add a further dimension of an ever-present ecology that influences behaviour within, and interpretations of, the trajectory.

First we have the patient who must use strategies of adaptation, as described in Chapter 4, to deal with the effects of their brain injury. These strategies will be informed by their biography (Wiener, Strauss, Fagerhaugh & Suczek,1997), i.e. their pre-morbid personality and experiences, by the challenges they face, the context they are in and the constraints and opportunities around them. Then we have the carers who shift through different levels of agency, as described in Chapter 5, which will also be informed by their pre-existing biography. There is an interaction between the adaptation strategy of the patient and the form of agency acted out by the carer, e.g. a patient who accepts their disability and redefines their life around it may encourage a quite controlling form of agency in the carer, as a high level of need is expressed. In converse, a controlling form of agency in care may also produce a more dependent patient and so there is a cycle of dependence to be aware of.

There are then further elements in this interaction. There are the health and social care professionals who will set standards of support and give or restrict information. Behind this there is their own biographies, the setting in which their exchanges take place, and the resources to which they have access. At the same time there are experiences that will affect the central interaction. There are societal constraints and opportunities, there are challenges and there are changing contexts. To take each of these in turn: a constraint

may be the difficulty in finding appropriate employment, which can reinforce a damaged sense of self and can leave the patient financially dependent. An opportunity might be gaining funding for intensive rehabilitation, indicating hope of improvement and presenting practical opportunities for increasing abilities and therefore the patient's level of independence. A challenge might be in the form of deficits such as memory loss or communication impairment, which can affect how patients view themselves, are perceived and are presented to others. The interaction at the centre of this ecology could be said to continue throughout the trajectories previously identified.

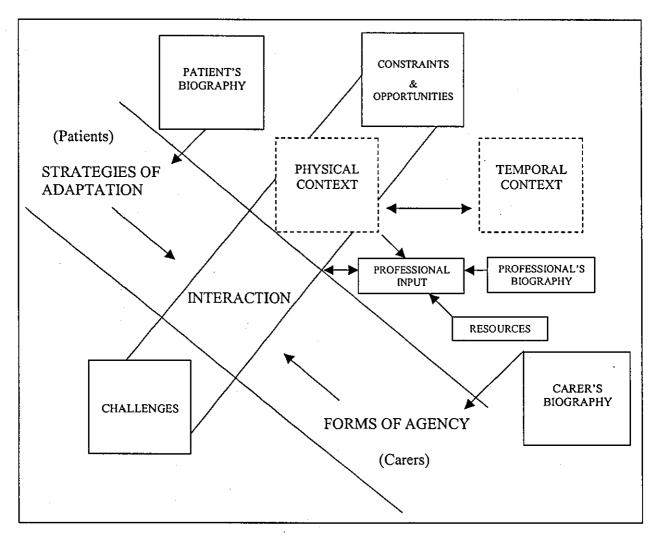


Figure 14. An Ecology of Care

As a concrete example, in Chapter 7 we saw that Rod often displayed a strategy of acceptance. The challenges he faced included reduced motivation and memory deficits. He was constrained by the dynamics of his home environment and by expectations of

what he should and should not do. The opportunities he was given (e.g. simple craft activities) fitted with a stereotype of disability. The temporal context was modern day — with a pressured health and social care system that rarely seeks to stretch itself further by offering undemanded support. The physical context was usually his home, where the care relationship was based. The greatest change in his adaptation strategy came with a change of context, when he decided while visiting his doctor that he would seek treatment, therefore struggling against rather than accepting his illness.

His wife Ann was encouraged to take a control level of agency by paramedics responding to Rod's first seizure. This advice will have been informed by the paramedics' past experience, and Ann's acceptance of it will have been influenced by her own biography and the relationship dynamics already established between her and Rod. As ongoing professional support was not offered, Ann continued to accept the balance of power, helping Rod to organise his life. During early stable periods she shifted towards being a rescuing agent, only stepping in to provide support in times of acute need. The move back towards control seemed to come easily though as Rod's health declined. Rod's acceptance of his condition facilitated this role in Ann alongside past experience of this being an effective way to motivate her husband when illness appeared to limit his cognitive functioning - and so these internal dynamics continued throughout the trajectory of care until Rod began to struggle against his illness. At this point Ann took on a supporting role, with agency shifting back to her husband. The challenge of further illness and the constraints this placed on the hospital providing the planned treatment motivated a final shift back towards control and acceptance. Moves away from this level of control only came when the responsibility of care was transferred to a nursing home, until in the final weeks Ann provided a role that steadily decreased in agency towards monitoring and assistance. This example illustrates how the ecology of care can be applied as a concept to understand changes in the internal dynamics between patients, carers and professionals at different points on the trajectory – therefore providing the concluding message of this research - there are commonalities between cases within this field that we can use to navigate the complex phenomenon that is living a life with brain injury.

8.4 Reflections on the Research Process and its Limitations

In this final part of the thesis I will reflect on the methodology, the validity of the findings, the issue of reflexivity and future possibilities for research. I will discuss the process of interview development, issues of truth and generalised applicability of the trajectory concept.

8.4.1 Learning Curve of Interview Techniques

Conducting interviews is a skill that is only acquired through practice. The earlier interviews in this research were shorter and more to the point, and it was only with time that I was able to open up my questioning technique, allowing people to talk more freely and according to their own agenda. As I identified themes through the Grounded Theory treatment of completed transcriptions, I was able to incorporate appropriate extension questions – such as asking parents of people who were injured during childhood what issues they have faced in the transition between childhood and adulthood. I became increasingly sensitised by the data and in later interviews I was able to quickly pick up these issues when participants made implicit references or talked about related concerns. I did consider asking some people to be interviewed again but felt it was more appropriate to discuss individual issues informally with these contributors and to seek a wider sample group, enabling sufficient data saturation to make generalized claims.

8.4.2 Reflexivity - A Personal Journey Through the World of Brain Injury

Central to the philosophy of Grounded Theory is the idea that themes emerge 'naturally' from the data, which can then be explored and developed to create theories. Observations produce ideas through a process of induction - rather than ideas shaping the observations. Through Grounded Theory the researcher is open to the creation of new and unique thought rather than being bound by established research, hypothesizing that they will be able to replicate, reinforce or develop existing knowledge rather than creating something that is entirely new. When considering this inductive process however, we are faced with the positivist assumption that data speaks for itself (Willig, 2001). This assumption is disputed by critics of positivism, who insist that we must not

neglect the role of the researcher who will bring their own perspective to any observations made (Dey, 1999). This issue of reflexivity is at the core of many criticisms of the Grounded Theory approach.

I however have tried to be clear in my belief that I have an important role in the production and analysis of my data. Glaser and Strauss, the founders of Grounded Theory (1965; 1967), famously split as each developed different ideas about the researcher's role. Glaser (1978; 1992) maintained the belief that theory would arise naturally, given time and patience; whereas Strauss (working in partnership with Corbin) declared a need for the researcher to play an active role in drawing out these theories and therefore recognised that the researcher is a critical part of the Grounded Theory process (Strauss & Corbin 1988a; 1998). Strauss argued that through constant comparison, theoretical sampling and data saturation, valid and reliable results would still be obtained. My application of Grounded Theory follows this Straussian school of thought.

As I entered the process of completing this thesis I openly considered my background and the beliefs that this has fostered. The key concepts that I developed have added to and altered these views. I began my work with knowledge of how patients' talked about their experiences of hospital, of rehabilitation and of life beyond their injury. It is only through this research that I have built a wider view of the complex interactions between patients, their families and service providers within a flexible ecology of care. I have also confronted personal and social values about the nature of dependency. I came to this research with the importance of independence drilled into me by years of working in medical and rehabilitative environments.

Listening to the many stories collected through this research I have developed a more open view as to the value of independence; seeing for the first time how in an obsession to push people back into an accepted normality, we may deprive them of a preferred way of life. That sometimes it really is ok to enjoy life for what it is, and that relying on family or state provision should not be taken as a measure of failure. I have come to realise that recovery is not something that we can define in medical terms alone. It is a personal experience, deeply embedded with the rich tapestry of beliefs, values and needs,

of the patient, their family, their community and of those whose profession it is to facilitate whatever they identify as recovery.

I entered this endeavour, sensitised to certain issues and bringing my own values, beliefs and needs. My response to the issue of reflexivity is to be clear and open about what I have brought to this research, how I have followed a rigid scientific approach to analysis and how my views have consequently changed. I have actively considered and worked through my professional sensitivities and moral commitments (Stam, 2000) and maintain that my experiences are not weights that encumber me, but valuable tools for accessing and responding to data that constitutes not just scales and numbers, but expressions of life in all its unpredictable glory.

8.4.3 The Future of Brain Injury Research

This thesis has presented individual experiences, drawing out details on the impact of service provision and its absence on the whole family and working up individual and shared trajectories of illness and care. It has shown how patient centred qualitative research can successfully be applied within the field of brain injury using a grounded theory methodology to encourage the development of new concepts rather than being bound by established beliefs and theories. The themes evident in this research might also usefully be applied to the related field of chronic illness, where people face the long-term impact of disabling conditions, often developed in adulthood and requiring similar reorganization of identity and roles (Charmaz, 1991).

Through analysis of this data I have been able to demonstrate a trajectory of care — worked up mainly through discussions of past events with patients and their families. The next step in developing this would be to follow people through their trajectories from the point of injury or diagnosis, to a plateau of recovery and maybe even beyond. Information gained would provide a valuable insight into events as they are lived, without the same level of editing that is found in long-term memories. Opportunities to observe patients in health and social care settings, at critical junctures, would also enrich the data, giving a fresh perspective. Longitudinal work from within the trajectory would allow a more detailed exploration of the issues raised in this thesis and would provide active

demonstrations of how time and context influence presentation and beliefs of illness.

This thesis has provided a starting point, establishing important concepts that can now be taken forward to assist in a broader understanding of care relationships within and outside of the field of acquired brain injury.

APPENDIX I

(Interviewer Guidance Sheet)

- 1. What was the cause of your [partner's/son's/daughter's] brain injury?
- 2. What have the short term effects of the brain injury been (first 6 months)?
- 3. What long term effects are you aware of?
- 4. What rehabilitation have you [has your partner/son/daughter] had?
- 5. What areas of rehabilitation do you think have been the most important to your [partner's/son's/daughter's] recovery?
- 6. What short and long term services have you [has your partner/son/daughter] used?
- 7. How easily available were these?
- 8. How did you access them?
- 9. Are there any other services which you feel that you or your [family/partner/son/daughter] need or needed?
- 10. How knowledgeable about brain injury do you think the different professionals who helped you and your [family/partner/son/daughter] were?
- 11. How useful was their input and advice?
- 12. Do you think that they had enough information on brain injury to support and advise you and your [family/partner/son/daughter] effectively and appropriately?

If no, then in what ways could they have improved?

13. Is there anything else that you would like to discuss?

APPENDIX II

(List of damaged items)

BREAKAGES 1999

SMALL RADIATOR OFF WALL - LEAK 7

LONG RADIATOR HIT CAUSING LEAK J PLUMBERS BILL

WARDROBE DOOR KNOCKED OFF RUNNERS

PELMET DISLODGED

BATHROOM SINK REMOVED FROM WALL - PLUMBERS BILL

LIVING ROOM UNIT CUPBOARD DOOR SMASHED THROUGH

DINING ROOM BLINDS DISLODGED

BEDROOM 'TROLLEY' TRAY BROKEN

DINING ROOM CUPBOARD DOOR - REMOVED!

SLIDING KITCHEN DOOR DISLODED FROM TRACK

KNIFE DRAW RUNNER BROKEN - TRAPPING MOTHERS ARM.

2000

KITCHEN CUBOARD DOOR SMASHED IN

SMASHED RECLINER CHAIR

DINING ROOM BLINDS DISLODGED AGAIN

SMOKIES RUN FLATTENED

KITCHEN SLIDING DOOR KNOCKED OF RUNNER (2ND time)

(1st Letter to Neurologist re: Benefits)

7.2.2001 Home Address Inserted

RE. Mr R.A.[*****] HOSP APPT. N° [** *******] NAT.HTH. N° [** *******]

Dear Mr [*****],

I have had some trouble recently regarding benefits for my husband, so we arranged to speak to somebody at the citizens advice centre.

We were lucky enough to be able to talk with an associate/friend of ours - [*** *******].

We had a long and helpful interview with him, and part of his advice to us was to write to yourself and ask you to put a letter together for me to present to the Disability Living Allowance office, stating my husbands condition and how it will affect him in the future.

I was advised to get a similar letter of confermation of Rod's condition from his G.P. DR [*****. Address Inserted].

I have already informed D.L.A. that Rod can-not cook a meal or take a bath un-attended, for safety reasons. I told them how he falls, resulting from the seizures (he had 17 in January) casue severe bruising and jarring of his joints, at times causing great discomfort.

What I <u>didn't</u> mention to them, was the confusion immediatly following a seizure, the slowness of dressing and general activities, lapses of memory, uncertainty of speech if asked to describe a situation or relate a conversation to me. Also, as a result of the medication? or the glyoma? He seems to have very little controll over his bowels and bladder. As he has almost continuous diarrhoea, the urge to use a toilet necessitates an <u>imediate</u> dash to the loo. Incontinence pads are used during the day as a precaution against "accidents" when he is out and about – one of his 'accidents' (at home) cost me a new bathroom carpet!!

The D.L.A. need to be officially made aware that his medical condition will not improve, and, with time, will deteriorate. Would you please make the DLA aware of the facts?

Your help in this matter will be much appreciated.

Sincerly
Ann [******]

APPENDIX IV

(Letter to General Practitioner re: Benefits)

7.2.2001

Home Address Inserted

RE. Mr [R.A.*****]

Dear Dr [*****],

I have been to the citizens advice centre in Loughborough because the DLA benefits office has reduced my husbands allowance to the minimum.

I was advised to ask you if you would put together a letter on my husbands behalf stating his condition. I can then forward it, with other information to the D.L.A. TRIBUNIAL for a hearing.

I enclose a copy of the letter I have sent to Mr [******] (Leicester General) making a similar request.

Thank you for reading this letter Sincerly Ann [******

APPENDIX V

(2nd Letter to Neurologist re: Benefits)

21.2.01 D.L.A. BENEFITS FORM [*****(**)] 30.11.00 I HOPE YOU RECEIVED THE LETTER 7.2.01 ASKING IF YOU WOULD BE KIND ENOUGH TO PUT A LETTER TOGETHER FOR ME TO PRESENT TO THE DLA TRIBUNAL, AS MY HUSBANDS BENEFITS HAVE BEEN SEVERLY REDUCED. I HAVE SINCE RECEIVED A COMPLETE COPY OF RODS RECORDS FROM THE BENFITS AGENCY AND THEY SEEM TO BE UNDER THE IMPRESSION THAT HE ONLY HAS TWO SEIZURES NIGHT AND DAY PER MONTH (DLA RECORD ABOVE). THIS IS TOTALLY INCORRECT. ACTUAL OCCURANCES ARE AS FOLLOWS 1999 14 15 16 14 10 7 7 10 5 9 8 12 = 127 13 10 10 10 14 14 15 2000 9 11 10 14 137 2001 18 APPROX HALF OF THESE SEIZURES HAVE RESULTED IN HIM FALLING DOWN - HE ALWAYS FALLS IF A SEIZURE OCCURES WHEN HE IS STANDING/WALKING. I HAD NOT REALISED THAT YOU WOULD NEED MY HUSBANDS PERMITION TO RELEASE INFORMATION TO ME. I'M SORRY IF MY IGNORANCE OF PROCEEDURES HAS CAUSED YOU ANY PROBLEMS. I ENCLOSE HIS AGREEMENT TO THE REALEASE OF PERSONAL DATA, I HAVE READ AND UNDERSTOOD ALL THAT MY WIFE HAS WRITTEN ON MY BEHALF AND AGREE TO ANY NOTES AND INFORMATION HELD BY YOURSELF BE MADE AVAILABLE TO HER AND [IAN HARRISON]. I HAVE WRITTEN THIS LETTER WITH HER HELP, BECAUSE I AM NOT VERY GOOD A PUTTING WORDS TOGETHER IN AN UNDERSTANDABLE FASHION, AS YOU WILL PROBABLY HAVE NOTICED WHEN I SEE YOU AT APPOINTMENTS.

POSTED TO MR [******] 22.2.2001

APPENDIX VI

(Neurologist's Reply)

23 February 2001

To Whom it May Concern

Re:

Rodney [******]
[Address Inserted]
DOB 21-08-19[**]

The above named is an outpatient under my care with epilepsy due to a malignant brain tumour glioma. His seizures are frequent, generalised and unpredictable. Unfortunately in the presence of a brain tumour it is not possible to prevent seizures occurring. It is sometimes possible to reduce their frequency and severity but the risk is that he may suffer significant side-effects from medication.

I understand from his wife that he is also troubled by urgency of defecation. In my opinion this man needs continuous 24 hour supervision lest he should come to any harm by virtue of having a seizure which puts him in danger of injury. Furthermore he is also at risk of coming to harm during the period of confusion following a seizure. I strongly support his wife in her attempt to obtain financial support in caring for him.

Yours sincerely

Dr [* ******]

Consultant in Neurology & Rehabilitation Medicine

APPENDIX VII

(General Practitioner's Reply)

Date: 8/3/01

To Whom it May Concern

The above named is registered with this practice and I have been seeing him regularly for ten years.

Mr [******] has a brain tumour which is not amenable to treatment or surgery as a result of which he regularly has fits. These fits are unpredictable in nature and as a consequence he is at risk of physical injury from falls.

As a result of his tumour Mr [******]'s judgement is adversely affective and he is currently not able to take preventative measures to reduce his risk of injury. He is not currently able to manage his own finances.

As a result of his illness Mr [******] is unpredictably incontinent of faeces.

His condition would be expected to progressively deteriorate over time.

I hope this information is sufficient for your purposes. I have Mr [******]'s signed consent to release further clinical details in response to specific questions.

Yours faithfully

Dr [*******

APPENDIX VIII

(Letter to GP re: current condition and future care)

Home Address Inserted 22.8.01

Dear Doctor [*****], Doctor [*****]

I hope you don't mind me writing again, I find this an easier way of getting information across.

Rods condition is about back to 'normal' for him, he improved very soon after his last visit to you, though I think his short-term memory has deteriorated slightly to what it was.

The reason I am writing is because I realise that Rod is not able to care for himself – mentaly – even at a very basic level – he needs constant reminders for medication, snacks, bathing etc. He is quite capable of carrying out these tasks most times.

He has no responsibilities – his job is washing up after meals and puting out the rubbish once a week – this he does volentarily, unless I <u>ask</u> him to do anything else it never occurs to him. (no doubt like many men – however – his outlook is more akin to a slow/backward 12year old)

After a serious talk with him, to the effect that looking after him, reminding him of things he needs to do, running a taxi service for him as well as repairing things that he has damaged, washing, shopping, cooking, cleaning and managing a large garden. I realy could do with some assistance from him – he can after all go out four or five times a week to enjoy himself. But there is no responsability involved and he dosen't have to think!

The day following our talk he volenteered to wash the car. I couldn't relax because the car stands on the road, so I was out on the pretext of removing weeds from the front, whilst keeping an eye on him – yes – you've guessed it – as soon as I went inside for a moment, he had a seizure and fell quite heavily. The road was, by now, very wet and gritty – and that is where he landed!

I helped him inside once he had recovered enough to stand. In his usual confused state. I helped him undress, ran a bath for him, then bathed him, with the help of an over-the-bath seat. He seemed a little better so I left him to dry himself. I had shown him his wet and soild clothing and left them in a heap for washing. Unfortunately I didn't take them down stairs. When Rod came down about ten minutes later, he was wearing said items. I called him a 'B____ idiot' and asked him what he thought he was doing – he replied that he had put them on clean that morning. The fact that they were absolutely sodden and were sticking to him like a second skin, did not regester with him at all, even though I pointed out this fact to him, he said that they were 'all right'. He just about remembers going out to clean the car (9.40am) and nothing about the rest of the day untill late afternoon (approx 4pm).

He has an 'alarm' watch set for between-meal snacks (because of the diabetes) but just recently I've noticed that he will switch off the alarm, then continue whatever he is doing, he is very easily distracted. He is not like this every day (fortunately) but often enough to cause himself real problems if left to his own devices.

Rod is not a violent person – never has been. He is mobile and talkative, but on matters of importance do not take what he says at face value – he will sound very convincing but when questioned and asked to describe or elaborate on times – places – sequence of events etc. the final picture will be totaly different to the origional because he will make up what he cannot remember and imagine what he doesn't know.

I'm not sure if this is relevant to your position as our G.P. but my worry is that he can not help himself so there is no chance of him being able to cope with me as well, should I become ill, and if I die either through illness or accident, before him, he will need immediate monitoring. How do I see to it that he will get the necessary attention?

His brother hasn't a clue of what Rod is <u>realy</u> like to look after and it would not be fair to them, though they are aware that he will need help.

Please put this letter with Rod's notes, I hope that this information is never

needed but I am trying to cover his future - just in case.

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