Dementia with Lewy Bodies: The Caring Experience

Kathryn Ann Nicholson

Submitted in total fulfilment of the requirements of the degree of Doctor of Philosophy

April 2010
Melbourne Graduate School of Education
The University of Melbourne

Produced on archival quality paper
Abstract

Dementia with Lewy bodies may well be the second most prevalent dementia in the ageing population. Initially it is often diagnosed as mild cognitive impairment, Alzheimer’s disease or Parkinson’s disease. The experience of caring for a person with dementia with Lewy bodies was explored in a qualitative study using heuristic methodology.

Thirteen spousal carers of people with a confirmed diagnosis of dementia with Lewy bodies were recruited for the study through memory clinics and Parkinson’s Australia. The carers completed a questionnaire which provided demographic information as well as an indication of the presentation and course of their partners’ illness. They were then interviewed using an open ended conversational approach and some participated in a focus group. Their experiences substantiate the anecdotal evidence that this is a poorly recognized and understood disease in the caring professions and has no public profile.

Thematic analysis of the interview data showed that the experience of caring is complex, challenging because of behavioural, autonomic and physical symptoms, and confused by perceptions of the nature of Parkinson’s disease and dementia. There is little understanding of sub cortical dementia, or implicit memory loss, yet this loss has a significant negative impact on spousal relationships, particularly as people with this dementia often retain the ability to reason, recognize and interact with others well into the course of the illness.

The carers in this study voiced a real need for targeted education for all and this study provides evidence to address this. The methodological approach demands a creative synthesis. The synthesis has been developed as a DVD presentation of a carer discussing her caring journey. The DVD will be used as an educational resource to highlight some of the issues associated with caring for a person with dementia with Lewy bodies. This thesis contributes to our understanding of caring in the presence of this illness and demonstrates a need for further psychosocial research in this area.
Declaration

This is to certify that:

(i) the thesis comprises only my original work towards the PhD,

(ii) due acknowledgement has been made in the text to all other material used,

(iii) the thesis is less than 100,000 words in length, exclusive of tables, maps, bibliographies and appendices.
Acknowledgements

It is a pleasure to thank those who made this thesis possible. First I thank my supervisors Dr Pamela St Leger and Professor David Ames. Pam and I met when I enrolled in a vocational education and training course and her drive and encouragement convinced me to keep raising the bar in the pursuit of academic goals. She is a friend and mentor and I am grateful for her guidance and encouragement. From our first meeting when I asked David if my topic was appropriate for a dissertation, he has assisted me in his inimitable way. Their diversity of skills and knowledge has enabled my journey and given me the courage to question, explore and be creative.

Thanks also to Ros Hurworth and Maree Farrow for being the backbone of my thesis committees. Again their diverse backgrounds and the questions and comments that they posed enriched my thinking and challenged me as did the research methods courses that I audited under the guidance of Ros and Lynn Yates.

Students always have administrative questions that seem to demand immediate resolution and I was fortunate to have the assistance of Marion, Philippa and Genevieve from the CPE and MGSE and staff from NARI. Their help was greatly appreciated, as was the collegiate opportunities that they organized to facilitate a sense of belonging with other researchers. Too numerous to name individually, I enjoyed the seminars, discussions and laughter shared.

I would also like to thank the staff and volunteers of Alzheimer’s Australia Victoria for their interest and encouragement. Eight months into the study I was fortunate to gain financial support from the Australian Government through a scholarship sponsored by Alzheimer’s Australian Research and the Dementia Collaborative Research Centre for Consumers and Carers. As well as having a sense of belonging within the Alzheimer’s community this also provided me with an opportunity to ‘belong’ to Queensland University of Technology and I thank Elizabeth Beattie, Patricia Shuter and Susi Wise for their friendship and interest.

Although friends and family questioned my sanity as I embarked on this study they have journeyed with me and provided so much diversional therapy that I have survived well. Walking, yoga, gardening, being active in a vibrant community and much laughter have rejuvenated me on a daily basis and I am grateful to them all. I owe my deepest gratitude to Ian, Kylie and Shaun: my immediate family – they sustain me.

Finally I dedicate this study to my father, Malcolm, and the carers who journeyed with me.
Contents

Abstract ....................................................................................................................................... ii
Declaration .................................................................................................................................... iii
Acknowledgements ................................................................................................................ iv
Contents .......................................................................................................................................... v
  List of Figures ........................................................................................................................ xxi
  List of Tables .......................................................................................................................... xii
  List of Abbreviations ............................................................................................................... xiii

Chapter 1  Initial Engagement ................................................................................................. 1
  1.1 Introduction ................................................................................................................... 1
  1.2 Context .......................................................................................................................... 2
  1.3 Heuristic Methodology ............................................................................................... 5
    1.3.1 Origins .................................................................................................................. 5
    1.3.2 Phases of Heuristic Research ........................................................................ 5
  1.4 Conceptual Framework .............................................................................................. 6
    1.4.1 Symbolic Interactionism ................................................................................... 7
  1.5 Research Question ....................................................................................................... 9
  1.6 Structure of the Thesis .............................................................................................. 11

Chapter 2  Dementia with Lewy Bodies: Interpreting the Research Literature .............. 13
  2.1 Basic Neuro-Anatomy ............................................................................................... 13
    2.1.1 The Nervous System ......................................................................................... 14
    2.1.2 A Typical CNS Neurone ................................................................................ 14
    2.1.3 The Cerebrum ................................................................................................... 15
    2.1.4 The Brain Stem ............................................................................................... 17
5.5 Recruitment and Informed Consent.................................................................82
5.6 Ethical Dilemmas and Risk Management .......................................................83
5.7 Data Analysis...................................................................................................85
  5.7.1 Data from the Questionnaire .................................................................. 86
  5.7.2 Transcribing............................................................................................ 86
  5.7.3 Coding .................................................................................................... 87
  5.7.4 Presentation of the Data.......................................................................... 89
5.8 Validity ............................................................................................................90
  5.8.1 Auditing.................................................................................................. 93
5.9 Summary..........................................................................................................93

Chapter 6 Something is Wrong- the Beginning of the Caring Journey ...............95
6.1 Demographics and Dates.................................................................................95
6.2 The Carers .......................................................................................................99
  6.2.1 Yvonne ................................................................................................. 99
  6.2.2 Ruth ..................................................................................................... 101
  6.2.3 Fran ...................................................................................................... 103
  6.2.4 Wendy ................................................................................................. 105
  6.2.5 Sara ..................................................................................................... 106
  6.2.6 Glenda ................................................................................................. 108
  6.2.7 Olive ................................................................................................... 109
  6.2.8 Trudy ................................................................................................. 110
  6.2.9 Betty ................................................................................................... 112
  6.2.10 Kerrie ................................................................................................. 113
  6.2.11 Norman ............................................................................................... 114
  6.2.12 Janet ................................................................................................. 116
  6.2.13 Lucy ................................................................................................... 118
<table>
<thead>
<tr>
<th>Chapter</th>
<th>Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>6.3</td>
<td>Summary</td>
<td>119</td>
</tr>
<tr>
<td>7.1</td>
<td>Relationships</td>
<td>122</td>
</tr>
<tr>
<td>7.1.1</td>
<td>Their Spouses</td>
<td>123</td>
</tr>
<tr>
<td>7.1.2</td>
<td>Family and Friends</td>
<td>134</td>
</tr>
<tr>
<td>7.1.3</td>
<td>The Medical Profession</td>
<td>140</td>
</tr>
<tr>
<td>7.2</td>
<td>Understanding DLB</td>
<td>144</td>
</tr>
<tr>
<td>7.2.1</td>
<td>Past Experiences and Social Perceptions</td>
<td>144</td>
</tr>
<tr>
<td>7.2.2</td>
<td>The Diagnosis</td>
<td>146</td>
</tr>
<tr>
<td>7.2.3</td>
<td>Sourcing Information</td>
<td>149</td>
</tr>
<tr>
<td>7.3</td>
<td>Support Services</td>
<td>150</td>
</tr>
<tr>
<td>7.3.1</td>
<td>Alzheimer’s Australia Victoria</td>
<td>151</td>
</tr>
<tr>
<td>7.3.2</td>
<td>Parkinson’s Victoria</td>
<td>154</td>
</tr>
<tr>
<td>7.3.3</td>
<td>Other Services</td>
<td>155</td>
</tr>
<tr>
<td>7.4</td>
<td>Issues of Significance</td>
<td>157</td>
</tr>
<tr>
<td>7.4.1</td>
<td>Driving</td>
<td>157</td>
</tr>
<tr>
<td>7.4.2</td>
<td>Continence Management</td>
<td>159</td>
</tr>
<tr>
<td>7.4.3</td>
<td>Care Options</td>
<td>162</td>
</tr>
<tr>
<td>7.5</td>
<td>Reflection</td>
<td>165</td>
</tr>
<tr>
<td>8.1</td>
<td>The Framework</td>
<td>167</td>
</tr>
<tr>
<td>8.2</td>
<td>Validity</td>
<td>168</td>
</tr>
<tr>
<td>8.3</td>
<td>Creating the Synthesis</td>
<td>169</td>
</tr>
<tr>
<td>8.4</td>
<td>The Synthesis</td>
<td>170</td>
</tr>
<tr>
<td>8.4.1</td>
<td>The Audit Trail</td>
<td>171</td>
</tr>
<tr>
<td>8.5</td>
<td>Research Participants’ Reactions</td>
<td>174</td>
</tr>
</tbody>
</table>
List of Figures

Figure 2.1: Lateral view of the brain from Nolte, 2001, p.55……………………………16

Figure 2.2: Medial view of the brain from Nolte, 2001, p.58…………………………17

Figure 2.3: Representation of the diagnostic criteria for DLB
   based on McKeith (2005)……………………………………………………………………24

Figure 3.1: Comparison of visuo-constructional abilities.
   Source Mosimann & McKeith, 2003 p.134………………………………………………39

Figure 8.1: Scenario for role-play…………………………………………………………170

Figure 9.1: Chronic illness in the elderly typically follows one
   of the three trajectories. (Lynn & Adamson, 2003 p.8)……………………………201
**List of Tables**

Table 3.1: Prevalence (total number of people 000s)

Source: Access Economics 2005 & * 2009……………………………………33

Table 3.2: Incidence (new people diagnosed 000s)

Source Access Economics 2005 & * 2009……………………………………33

Table 3.3: Extrapolated prevalence & incidence of people

with DLB in Victoria…………………………………………………………..36

Table 3.4: Extrapolation of the prevalence & incidence of DLB in Australia

from PD figures. Source figures Access Economics 2007………………..40

Table 3.5 Extrapolation of the prevalence & incidence of DLB in Australia

From PD figures. Source figures Access Economics 2007………………..43

Table 5.1: Grid Header: Relationships - Carers & Medical Profession………………88

Table 5.2: Code for Participants & Spouses……………………………………89

Table 6.1: Demographic information for research participants……………………96

Table 6.2: Carers' reports of diagnoses…………………………………………97

Table 6.3: Carers' perceptions of spouses' early problems…………………………98

Table 9.1: Public profiles of Alzheimer's Australia &

### List of Abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>ACAS</td>
<td>Aged Care Assessment Service</td>
</tr>
<tr>
<td>AD</td>
<td>Alzheimer’s disease</td>
</tr>
<tr>
<td>AAV</td>
<td>Alzheimer’s Association Victoria</td>
</tr>
<tr>
<td>CDAMS</td>
<td>Cognitive Dementia and Memory Service</td>
</tr>
<tr>
<td>ChEI</td>
<td>Cholinesterase inhibitors</td>
</tr>
<tr>
<td>DLB</td>
<td>Dementia with Lewy bodies</td>
</tr>
<tr>
<td>DSM</td>
<td>Diagnostic and Statistical Manual of Mental Disorders</td>
</tr>
<tr>
<td>EACH-D</td>
<td>Extended Aged Care at Home – Dementia</td>
</tr>
<tr>
<td>FTLD</td>
<td>Fronto temporal lobar degeneration</td>
</tr>
<tr>
<td>GP</td>
<td>General Practitioner</td>
</tr>
<tr>
<td>LBDA</td>
<td>Lewy Body Dementia Association Inc. of America</td>
</tr>
<tr>
<td>MMSE</td>
<td>Mini Mental State Examination</td>
</tr>
<tr>
<td>PD</td>
<td>Parkinson’s disease</td>
</tr>
<tr>
<td>PDD</td>
<td>Parkinson’s disease dementia</td>
</tr>
<tr>
<td>PV</td>
<td>Parkinson’s Victoria</td>
</tr>
<tr>
<td>RBD</td>
<td>REM sleep behaviour disorder</td>
</tr>
<tr>
<td>REM</td>
<td>Rapid eye movement sleep</td>
</tr>
<tr>
<td>SFG</td>
<td>Specialists’ focus group</td>
</tr>
<tr>
<td>YOPD</td>
<td>Younger onset Parkinson’s disease</td>
</tr>
</tbody>
</table>
Chapter 1 Initial Engagement

1.1 Introduction

There are some interactions in life that leave an indelible impression. It was in late 1989, I stood in my kitchen preparing a meal over which we were to discuss a forthcoming holiday. My mother asked what time my daughter would be home. I replied and was surprised when, some minutes later, she repeated the question. Again I replied and again, and again, the same question came back. Suddenly numerous disconnects connected and I knew that this was a defining moment in our family’s life. I had the opportunity on that holiday to gently raise my concerns with my father and it soon became evident that our journey with dementia had begun. On our return I contacted my mother’s general practitioner who referred us to a neurologist where the formal diagnosis was made.

Over the following eight years I had the privilege of caring for the carer. Through our interactions I educated, supported, laughed, cried, and grieved with my father as a counsellor, friend and daughter. For me, some of the pain endured during that journey was alleviated by the enriched relationship with my father and my ability to help him adjust to his changing relationship from husband of 50 years to carer. He was able to grieve at a time that was appropriate for him, some years before my mother’s death, and move on with his life which was rich and fulfilling until his death.

During the years of my mother’s illness, whilst I was pursuing my interests in skills training for manual handling injury prevention, I worked as a physiotherapist in aged care; initially in a hospital based extended care unit and then in an aged care assessment team. This provided me with access to current research and medical opinion and I recall attending an in-service seminar in which dementia was defined by two constructs: loss of short term memory and loss of learnt skill. In the ensuing years I worked with many carers, both family and professional, and was often surprised by their lack of knowledge of a disorder that is endemic in our community.
In order to further my career in occupational health and safety, I returned to formal study in 1993 in the field of vocational education and training. However, in 2006, semi retirement and a “tree change” to living in the country beckoned. With time on my hands I volunteered at Alzheimer’s Australia Victoria (AAV) initially in Education Services and then, after completing training, as a Dementia Helpline Advisor. I was also offered a position as a sessional educator. It was in that capacity that I was asked to develop a presentation on dementia with Lewy bodies as it was (mistakenly) thought that I had some understanding of the disease. However, the more that I researched the topic for the presentation the more unsettled and curious I became. With hindsight, I see that this experience was the beginning of a transformational journey for as Butler contends:

....learning is and should be, on some occasions, a
disturbing and unsettling process. If the learning event is
to be transformational, then there must be a period when
the participants are unsettled, wondering and challenged
(Butler, 1996 p.61).

I discussed my findings with colleagues and reflected on community perspectives of dementia and Parkinson’s disease. The notion of exploring dementia with Lewy bodies, and specifically the impact early stages of the disease has on carers, became consuming.

1.2 Context

Dementia with Lewy bodies (DLB) is a common, progressive neurodegenerative disease of ageing. Although those with an interest in vascular dementia may argue to the contrary, DLB is now thought to be the second most prevalent dementia (Brayne, Zaccai, & McCraken, 2006; Hecker, 2002; K Kosaka, 2008; Woodward, 2005), Alzheimer's disease (AD) being the most prevalent. DLB was recognized as a disease relatively recently (1995), although researchers continue to postulate that DLB, Parkinson's disease (PD) and Parkinson's disease dementia (PDD) may constitute manifestations of one disease process – Lewy body disease, with the differential diagnoses being dependent on the sequencing of the symptoms.
I explore DLB and its relationship to both AD and PD in subsequent chapters but, at this point, it is sufficient to say that people with DLB differ in their presentation from people with AD in a number of subtle yet significant ways; the retention of short term memory and fluctuations in cognitive state being two examples of significance, both for the carer and the cared for. The following excerpts from an interactive carer’s forum posted on the American Lewy Body Dementia (their preferred terminology) support site provide examples of the impact this has….

(He) is so much better when people are around that I feel that nobody else knows what my reality is (except you all of course). Feeling that I’m not believed, whether or not this is the case, is isolating.
Words are meaningless to someone who hasn’t seen one of these LBD sufferers (sic) in action.

(He) was very bad when we went in April - so much so that the doctor could hardly do anything with him. In July he was superb - walking, chatting doing everything perfect, even on the Mini Mental test (Anonymous, 2003).

There is a significant body of work that explores the impact of the generically applied term “dementia” and AD on carers, however there is little on the impact of DLB specifically. In the definitive DLB text to-date, a carer provides a personal perspective and states: “DLB is a horrible illness. Anything we can do to be more effective will be worth the effort” (Wilkes, 2006 p.207).

Although I was determined to “do” something I was not sure what that something would be, however I decided that an academic approach would provide me and the study with structure and credibility as it is bound by the requirements of academic discipline. My previous forays into the research world have had a quantitative focus, so many early conceptions of the project used quantitative methods such as large surveys, questionnaires and evaluative paradigms. Although many (Hansen, 2006; Hawe, Degeling, & Hall, 1998; Owen & Rogers, 1999; Patton, 2002) would posit that I
therefore did not have a clear purpose, I would argue that any approach to get “evidence to inform professional practice” (Nutley, Walter, & Davies, 2003 p.126), particularly in an area where there appeared to be none, is purposive. However, I ultimately recognized that I required an inductive approach and therefore a qualitative one. This argument has been well expressed by Black and Rabins who state that:

some research questions are best addressed using a qualitative approach….qualitative research is best suited to questions such as the what how and why of an emotional experience... [and]... is ideal for exploring topics about which little is known (B. S. Black & Rabins, 2007 p.168).

In my explorations of possible routes I was fortunate in that I experienced the reverse of one researcher who, when faced with a similar problem, was “bewildered by the lack of enthusiasm” (Humphrey, 2007 p.14) of supervisors and mentors. My early conversations only raised dilemmas for me to wrestle with, not least of which was whether I could make the transition from a quantitative to a qualitative researcher.

Investigating aspects of an emerging health dilemma from a psychosocial perspective is problematic. It is suggested that randomized controlled trials (RCTs), the most rigorously pursued quantitative form of inquiry in evidence based practice in health care, do not embrace either context or personal experience and are therefore “lacking in explanatory or educative power” (Simons, Thompson, Smith, & Pasqualini, 2006 p.410). These are two dimensions of the experience of DLB that interest me, yet I come from a profession that now champions evidence based practice, particularly RCTs. Fortunately, I am also of an era that is sympathetic to the view that “tacit knowledge has always been an important part of being a skilled practitioner” (Nutley et al., 2003 p.128). Yet tacit knowledge by itself is inadequate when exploring a “green field” and anticipating that the exploration will value add to practice. As the essence of my study was to explore experience a qualitative approach was my only option and so the challenge began.

I stated earlier the notion of exploring DLB, and specifically the impact that early stages of the disease has on carers, became consuming. I am immersed in a self directed search
to find meaning in both the disease and the experience of caring in its presence. Although I have not experienced (and hope not to experience) the exact phenomena of caring for a person with DLB, my experience in dealing with people with dementia and PD and with their carers, my intuition and tacit knowledge combine to reinforce my concerns that this is an experience that differs from that of caring for a person with either other dementias or PD. It also appears to be an experience that is not well understood or catered for. We, as health professionals and as a community, could do better.

These concerns propelled me to further understand and expose the nature of the experience. In essence this is heuristic.

1.3 Heuristic Methodology

1.3.1 Origins

Moustakas (1990) a contemporary American psychologist, is credited as developing the methodology of heuristic research. Moustakas states that the root meaning of heuristic is the Greek word *heuriskein* which means to discover or to find, and he cites numerous educational psychologists and sociologists including Maslow, Polanyi and Rogers, as inspiring his work. Centering initially on the personal experience of loneliness he states:

> I begin the heuristic journey with something that has called to me from within my life experience, something to which I have associations and fleeting awareness but whose nature is largely unknown. In such an odyssey, I know little of the territory through which I must travel……essentially I am creating a story that portrays the qualities, meanings, and essences of universally unique experiences (Moustakas, 1990 p.13).

1.3.2 Phases of Heuristic Research

Moustakas (1990) details six phases of heuristic research: initial engagement, immersion, incubation, illumination, explication, and culmination in a creative synthesis. These phases resonated with my conceptions of the development of this
study; the engagement came per chance and the immersion – the process through which I developed a deeper understanding of the nature of DLB and the caring experience stimulated me to keep probing and questioning. The academic process, confirmation of candidature and ethics approval, facilitated incubation, the third stage of the process and made me “retreat from the intense, concentrated focus on the question!” (Moustakas, 1990 p.28) The final three phases may be classified as “the research”. The illumination phase in Moustakas’s terms is “the awakening to new constituents of the experience, thus adding to new knowledge” (1990 p.29). This was the data collection phase, the explication phase, the analysis of that data and the creative synthesis the resulting discussion. The processes of immersion and incubation were also elements of these phases in that I, as the researcher, lived with and in the experience under investigation.

Heuristic research has been summarized as: “What is my experience of this phenomenon and the essential experience of others who also experience this phenomenon intensely?” (Patton, 2002 p.107). Douglass and Moustakas (1985) explain that heuristic inquiry emphasizes connectedness and relationships, leads to depictions of essential meanings and portrayal of the intrigue and personal significance that imbue the search to know. The research concludes with a creative synthesis that demands the voice (intuition and tacit knowledge) of the researcher and the representation of the co-researchers or research participants as whole persons. Within the methodology of heuristic inquiry, Moustakas (1990) is prescriptive in the methods that the researcher should employ in preparation, data collection, organizing and synthesising data and the analysis of data. Those guidelines underpin the process utilized in this study and are discussed in Chapter 5.

1.4 Conceptual Framework

At its core this project is a psycho-social study of carers – their perspectives, interactions with the cared for, their families, health professionals, those in support services, me, as the researcher, and the meanings those carers make from their interactions. It seemed apt therefore in establishing a conceptual framework to consider the work of George Herbert Mead, a pragmatist and social psychologist lecturing at the University of Chicago in the early 1900s. Charon, in a discourse on Mead, defined pragmatism as a school of philosophy that emphasises that:
the human intervenes in determining what is real, knowledge is judged by the individual according to its usefulness, objects too are defined according to their use and humans must be understood through what they do in the world (Charon, 1989 p.30).

Mead lectured prolifically on the development of the individual as a social being and his students collated the material from his courses into a text (Hewitt, 1997). Mead defined intelligence as “the ability to solve the problems of present behaviour in terms of its possible future consequences as implicated on the basis of past experience” (Mead, 1956 p.178). He developed a construction of “self” as a social process that has an “I” and a “me”. He saw “I” as impulsive and needs driven – the initiator of action and describes the “I” as the acting subject where “action always is initially unorganised and undirected ..... for it represents a response to something” (Hewitt, 1997 p.51). In contrast the “me” “is a set of organised attitudes of others that the individual himself assumes - those perspectives on oneself that the individual has learned from others” (Wallace & Wolf, 2006 p.206), the “me” setting the limits within which the “I” can act. Mead wrote:

\[
\text{The self is essentially a social process going on with these two distinguishable phases. If it did not have these two phases there could not be conscious responsibility, and there would be nothing novel in experience (Mead, 1934 p.178).}
\]

In his lectures Mead developed these themes in relation to self action, the conversations one has with oneself and group action where attitudes are aligned to those of the group with which one is interacting. It was Herbert Blumer who first coined the term symbolic interactionism to embody Mead’s work with other sympathetic scholars including Dewey and Cooley (Blumer, 1969).

1.4.1 Symbolic Interactionism

Blumer argued that symbolic interactionism is:
grounded in a number of root images: human groups or societies, social interaction, objects, the human being as an actor, human action and the interconnection of the lines of action (Blumer, 1969 p.6).

This framework has been interpreted by numerous sociologists since (for example Charon, 1989; Hewitt, 1997; Lauer & Handel, 1983; Wallace & Wolf, 2006) with significant attention being given to “objects”. Objects are central to the concept of the symbol in symbolic and are the product of symbolic interaction as an object is anything that is pointed to or referred to (Blumer, 1969). Blumer classifies objects into three categories, physical, social and abstract and Charon suggests that “objects are pointed out, isolated, catalogued, named, interpreted and given meaning to as we interact with others” (Charon, 1989 p.37) – they are the symbols that we use for representation and communication in our daily lives, both when we interact with others or with ourselves. This interpretation clarifies Mead’s discussions on the “I” and the “me” as the “me” can be viewed as an object or symbol by the “I”.

A more simplistic explanation of symbolic interactionism is offered in a recent paper, investigating the lived experience of undergoing augmentation mammoplasty, in which the authors state:

symbolic interactionism consists of three core principles, namely: meaning, language and thought. These core principles lead to conclusions about the creation of a person’s self and socialization into a larger community (Wu, Chung, & Chang, 2007, p.108).

Wallace and Wolf’s (2006) interpretation of Blumer’s writings provided a cogent framework for this study. In their discourse they substituted “thing” for “object” and to set my framework I paraphrased their words substituting my own “objects”. Therefore in exploring my research questions, I took a symbolic interactionist’s perspective being that:
1. People act towards their relatives, health professionals, support services, themselves and wellness/illness, on the basis of the meaning that those people and wellness/illness has for them;

2. The meanings of relationships and wellness/illness arise out of the social interaction people have with each other; and

3. The meanings of relationships and wellness/illness are handled in and modified through an interpretative process used by people in dealing with the issues they encounter.

This perspective provided a useful paradigm through which to explore not only my research question, but also some of the intriguing quandaries of DLB that compound the complexities of the understanding of this disease.

1.5 Research Question

DLB and the challenges it presents has “captured my imagination and is also considered sufficiently important or interesting by others” (Hansen, 2006 p.42). Consequently I developed this study through exploration of the research question:

What is the experience of caring for a person with dementia with Lewy bodies?

In order to provide some focus within this question, the following four questions provided guidance in the exploration:

1. To what extent do carers’ perceptions of impairment provide evidence for the differential diagnosis of DLB?

2. How do carers’ perceive and experience the changes in their relationship with the person being cared for and with others from the onset of change until diagnosis?

3. To what extent does knowledge impact on perceptions of the experience of caring?

4. What are the implications for carer support services?

In focusing my research question to areas that hold personal relevance to me, I was conscious of two predicaments that could be contentious from the research perspective
and my choice of heuristic methodology: (1) the evaluative component of the study, implicit in the last question, and (2) the insider-outsider paradigm.

Central to the concept of evaluation are three entities: commissioner, client and evaluator. When, as in this study, the three entities are one it is considered an extreme of evaluative practice (Owen & Rogers, 1999). House (1980) uses the term private evaluation to categorize this situation. These authors suggest that private evaluations are not open to wider audiences and are a tool for self development. Yet self development is at the heart of heuristic inquiry, as is Butler’s (1996) notion of transformational learning. Where I perceived that conflict could arise was in the “what next” discussions of the final chapters. A possibility, right from the commencement of the study, was that my journey had the potential to influence practice and from its inception senior members of staff, at Alzheimer’s Australia Victoria and the Parkinson’s Association, were cognizant of the study, supportive of it and anxious for the findings. There was an expectation that, as the study progressed, staff from those agencies could be involved in some capacity, however neither agency commissioned any aspect of the study nor were they clients.

My insider-outsider status was also blurred. I have referred previously to the bewilderment of Humphreys who suggested that “the fertility of the project hinged upon my capacity to activate the hyphen by journeying between different life-worlds” (Humphrey, 2007 p.11). Although I doubted that I would be faced with personal, professional or political dilemmas, I was aware that I was “sitting on the hyphen” particularly from an heuristic perspective. It is feasible to present myself as a secondary not primary carer of a person with Alzheimer’s disease not DLB, a retired physiotherapist not a medical practitioner or sociologist, a sessional, contracted educator with AAV not a staff member of AAV or the Parkinson’s Association. On the other hand I can say that I have first hand knowledge of the caring experience of a person with dementia, as an allied health professional in numerous roles I have assessed and worked with clients with dementia and Parkinson’s disease, and I counsel and educate families and professional carers of people with dementia. Consequently I expected to move between the two worlds driven by the want to know because I want to know paradigm of personal enquiry (Patton, 2002) and the core of heuristic inquiry;
“the experience in a vital, intense and full way - if not the experience as such, then a comparable, or equivalent experience” (Moustakas, 1990 p.14)) enriched with intuition and tacit knowledge.

1.6 Structure of the Thesis

The purpose of this chapter is to provide an outline of the research topic, explain briefly both the methodological and a conceptual framework used in the study and to articulate my research question. This, in the words of Moustakas (1990), is the initial engagement.

I started with an “I” perspective, firmly siting myself in the journey, because of the heuristic nature of the research. At the same time I was mindful of Sela-Smith’s caution that:

When heuristic research is initiated to fulfil dissertation requirements for graduation instead of growing out of the very being of the researcher, it is possible that the researcher may not be intimately and autobiographically connected to the question (Sela-Smith, 2002 p.66).

In a similar manner to Sela-Smith (2002), who understood a deep connection to her topic in a reflective sense, I realized after the fact that the process I was experiencing and writing about paralleled the Moustakas method precisely and that all I was missing was the label. So how did I proceed?

In the subsequent Chapters, 2-4, I immersed myself in exploring DLB and its relationship to AD and PD and the caring experience. I moved between my worlds, seeking understanding both from my perspective as an educator, with an established knowledge base, and the perspective of the “other” whom, I anticipate, may ultimately benefit. I explored the process of incubation and justified my chosen methods to illuminate and explicate the experiences of my co-researchers in Chapter 5. Chapter 6 provided some insights into the research participants and their individual journeys in identifying and adjusting to life with their spouses and neurodegenerative disease. That is followed by a thematic analysis of the data in order to explicate the experience.
My interpretation of their experiences and the meaning that I have made of the experience of caring for a person with DLB is presented as a creative synthesis (Moustakas, 1990) in Chapter 8. The synthesis takes the form of an audio visual presentation (DVD) of me role playing a spouse coping with a partner with DLB. The development of a creative synthesis fulfilled two goals. Firstly, it satisfied the demands of my chosen methodological approach and hence provides academic coherence. Secondly it gave me a powerful resource through which I can educate the “other”. The “other” is multifaceted. Ultimately, I envisage that the DVD will be a useful educational resource through which I can present the experience of caring for a person with DLB to new carers, the general public, health professionals and formal carers.

From a heuristic perspective I could argue that, with the development of the creative synthesis my journey was complete, however the symbolic interactionist’s perspective is that meaning is socially created. Consequently, the penultimate chapter addresses the societal implications of caring in the presence of DLB - lack of knowledge, understanding, resources – and in the final chapter I reflect on my journey and project a way forward for carers of people with DLB.

To understand the experience of caring for a person with DLB my first task was to understand, at least at an elementary level, DLB from an anatomical and pathological perspective. That is the topic of the next chapter.
Chapter 2  Dementia with Lewy Bodies (DLB):
Interpreting the Research Literature

In this and the following chapter I explore the phenomenon that is DLB. My reading has led me to explore a significant body of scientific research dedicated to this topic that has informed my understanding of the disease but which, for the purposes of this study, I will not address in depth. Details of much of the epidemiology, histo-pathology and genetic research are outside the scope of the study and the intricacies of the pharmacology and medical management of the condition are certainly best left to psycho-geriatricians and neurologists.

My aim is to understand the subject myself and to reflect that understanding in a manner which is accessible to carers, recognizing that I will need to be able to do that when interacting with my research participants and sharing my knowledge with others.

Consequently, before tackling DLB, I need to start at the beginning with a review of some neuro-anatomy. As a student physiotherapist I was daunted by the complexities of the brain and I can identify with an editorial in the British Medical Journal which suggests there is “a ‘neuropobia’ that arises from the deficiencies of undergraduate medical education”. I am reassured that the editorial continues:

> knowing how to deal with common neurological problems
> requires little knowledge of complicated neuro-anatomy,
> and the neurology needed to manage patients with Parkinson’s disease, dementia or strokes is well within the ability of students who enter medical school with plenty of “A”s (Kale & Menken, 2004 p.63).

So it is time to address my phobia.

2.1 Basic Neuro-Anatomy

There are numerous texts on this complex topic and our understanding of the brain and how it works comes from the work of neuroscientists and pathologists who have studied human behaviour, anatomy and the impact of illness and injury. With the increasing sophistication of neuro-imaging techniques and computer aided modelling our understanding has been significantly enhanced through science programs on television.
In updating my knowledge on neuro-anatomy, as an educator at AAV and for this study, I have relied extensively on a text by John Nolte (2001) and I acknowledge him as the source for much of the following. It is the text used in undergraduate education in our medical schools and although it is described as an elementary text it has been more than sufficient for my needs in gaining insight into, and in expressing a simplistic account of, an amazing and complex structure.

2.1.1 The Nervous System

The nervous system is traditionally classified as having two parts - the central and peripheral. The central part is the brain and spinal cord and the peripheral refers to the nerves in the rest of the body that carry the messages to and from the central system. My focus is the central nervous system (CNS) and in particular the brain. The brain is made up of billions of nerve cells or neurones that are organized into discrete units that have particular functions.

2.1.2 A Typical CNS Neurone

Although they come in a variety of shapes and sizes there are common basic components to each neurone. Analogy is useful in conveying complex information - the Lego® approach (Rothhaar, Pittendrigh, & Orvis, 2006) is used extensively to teach students the fundamentals of genetics and a Nobel laureate recently likened telomeres – the protective sections of DNA at the ends of chromosomes to the plastic seals on the end of shoelaces (Blackburn, 2010). Using an analogy one way to visualize neurones is to think of a bunch of spring onions lying haphazardly on the kitchen bench. Each spring onion represents one neurone. The roots represent the area of the neurone known as the dendrites that receive messages from other neurones. The messages arrive in the form of a chemical substance or neurotransmitter. Commonly known neurotransmitters are acetylcholine, dopamine and serotonin. Once the dendrites come in contact with the chemical, the message is sent to the bulb of the onion, the cell body, usually as an electrical signal. In the cell body the message is interpreted and the response (or next message) is sent out along the green part of the spring onion, the axon. When the message gets to the end of the axon the electrical current causes the bursting of the flower or small sacs of neurotransmitters that carry the message to the dendrites or roots of other onions and so the messages are continuously received, interpreted and sent. The
bulb of the onion, the cell body is also responsible for the metabolic function and life of the neurone.

In our brains the neurones are not haphazardly strewn. They are arranged in an amazingly complex system that allows us to function – to meet our basic needs and survive and to be human, to think, reason, plan, communicate and experience life. Specific groups of neurones have specific functions and are concentrated in the different parts of our brains – the cerebrum, brain stem and cerebellum.

### 2.1.3 The Cerebrum

From an anatomical perspective the cerebrum is divided into three sections: (1) the cerebral hemispheres which are our doing and thinking brains; (2) an area called the diencephalon which is the area of the brain that can be thought of as the central processing unit, as all messages between our thinking brains and our bodies, except what we smell, pass through this area; and finally (3) the basal ganglia, a collection of neurons closely associated with the brain stem and important for movement control. An image of the brain that is commonly explored in dementia education is shown in Figure 2.1.

The cortical area of the cerebrum, the areas labelled in Figure 2.1 as lobes, is called the cortex, new brain or grey matter. Each lobe has conglomerations of neurones that have specific functions which are usually the same on the left and right side of the brain.

Each occipital lobe has an area that is responsible for interpreting what is seen and the surrounding area is called the visual association area. No area of the brain can be considered in isolation as the pathways between areas are numerous and complex. The occipital lobe extends into the temporal lobe, which, as well as processing visual messages is responsible for interpreting what is heard. On the dominant side of the brain in the temporal lobe there is an area that interprets language. The temporal lobe is often considered as the part of the brain responsible for memory, but it is now recognized that the formation of memories is associated with structures that lie adjacent to the temporal lobe and deeper within the brain.
The parietal lobes are the areas of the brain where there are some significant functional differences on the left and right sides. Both sides are responsible for interpreting the sensory information from our bodies – touch and joint position or proprioception (as well as visual stimuli through connecting pathways from the occipital cortex). The dominant (usually left) parietal lobe is associated with language, mathematical ability and problem solving and sequential activities like cooking, dressing and shopping, whilst the right is often referred to as the creative side. The main functions of this artistic parietal lobe are drawing and musical ability and the ability to understand our surroundings and our place in them – often referred to as spatial perception. This is an important perception implicated in activities as diverse as finding the way home, finding the car in the car park, threading a needle or fixing a broken piece of furniture, to simple things like understanding the height of a chair before sitting on it.

The last lobe in Figure 2.1 is the frontal lobe. One part of the frontal lobe is called the motor cortex and is the area of the brain that is responsible for organizing our voluntary movement. There is another area that is responsible for our ability to communicate through written and spoken language that we initiate. The rest of the frontal lobe is concerned with Mead’s “me” (refer p.7). Nolte, in labelling this area the prefrontal cortex states that it is the area that can “very generally be described as personality, insight and foresight” (Nolte, 2001 p.60).
If the brain is presented as if it were separated in two, as in Figure 2.2, it is possible to grapple with some of the areas often ignored in educational sessions for carers but pertinent to understanding memory and particularly DLB.

![Figure 2.2: Medial view of the brain from Nolte, 2001, p. 58](image)

The areas of the cortex already discussed can still be seen but now it is possible to also see the limbic lobe, the diencephalon or central processing unit, and more of the brainstem and cerebellum.

Broadly speaking, the limbic lobe is Mead’s “I” (refer page 7) as it is the area of the brain that is associated with drive-related behaviour, impulses and importantly, aspects of learning and the creation or encoding of explicit memories associated with experiences (episodic memory) and knowledge (semantic memory).

### 2.1.4 The Brain Stem

The brain stem is often referred to as the “old brain”. It is the connection between the cerebrum and the spinal cord. Put simply, it is also the spinal cord of the head in that it contains the neurones and pathways associated with touch, temperature and positioning sensations of our head and face. As well, it is responsible for the other special sensory and motor aspects of smell, sight, eye movement, chewing, facial expression, hearing, balance, taste, and swallowing. An additional function is to regulate and integrate the
basic functions of our body that we do not have to think about at a conscious level and take for granted until something goes wrong – activities like breathing, sleeping, having a heart beat and digesting our food, eliminating waste and our flight or fight system.

This is an extremely complex system of interconnecting neurones, neural bodies (or collections of neurones responsible for a particular function) and pathways or tracts. The old brain concept comes from the notion that this part of the brain is the elementary brain of our evolutionary ancestors in that it regulates our basic survival.

2.1.5 The Cerebellum

The final part of the brain visible in both Figures 2.1 and 2.2 is the cerebellum or ‘little brain’. Many of the sensory and motor messages detour through this area of the brain because its main function is to fine tune our equilibrium, posture and movement such as our ability to react to stimuli and make changes to keep walking if we turn a corner in the city and get hit by a howling wind and a crowd of people. More recently it has been found that the cerebellum is also implicated in skill learning and habitual memory.

2.1.6 Learning and Memory

Learning and memory are significantly demanding on brain power. Researchers are now recognizing the complex pathways associated with these functions and how we as human beings refine innate abilities to meet our needs. An example of this capacity and complexity is the concept that when six months old we can differentiate the facial features of lemurs, but by ten months we intuit that particular skill as one that we can discard (Winston, 2007). Gabrieli provides a succinct view of the development of this aspect of neuroscience:

Studies of patients with brain lesions have provided the foundations of our knowledge about the biological organization of human memory. Lesions have produced dramatic and often unexpected mnemonic deficits that provide clues about which brain regions are necessary for which memory processes.....Although lesion studies continue to provide new evidence, functional neuroimaging studies using positron emission
tomography (PET) or functional magnetic resonance imaging (fMRI), now permit the visualization of memory processes in the healthy brain (Gabrieli, 1998 p.88).

Memory has its own taxonomy: working memory, short term memory, long term memory, declarative (explicit) memory, implicit memory, skill learning and habits to name some. Each facet of memory is being explored to determine the areas of the brain that are used. Working memory is said to be:

- a central cognitive function at the interface of perception and action. It is assumed to operate whenever information has to be retained and manipulated over brief periods of time to guide an immediate response (Linden, 2007 p.257).

This memory is primarily a function of the cortex, where verbal and visual pathways are integrated by areas of the frontal and parietal lobes. Recent research (Chang, Crottaz-Herbette, & Menon, 2007) has shown that the basal ganglia also have an integrative role.

Closely associated with working memory is short term memory where the information is retained, and it is thought that the hippocampus, an area in the limbic lobe, gives the information a global context, modulates the worth of the memory and, if merited, accelerates the learning process (Pan & Tsukada, 2006). The hippocampus appears to be a critical pathway in forming memories. It has been found that people who have had limbic encephalitis, resulting in damage to the hippocampus, were not only unable to remember, but were also unable to imagine new experiences (Hassabis, Kumaran, Vann, & Maguire, 2007).

Another collection of neurones in the limbic lobe is the amygdala. Whilst it is believed that the hippocampus is critical in creating memory, the amygdala is thought to be responsible for the emotional component of learning and memory, particularly in episodic memory (see Lucas, 2005; Masella & Meister, 2007; Nolte, 2001; Tully, Li, Tsvetkov, & Bolshakov, 2007). Put simply, the hippocampus works out what to
remember, and the amygdala works out how we remember it – as a happy, sad, fearful, poignant episode.

Although the limbic area is responsible for the formation or encoding of memory, it is thought that memories live or are retained in the association areas of cortex and are retrieved by activating enough “subcomponent constituent features to reconstruct the memory” (Lucas, 2005 p.591) – a complicated process requiring good neural connections.

Skill learning and habits are different forms of memory involving physical (motor) activity as well as some degree of cognition. Knitting, running and driving a car are examples of skill learning, as are table manners and many acts of personal hygiene. Learning of this type is thought to involve areas of the cerebellum and the motor areas of the cortex, particularly the basal ganglia (Gabrieli, 1998; Nolte, 2001). However, there is ongoing debate about the specific contribution each area makes in association with error detection and repetitive patterning; one study suggests that there is an independent (non motor) habit-learning system located in the basal ganglia (Witt, Nuhisman, & Deuschl, 2002). Parts of the basal ganglia, the caudate nuclei, appear to be particularly important in the emotional aspects of drive related behaviour and Heimer and Hoesen (2006) assert that the cholinergic basal nucleus of Meynert serve as the interface between the limbic lobe and the rest of the association cortices. The consensus is that there are three re-entrant circuits from the basal ganglia:

1. the reward-guided choice behaviour loop;

2. the executive circuit for planning and working memory; and

3. the motor circuit.

This excursion into the function of the brain and memory adequately demonstrates both the complexity and mystery of the mind, perceived by Mead as actions that take place whenever problems arise in situations and by Blumer as a continuous process of individuals making indications to self all day long (Charon, 1989). Importantly, it sets the scene in understanding DLB and subsequently its relationship to AD and PD.
2.2 Dementia with Lewy Bodies

Dementia with Lewy bodies (DLB) is a progressive neurodegenerative disease of ageing which, until the 1990s, was poorly understood and often misdiagnosed (O’Brien, McKeith, Ames, & Chiu, 2006). The first international meeting on DLB was convened in 1995 and the third meeting of the DLB Consortium was held in Newcastle upon Tyne (UK) in September 2003. After a follow up meeting in Washington in September 2004, the revised consensus criteria for the clinical and pathological diagnosis of the disease were released by the DLB Consortium (McKeith et al., 2005).

2.2.1 Pathological Criteria

The pathological criteria are not of significant relevance to this study except for providing information on the areas of the brain that are affected in the disease. Lewy bodies are identified through biochemical and immunohistochemical staining of brain tissue collected after death. They are accumulations found predominately in cell bodies and are composed primarily of alpha-synuclein (asynuclein) (Dickson, 2006), hence the disease is referred to as an asynucleinopathy. Although it is not known why, some neurones are more vulnerable than others, and in some areas of the brain these bodies are also seen in the processes of the cells, the dendrites and axons, alongside or as a successor to abnormal formations called Lewy neurites (Dickson, 2006; Jellinger, 2004). asynuclein is a naturally occurring protein which is made by the neurones and associated with the chemical transmission of messages from one neurone to another (Dickson, 2006). There is still conjecture as to whether the Lewy bodies are cause or effect of cell death (O’Brien et al., 2006), but there is some evidence to suggest that ‘something goes wrong’ in that there is a mutation or translation of the glucocerebrosidase gene in the mitochondria or the power generating plants (Goker-Alpan et al., 2006; Willet, 2006). The product of this gene is an enzyme which balances the amount of the protein.

There is some new evidence to suggest that the underlying pathological changes that occur in DLB are extra cellular aggregations at the synapse which do not lead to cell death (as is reported in the majority of the literature) but to a loss of synaptic function.
(Kramer & Schulz-Schaeffer, 2007; McKeith, 2009). In clarifying this research Schulz-Schaeffer stated:

> the problem seems to be the decrease of transmitter release from the pre-synapse, which leads to degeneration of the post-synapse...we [are] working on the link between the presynaptic protein aggregation with postsynaptic degeneration, aspects of the spread of the disease, and aspects of the selective neuronal vulnerability (Schulz-Schaeffer, 2009).

Early studies indicated that the vulnerable areas of the brain were the brain stem, areas of the limbic lobe and diffuse areas of the other lobes of the cortex. However, increasingly sophisticated staining is finding that many of areas of the brain stem, basal forebrain, hypothalamus, amygdala and temporal cortex, as well as the spinal cord and autonomic ganglia can be affected (Dickson, 2006; Ferman & Boeve, 2007). The areas most affected in the brain stem are the nuclei of the vagus nerve that regulates and integrates some of the basic functions of the body, and the glossopharyngeal nerve, associated with taste, swallowing and salivation, the locus ceruleus in the brain stem and the substantia nigra of the basal ganglia. The latter two areas, the locus ceruleus and the substantia nigra have specific functions.

The locus ceruleus is the flight / fight centre. The axons from this area synapse to other neurones throughout the brain and use the chemical associated with adrenaline as their transmitter. Nolte reports that these cells are:

> nearly silent electrically during sleep, become somewhat active during wakefulness and are most active in situations that are startling or call for watchfulness.....they play a role in attention and vigilance (Nolte, 2001 p.281).

The substantia nigra has a close association with other deep structures that are responsible for aspects of movement, cognition and the initiation of drive related behaviour (Nolte, 2001). In contrast to the neurones of the locus ceruleus, the neurons of the substantia nigra use dopamine as their neurotransmitter, and it is thought that
interaction between these neurones, neurones in the locus ceruleus and cholinergic neurones in the basal ganglia assist in the regulation of wake/sleep cycles.

Magnetic resonance imaging (MRI) studies have also shown discrete clusters of pathology in the cholinergic basal nucleus of Meynert (Whitwell, Weigand, & Josephs, 2007), an area of the brain that floods the cortex with acetylcholine – the neurotransmitter usually implicated in Alzheimer’s disease.

Although neuropathologists use the locations of the Lewy bodies to classify the type and intensity of the pathology for research purposes (Dickson, 2006), the clinical manifestations of the illness also reflect the areas of brain that are affected.

2.2.2 Clinical or Diagnostic Criteria

The criteria (McKeith et al., 2005) are grouped to provide clinicians with the ability to diagnose probable and possible DLB in people who present with a range of symptoms (any subjective evidence of disease) and a range of signs (any objective evidence of disease). The intricacies of probable and possible are academic to this study; however the groups provide a framework through which the disease can be classified and I have represented them in Figure 2.3 below, a graphic that I use in my presentations.

Central Feature

The central feature of DLB is dementia; defined as progressive cognitive decline of sufficient magnitude to interfere with normal social or occupational function (other definitions of dementia are discussed in Chapter 3). The DLB Consortium emphasise that prominent or persistent memory impairment may not be an early feature of the disease and that fronto-subcortical (attention and executive function) and parietal (visuospatial) symptoms are more prominent.
The fronto-subcortical deficit means that a person with DLB may have difficulty with their executive functions and working out probabilities (see Salmon & Hamilton, 2006; Witt et al., 2002), for example, ‘if I don’t put money in the bank I probably won’t be able to pay the wages’; ‘if I don’t do the shopping I probably won’t have anything for dinner’ – rather than just forgetting things. Consequently, life seems muddled and a bit confusing, but it is often difficult to pinpoint exactly what is amiss. Anecdotally I have heard this deficit expressed as ‘the work/business just got a bit much for Dad to manage so he decided to retire/sell early’. Bradshaw, in her seminal research on DLB, AD and attention succinctly states:

*attentional deficits (are) most pronounced under task conditions that require more active recruitment of executive control and visuo-spatial cognitive processes* .........mediated by cortical and subcortical mechanisms
Although the visuo-spatial and constructional deficits that contribute to this muddled picture have been attributed traditionally to the disease process in the parietal lobe, Salmon and Hamilton (2006) report on a number of neuroimaging studies that show significant pathology in the occipital lobes of people with DLB.

**Core Features**

As well as the central feature of dementia, a person must have at least one, but usually two core features to be diagnosed with DLB. The core features are fluctuating cognition, visual hallucinations and features of parkinsonism.

Fluctuating cognition can be translated loosely as good days (hours) and bad days (hours) and rising to the occasion. Meg Wilkes, writing from the caring perspective in the seminal text on DLB, said of her husband:

> For years, professional and lay people alike normalized his mental state and disregarded or rejected my attempts to alert them to the changes. Several times, they even told me that if what I was saying was true, I was the cause of it. It seemed as though my descriptions of his changing behaviour were taken by clinicians as nothing more than criticism of their charming patient (Wilkes, 2006 p.213).

Although the literature does not offer an explicit explanation for this phenomenon, McKeith and Schulz-Schaeffer (Alzheimer Research Forum, 2009) raise the possibility that the synaptic dysfunction may be a potential explanation. It is stated that it is a significant feature in 50-90% of people with the disease (Cercy & Bylsma, 1997) and has a significant independent impact on activities of daily living (Ballard, Walker, O'Brien, Rowan, & McKeith, 2001 p.494). Researchers (Bradshaw et al., 2006) investigating attentional impairment and fluctuating attention using an experimental computerised reaction time paradigm in AD, DLB and healthy subjects found that in their DLB group:
fluctuation is a multidimensional phenomenon, characterised by fluctuation not only in attention but also in behaviour, functional abilities and cognitive function more generally. .......gross, clinically observable fluctuations in behaviour and functional ability may be cognitively modulated, depending on situational factors and the degree to which demands are being placed on impaired cortical functions (Bradshaw, Saling, Hopwood, Anderson, & Brodmann, 2004 p.1134).

Neef and Walling (2006) describe fluctuating cognition as delirium or pseudo-delirium and suggest the following as typical: daytime drowsiness and lethargy, daytime sleep of more than two hours, staring into space for long periods and episodes of dis-organized speech which occur over minutes, hours or days.

Visual hallucinations are an early indicator of DLB and are described as complex detailed brightly coloured three-dimensional images of people and animals that are of normal size, animated and complete (McKeith et al., 1996 p.1119). Although people with DLB see people, often relatives, and animals (and sometimes insects, fire, birds and objects (Apostolova & Cummings, 2006)), their reactions can range from indifference to amusement, fear and anger (McKeith et al., 1996). Reports of the incidence of visual hallucinations vary considerably (13-93%) (see Apostolova & Cummings, 2006; Ballard & Oyebode, 1995; McKeith et al., 1996). However Apostolova and Cummings (2006) report that hallucinations are the earliest indicator of the disease in 14-18% of people. Harding (2002) also claims that they are more pronounced when the deep temporal and limbic structures are affected.

A presenting feature of DLB in a range of people (10-78% (Burn, 2006)) is the presence of a number of motor signs usually referred to as “small p parkinsonism” or extra pyramidal tract signs. While features of parkinsonism do not equate to Parkinson’s disease as it is commonly understood (I explore this in greater depth in the next chapter), parkinsonism indicates evidence of disease in the basal ganglia and substantia nigra, areas associated with the neurotransmitter dopamine (Nolte, 2001). The motor problems commonly seen in people with DLB are rigidity (or stiffness of the whole
body), lack of facial expression, an inability to control the muscles of the trunk leading to a stooped posture, difficulty with walking and a high risk of falls (Burn, 2006). There are also some other more subtle motor signs associated with reflexes and eye movements that require clinical examination to elicit.

**Suggestive Features**

Added to the central and core features of the disease are a number of other features that, if present in a person at examination, are suggestive of a diagnosis of DLB. They are REM sleep behaviour disorder, severe neuroleptic sensitivity and low dopamine transporter uptake in the basal ganglia demonstrated by single photon emission computed tomography (SPECT) or positron emission tomography (PET) imaging.

Rapid eye movement (REM) sleep is the sleep of dreams. When a person sleeps, complex (yet to be fully understood) neural pathways are activated to paralyse the skeletal muscles so that the body can lie quietly in bed in a state of atonia (or temporary paralysis) whilst the mind is engaged in all manner of vivid experiences (Thomas, Bonanni, & Onofrj, 2007). Recently it has been suggested that the hippocampus is also inactive which explains why dreams are fleeting (Cai, Mednick, Harrison, Kanady, & Mednick, 2009). In REM sleep behaviour disorder (RBD) something prevents the atonia and consequently, people act out their dreams. For a person to be diagnosed with RBD, poly-somnographical studies (sleep studies where a person is monitored and videoed in a sleep laboratory) must show limb or body movement associated with dream activity, and at least one of harmful or potentially harmful sleep behaviour, acting out of dreams, or disturbed sleep patterns (Thomas et al., 2007). In every day life it is anecdotally reported that people with RBD hit, knee or try to attack their sleeping partners, fling their limbs around knocking lights off bed side tables, or leap out of bed as though being chased.

RBD is an area of significant research interest as it affects more than 75% of people with DLB (Boeve et al., 2007). There is an increasing body of work to suggest that it is an early predictor of neurodegenerative disease, particularly synucleinopathies like DLB (see Boeve et al., 2007; Stiasny-Kolster et al., 2005; Terzaghi et al., 2007; Thomas et
Apostolova and Cummings (2006) report that RBD predates dementia by an average of nine years.

Severe neuroleptic sensitivity is, in simple terms, an allergic reaction to medication. Unfortunately this allergy can be discovered in one of two ways. Without delving into the complexities of pharmacology, sometimes a drug is given to a person and their response to it is monitored in order to clarify a diagnosis. For example, a person with Parkin disease (a genetic form of Parkinson’s disease) will react positively and rapidly to a drug which increases the levels of the neurotransmitter dopamine, and the reaction is considered diagnostic. In other cases clinicians treat a person’s symptoms without having a definitive diagnosis. According to McKeith about 50% of people with DLB, both diagnosed and undiagnosed, have a severe allergic reaction to neuroleptic drugs, the most commonly known being haloperidol or Serenace, which are used to treat hyperactivity, agitation and aggression. In severe cases a person can develop neuroleptic malignant syndrome which is life threatening. Consequently these drugs should not be used to confirm a diagnosis (McKeith et al., 2005) or, if prescribed without a definitive diagnosis, the person should be monitored very closely for adverse reactions. Less life threatening adverse reactions to these drugs include an increase in parkinsonism, seen in up to 81% of people (Apostolova & Cummings, 2006). Adverse reactions are strongly suggestive that the diagnosis is DLB (McKeith et al., 2005).

The final suggestive feature is low dopamine transporter uptake in the basal ganglia demonstrated by SPECT or PET imaging. The easiest way to explain this is to imagine watching a science show on television about the brain. At some point a person will be wheeled into the large tunnel of a scanner or sophisticated type of X-ray machine and then parts of their working brain will light up on the computer monitor in the control room. Someone will be saying ‘you are doing well, almost done’ while everyone else will be fascinated by the green and red bits lighting up on the screen. PET imagining is the basic model of this process.

PET is an imaging technique which uses small amounts of radioactivity to help in the diagnosis of disease (Austin Hospital, 2007), in this case DLB. Small radioactive particles or ligands which attach to dopamine are introduced into the body, either by
injection or inhalation of a gas (O’Brien & Colloby, 2006), and a PET scanner produces an image showing the distribution of the dopamine in the basal ganglia. SPECT imaging produces a 3D version. This type of imaging is used at Austin Health to differentiate between DLB and Alzheimer’s disease in people with complex presentations.

Supporting Features

The DLB Consortium (McKeith et al., 2005) lists ten supporting features (see Figure 2.3) commonly present in people with DLB but not proven to have diagnostic specificity. A number of these features can have significant impact on the activities of daily living (ADL) for the person with the disease and for their carers, whilst some are only demonstrable through sophisticated medical investigations (Kenny & Allan, 2006). Most of the symptoms associated with the supporting features of DLB relate to Lewy bodies in the brain stem, particularly the cranial nerves and pathways that regulate the autonomic or involuntary functions of the body.

There are two major manifestations of the supporting features that impact on ADLs and the quality of life (Allan, McKeith, Ballard, & Kenny, 2006). The first manifestation is syncope or a loss of the body’s ability to regulate postural tone. Something like fainting, it results in a drop of blood pressure, a slowing of the heart beat and loss of consciousness (Zaqqa & Massumi, 2000). This can happen in a range of situations: when walking, resulting in repeated falls, or when sitting, and it is often accompanied by excessive day time drowsiness. Blood pressure can also drop suddenly when a person changes position, for example lying to sitting, sitting to standing or when straightening up after bending over to pick something up off the floor. This is called orthostatic hypotension.

The second manifestation, and thought to be more prevalent, is bladder, bowel and sexual dysfunction. Retrospective studies have shown that 97% of people with DLB have urinary incontinence, and 83% have constipation (Horimoto et al., 2003; Kenny & Allan, 2006). Other symptoms of autonomic failure can include dry mouth, dry eyes, bloating, nausea, vomiting and an inability to regulate body temperature (Kenny & Allan, 2006).
Other supporting features are hallucinations associated with senses, other than sight, including hearing (auditory), smell (olfactory) or touch (tactile). Auditory hallucinations are frequently reported by people early in the course of the disease and are often linked to the content of visual hallucinations (Apostolova & Cummings, 2006). Although fewer people report olfactory hallucinations, it has been shown that people who have RBD also lose their sense of smell (anosmia) (Stiasny-Kolster, Clever, Moller, Oertel, & Mayer, 2007) and this may be another early indicator of the disease (Olichney et al., 2005).

Delusions are also a disturbing feature of DLB. They are often seen in people with hallucinations and can result in aggressive and agitated behaviour. The medical definition of a delusion is:

> A false belief based on incorrect inference about external reality that is firmly sustained despite what almost everybody else believes and despite what constitutes incontrovertible and obvious proof or evidence to the contrary. The belief is not one ordinarily accepted by other members of the person's culture or subculture (e.g., it is not an article of religious faith) (APA, 2000).

Typically in DLB, delusions are phantom border delusions – the belief that strangers live in the home, or paranoid delusions of persecution and theft (Mosimann & McKeith, 2003). Researchers have also reported delusions of harassment, abandonment and infidelity (Apostolova & Cummings, 2006) as well as Capgras syndrome (Boeve, 2004). Capgras syndrome refers to situations people have misidentification errors – the most notable portrayal being that given by Sacks, a neurologist, in his essay “The Man Who Mistook His Wife for a Hat” (Sacks, 1986). It is suggested that this syndrome is exhibited in people with Lewy bodies in the visual pathways and the amygdala (Yamamoto et al., 2006). Finally depression and anxiety are also features of DLB.

DLB is a complex disease. I have referred to the possible, probable delineations applied in the diagnostic process and the terminology of supportive and suggestive provides some indications of how decisions are made. It is sufficient to say that to be diagnosed
with DLB a person must have evidence of subcortical dementia and some, but not necessarily all, of the other features.

2.3 Summary

In this chapter I have presented an overview of the basic anatomy of the brain in order to provide a framework against which to explore the complex signs and symptoms that constitute DLB. In presenting the criteria for DLB, I have relied on the criteria as listed by the DLB Consortium (McKeith et al., 2005) supplemented with information from other sources. Many of the percentages quoted come from studies using small sample populations or retrospective data, and these limitations are acknowledged by the researchers.

Adopting an insider perspective, as an educator, I have attempted to demystify both the anatomical terminology and the information pertaining to DLB. This has consolidated my knowledge and understanding and will facilitate me in my efforts to make it accessible to others, particularly those who are making the transition into a caring role. In the next chapter I discuss dementia and DLB more generally, and explore DLB in relation to Alzheimer’s disease and Parkinson’s disease.
Chapter 3  DLB and its Relationship to Alzheimer’s Disease and Parkinson’s Disease

Many factors influence how people act when dealing with situations that do not conform to their world view. Without realizing it at the time, when I was initially confronted with DLB I adopted a symbolic interactionist’s framework to interpret and deal with a situation that challenged me. Iterated previously, the framework has three tenets: (1) people act towards others based on the meanings that the others have for them; (2) meanings arise out of social interactions; and (3) people interpret and deal with situations they encounter. From a symbolic interactionist’s perspective the “other” can refer to both the animate and inanimate and my first task was to examine my understanding of the inanimate other, that is, neurodegenerative illness, specifically dementia and Parkinson’s disease (PD). I found that there were a number of conundrums that confound the relationship between DLB, Alzheimer’s disease (AD) and PD: the definition of dementia, the lay understanding of dementia, the acceptance of DLB as a disease entity, and the medical view of PD. In this chapter I will explore these conundrums and their potential consequences.

3.1  Dementia – What is it?

Dementia is endemic. The number of new cases of dementia in the Asia-Pacific region (excluding the Americas) is projected to increase from 4.3 million new cases per year in 2005 to 19.7 million new cases by 2050 (Access Economics, 2006). Currently in Australia about 52,000 people are diagnosed with dementia each year – 1,000 people every week (Alzheimer's Australia, 2005a). The sister organization in the United States of America has titled their recent release on the statistical data as ‘Every 72 seconds someone in America develops Alzheimer’s’ (Alzheimer's Association, 2007) – an alarming figure that informs the global situation of 4.6 million people newly diagnosed each year (Alzheimer's Australia, 2007) or as, one study reported, a new case every seven seconds (Ferri, Prince, & Brayne, 2005).

Alzheimer’s Australia is the peak advocacy body for people with dementia in Australia. Much of the demographic information it uses to advocate for research and health care reform comes from reports it has commissioned from Access Economic Pty Ltd. This
organization estimates that, in Victoria in 2030, there will be just over 46,000 people who will be diagnosed with dementia (Access Economics, 2009), which is about the same number of Victorians living with dementia at the turn of the century. To demonstrate this disturbing increase, and how the projections are changing, I have amalgamated data from two reports (Access Economics, 2005a, 2009), that show projections of the prevalence (the number of people with dementia in a population at a given time) (see Table 3.1), and incidence (the number of people diagnosed in a given period, usually a year) (see Table 3.2) of dementia cases in Australia by state and territory. Access Economics uses data from the Australian Bureau of Statistics and meta-studies of noted researchers such as Jorm at the Australian National University for their studies (Access Economics, 2005b).

<table>
<thead>
<tr>
<th></th>
<th>NSW</th>
<th>VIC</th>
<th>QLD</th>
<th>SA</th>
<th>WA</th>
<th>TAS</th>
<th>NT</th>
<th>ACT</th>
<th>AUST</th>
</tr>
</thead>
<tbody>
<tr>
<td>2010</td>
<td>83.2</td>
<td>61.9</td>
<td>44.3</td>
<td>21.8</td>
<td>21.6</td>
<td>6.2</td>
<td>0.7</td>
<td>2.9</td>
<td>242.5</td>
</tr>
<tr>
<td>*2010</td>
<td>87.9</td>
<td>65.8</td>
<td>46.9</td>
<td>23.1</td>
<td>23.0</td>
<td>6.5</td>
<td>0.8</td>
<td>3.1</td>
<td>257.2</td>
</tr>
<tr>
<td>2050</td>
<td>227.2</td>
<td>176.1</td>
<td>171.1</td>
<td>50.7</td>
<td>79.2</td>
<td>14.3</td>
<td>2.7</td>
<td>9.6</td>
<td>731.0</td>
</tr>
<tr>
<td>*2050</td>
<td>341.4</td>
<td>275.2</td>
<td>258.3</td>
<td>80.8</td>
<td>125.3</td>
<td>26.3</td>
<td>6.4</td>
<td>17.0</td>
<td>1130.7</td>
</tr>
</tbody>
</table>

Table 3.1: Prevalence (total number of people 000s) Source: Access Economics 2005 & * 2009

<table>
<thead>
<tr>
<th></th>
<th>NSW</th>
<th>VIC</th>
<th>QLD</th>
<th>SA</th>
<th>WA</th>
<th>TAS</th>
<th>NT</th>
<th>ACT</th>
<th>AUST</th>
</tr>
</thead>
<tbody>
<tr>
<td>2010</td>
<td>20.8</td>
<td>15.6</td>
<td>11.1</td>
<td>5.4</td>
<td>5.4</td>
<td>1.6</td>
<td>0.2</td>
<td>0.7</td>
<td>60.6</td>
</tr>
<tr>
<td>*2010</td>
<td>25.7</td>
<td>19.4</td>
<td>13.8</td>
<td>6.7</td>
<td>6.8</td>
<td>1.9</td>
<td>0.2</td>
<td>0.9</td>
<td>75.3</td>
</tr>
<tr>
<td>2050</td>
<td>54.7</td>
<td>42.9</td>
<td>41.3</td>
<td>12</td>
<td>19</td>
<td>3.4</td>
<td>0.7</td>
<td>2.3</td>
<td>175.6</td>
</tr>
<tr>
<td>*2050</td>
<td>116.3</td>
<td>94.1</td>
<td>87.7</td>
<td>27.6</td>
<td>42.8</td>
<td>8.9</td>
<td>2.0</td>
<td>5.9</td>
<td>385.2</td>
</tr>
</tbody>
</table>

Table 3. 2: Incidence (new people diagnosed 000s) Source Access Economics 2005 & * 2009

Dementia, from the Latin without mind, is an umbrella or generic term that describes over 100 different diseases. This term is frequently used in research literature, the media and conference arena and is often synonymous with AD. The other prominent
dementias are vascular dementia, Parkinson’s disease dementia, fronto-temporal dementia and alcohol related dementia (Alzheimer's Australia, 2007). In its Help Sheet for Carers entitled “What is Dementia” Alzheimer’s Australia states:

Dementia is the term used to describe the symptoms of a large group of illnesses, which cause a progressive decline in a person’s mental functioning. It is a broad term, which describes a loss of memory, intellect, rationality, social skills and normal emotional reactions.

The World Health Organization (WHO) describes dementia as:

a syndrome due to disease of the brain, usually of chronic or progressive nature in which there is a disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgement.

Consciousness is not clouded. Impairments of cognitive function are commonly accompanied and occasionally preceded, by deterioration in emotional control, social behaviour and motivation ……the primary requirement for diagnosis is evidence of a decline in both memory and thinking which is sufficient to impair personal activities of daily living, as described…(World Health Organization, 1992 p.45).

Although there is a slight variation in the presentation of the definition of dementia for AD and dementia of other causes, the revised 4th edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV TR) states in part that dementia is:

A: the development of multiple cognitive deficits manifested by both:

memory impairment (impaired ability to learn new information or to recall previously learned information) (insert “and” in the definition of AD)

one (or more) of the following cognitive disturbances:
aphasia (language disturbance,
apraxia (impaired ability to carry out motor activities
despite intact motor function,
agnosia (failure to recognize or identify objects despite
intact sensory function),
disturbance in executive functioning (i.e., planning,
organizing, sequencing, abstracting).

B: The cognitive deficits in Criteria A1 and A2 each cause
significant impairment in social or occupational
functioning and represent a significant decline from a
previous level of functioning (APA, 2000).

This is the definition favoured in the definitive Australian text on general practice where
the section on dementia is included in a chapter on ‘The Elderly Patient’ and it is stated
that “the characteristic feature [of dementia] is impairment of memory…” (Murtagh,
2006 p.61).

In all of these definitions memory impairment is either the predominant or primary
feature and, anecdotally, many people equate dementia, memory loss and AD as one
entity. Memory loss, particularly short term memory loss, is a hallmark feature of AD.
It is thought that the disease process starts in the hippocampus in the limbic lobe, or
more specifically through the inability of the brain to receive messages into the
hippocampus (deToledo-Morrell, Stoub, Wang, & Scharfman, 2007; Di Paola et al.,
2007) thus preventing the encoding of new memories.

In the previous chapter I enumerated the clinical criteria for DLB (McKeith et al.,
2005). The central feature of DLB is dementia, defined in this instance as progressive
cognitive decline of sufficient magnitude to interfere with normal social or occupational
function. The DLB Consortium add a rider to their interpretation of dementia stating
that “prominent or persistent memory impairment may not necessarily occur in the
early stages but is usually evident with progression” (McKeith et al., 2005 p.1864) and
continuing research supports this contention (see D Aarsland et al., 2003; Neef & Walling, 2006; Tiraboschi et al., 2006). Although there is scant research into lay perceptions of dementia (Werner, 2005), it has been suggested that carers’ knowledge of dementia might be “related to medical professionals’ inadequate explanation of the multifaceted dimensions of dementia” (Chung, 2000 p.369). There is evidence in the literature to suggest that in some populations dementia is still viewed as a normal part of ageing (Sahin et al., 2006), and that clinicians (predominately general practitioners) are ill prepared to diagnose dementia (Chodosh et al., 2004; Iliffe, Manthorpe, & Eden, 2003; Lopponen, Raiha, Isoaho, Vahlberg, & Kivela, 2003; Pucci et al., 2004). One study (Chodosh et al., 2004) cites failure to diagnose cognitive impairment in over 40% of people with an impairment. If general practitioners are not well equipped to diagnose dementia, or believe that labelling it is of no benefit (Hansen, Hughes, Routley, & Robinson, 2008), and the predominant meaning of dementia is a disease involving memory loss, then it is conceivable that people presenting with the early stages of DLB, if they do present for medical assessment, may be misdiagnosed or under diagnosed.

The consensus of Victorian medical specialists is that of those diagnosed with dementia, 5% have DLB (Woodward, 2005), and figures from the literature suggest rates of 20-30% (Brayne et al., 2006; J. E. Galvin et al., 2008). To provide an indication of the potential for DLB in the Victorian community I used the projections of prevalence and incidence from the Access Economics 2009 figures for 2010 and 2050 to extrapolate numbers of people who could be affected (see Table 3.3 below).

<table>
<thead>
<tr>
<th></th>
<th>Dementia</th>
<th>5% DLB</th>
<th>20% DLB</th>
</tr>
</thead>
<tbody>
<tr>
<td>2010 Prevalence</td>
<td>65,844</td>
<td>3,792</td>
<td>13,168</td>
</tr>
<tr>
<td>2010 Incidence</td>
<td>19,356</td>
<td>968</td>
<td>3,872</td>
</tr>
<tr>
<td>2050 Prevalence</td>
<td>275,237</td>
<td>13,762</td>
<td>55,048</td>
</tr>
<tr>
<td>2050 Incidence</td>
<td>94,114</td>
<td>4,705</td>
<td>18,822</td>
</tr>
</tbody>
</table>

Table 3.3: Extrapolated prevalence & incidence of people with DLB in Victoria
Even at 5% the 2010 extrapolations would seem to be excessive, however it is suggested that for every person with DLB correctly diagnosed there are two or three people with the disease who are not detected (McKeith, 2009).

3.2 **DLB and Alzheimer's Disease**

Other than the significant feature of memory loss, discussed above, what is the relationship, if any, between DLB and AD? AD has been considered a disease entity from the early 1900s when Dr Alois Alzheimer (1864-1915) described the pathological changes in a patient (Auguste D) he had first observed in 1901 and who died in 1906 from progressive neurological decline. It was a colleague of his, Emil Kraepelin, who was responsible for naming the disease (and demonstrated that mental illness has a pathological basis) (Masters, 2007). We now know that the plaques or collections that form outside the neurones (extracellular) described by Alzheimer are formed when there are changes to the amyloid protein precursor which result in the production of β amyloid instead of the non toxic amyloid protein. Alzheimer also described the neurofibrillary tangles which occur when another protein, tau, which is responsible for maintaining the structure of the neurone, is altered. The third clinical feature of AD is a lack of the neurotransmitter acetylcholine (ACh). At this time it is this last feature which is targeted when people with AD are prescribed medications such as Aricept (donepezil hydrochloride). These medications inhibit the enzyme which removes excess ACh after messages have been passed across the synapses and, in some people, this improves cognitive function in the early stages of the disease (Alzheimer's Australia, 2006; National Prescribing Service Limited, 2008b).

In contrast to DLB, AD changes are seen predominately in the cerebrum, particularly the temporal, parietal and limbic lobes (Small, Keppe, & Barrio, 2006). Unfortunately, the picture is far more complex than separating the amyloid plaques from the Lewy bodies. Both types of pathology are seen clinically on imaging studies in people with DLB (Villemagne et al., 2009), at post mortem examination in people with DLB and familial AD (J. M. Burns, Galvin, Roe, Morris, & McKeel, 2005), and in those who have been labelled normal controls (Jellinger, 2004). It is not surprising therefore to learn that people with AD also have hallucinations and delusions and people with DLB, memory loss. There are however patterns to the deficits; people with AD often have
better visuo-spatial and visuo-constructional skills early in their disease, but poorer short term memory. Hallucinations and delusions are a more prominent, persistent and early features of DLB, whilst in AD they occur later in the course of the disease and are transient in nature (see D Aarsland et al., 2003; Apostolova & Cummings, 2006; Neef & Walling, 2006; Stavitsky et al., 2006; Tiraboschi et al., 2006). A case example from Mosimann and McKeith (2003 p.134) provides an illustration of some of these points in Figure 3.1. The clock drawing test is a standard, (yet contentious because of a number of issues including its questionable trans cultural acceptance and numerous scoring methods (Philpot, 2004)) assessment instrument and the intersecting pentagons, where a person is shown a diagram and asked to copy it, is part of the Mini-Mental State Examination (MMSE) assessment. The MMSE is the basic dementia screening assessment instrument advocated for use in general practice (Murtagh, 2006), although the GPCOG assessment tool (Brodaty et al., 2002) and the Rowland Universal Dementia Assessment Scale (RUDAS), developed by the Liverpool Hospital (Storey, Rowland, Conforti, & Dickson, 2004) are gaining currency. The scores at the bottom of the figure indicate that the person with DLB is more orientated to person, time and place and has better short term memory than the person with AD.
Fluctuating cognition provides a further illustration of the subtleties of early presentation. Bradshaw and her colleagues (2004) compared carer reports whilst trialling assessment tools to quantify this criterion at the Austin Hospital. They recorded ‘Yes’ responses to the presence of fluctuations in 10 of the 13 people with probable DLB and 8 of the 12 people with probable AD. When the respondents were given the opportunity to be descriptive, significant differences in the nature of the fluctuations became evident as illustrated in Table 3.4.

Figure 3.1: Comparison of visuo-constructional abilities. Source Mosimann & McKeith, 2003 p.134
AD correlates well with the definitions of dementia and is the most common form of dementia diagnosed. AD is usually quoted as the diagnosis for about 60% of all people who present for assessment at Cognitive Dementia and Memory Service (CDAMS) clinics, the diagnosis of AD being given because of memory loss (LoGiudice, 2002).

Although Lewy bodies were first described in 1912 by Dr Fritz Heinrich Lewy (1885–1950), a German neurosurgeon and pathologist, DLB, as it is now understood, was first described in detail by Japanese researchers in the early 1980s (K. Kosaka, Yoshimura, Ikeda, & Budka, 1984). The first consensus conference that ratified the nomenclature and diagnostic criteria was held in the United Kingdom in 1995 (McKeith et al., 1996). Consequently, although DLB is regarded as an unwelcome newcomer (O’Brien et al., 2006), it is now considered by many to be the second most prevalent form of dementia in the elderly (fronto-temporal lobar degeneration (FTLD) being the second most prevalent younger onset dementia (Hodges, 2009)). Figures to support this contention

<table>
<thead>
<tr>
<th>Table 4: Care giver descriptions of FC in response to question two of the One Day Fluctuation Assessment Scale (“Has the patient had a period (or periods) today when he or she seemed to be confused and muddled and then a period (or periods) when he or she seemed to be improved and functioning better? Give examples of the worst and best period of function.”)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Probable DLB</strong></td>
</tr>
<tr>
<td><strong>Worst:</strong> He was hallucinating, his character changed and he got loud, almost aggressive.</td>
</tr>
<tr>
<td>Best: He was only slightly muddled.</td>
</tr>
<tr>
<td><strong>Worst:</strong> She required full direction with ADLs, was lethargic, dribbling and confused to time, place and routine.</td>
</tr>
<tr>
<td>Best: She was alert, aware of her routine and familiar with the other residents.</td>
</tr>
<tr>
<td><strong>Worst:</strong> He couldn’t work out how to charge his electric razor or plug it in.</td>
</tr>
<tr>
<td>Best: He attended to clerical work and paid the bills.</td>
</tr>
<tr>
<td><strong>Worst:</strong> She was nonsensical, confused, and mumbled incoherently.</td>
</tr>
<tr>
<td>Best: She was almost as she was.</td>
</tr>
<tr>
<td><strong>Worst:</strong> She got up at 2:30 am and got dressed for an appointment.</td>
</tr>
<tr>
<td>Best: Periods where she seems to think quite clearly, made sense and remembered things.</td>
</tr>
<tr>
<td><strong>Worst:</strong> He woke in the morning and thought there was a drama somewhere and he had to be there, I couldn’t convince him otherwise.</td>
</tr>
<tr>
<td>Best: He woke up calm, and was more easily convinced not to worry.</td>
</tr>
<tr>
<td><strong>Worst:</strong> He kept looking for “the exit”, couldn’t find the bedroom or the bathroom and had trouble recognising me (wife)</td>
</tr>
<tr>
<td>Best: He was alert, opened the door, and greeted me after work. He knew me and seemed pleased to see me.</td>
</tr>
<tr>
<td><strong>Worst:</strong> She was seeing people, preparing extra meals, and asking how many people to cook for.</td>
</tr>
<tr>
<td>Best: Normal conversation, made sense, nothing unusual.</td>
</tr>
<tr>
<td><strong>Worst:</strong> Illogical discussion, all jumbled, and didn’t make sense.</td>
</tr>
</tbody>
</table>

Table 3.4: Descriptive differences in fluctuations DLB/AD. Source Bradshaw et al., 2004, p.386
vary significantly from 0% to 30.5% of all dementias (Brayne et al., 2006), with 15-20% being the commonly accepted figure (Woodward, 2005). One study suggests that the prevalence is 3.2% of newly diagnosed people with dementia per annum (Zaccai, McCracken, & Brayne, 2005) and another suggests that 5% of non institutionalized adults 85 years and older have DLB with the disease incidence at 22% (Neef & Walling, 2006). These figures come primarily from post mortem studies, as do a number of studies that support the contention that, in the past, people with DLB may have been diagnosed with AD (McShane et al., 2001; Tiraboschi et al., 2006; Tsuang et al., 2006).

### 3.3 Parkinson’s Disease

Dr James Parkinson (1755-1824), an English physician, is known for his 1817 “*Essay on Shaking Palsy*” in which he described the aberrant motor symptoms of six people, three whom he had observed on daily walks. In this short essay, Parkinson established the disease as a clinical entity and gave the following description of the illness:

> Involuntary tremolous (sic) motion, with lessened muscular power, in parts not in action and even when supported; with a propensity to bend the trunk forwards (sic), and to pass from a walking to a running pace: the senses and intellect being uninjured (Parkinson, 2002 reprint).

Some 40 years later (1861-2) Jean Martin Charcot, a French neurologist and anatomical pathologist (who was the first doctor to name and describe multiple sclerosis), working with Alfred Vulpian, added more symptoms to James Parkinson's clinical description and then attached the name Parkinson's disease to the syndrome. They stated that *in general, psychic faculties are definitely impaired and the mind becomes clouded and lost* (Bak & Lennox, 2006). Therefore it could be argued that this divergence in the descriptions of PD has survived as a testament to the Anglo/Francophile impasse resulting, in the English speaking world, in Parkinson’s disease being viewed as predominately a motor behaviour disorder. Despite this dichotomy, history records that Dr Lewy (pronounced Leevee) found the inclusions (bodies) in the cells in the brains of people who had died of Parkinson’s disease in 1912 and it was Tretiakoff who, in 1919,
found them in the substantia nigra and named them Lewy bodies (Bak & Lennox, 2006).

If Lewy described intracellular inclusions that were associated with Parkinson’s disease and which are now known to be a feature of DLB - are these two diseases the same disease, and is Parkinson’s disease dementia just another manifestation? Much is written on the subject and the following passage provides a succinct explanation of the two ends of the spectrum with PD sitting in the middle somewhat like a ‘hyphen’.

*The diagnosis of Parkinson's disease with dementia (PDD) or dementia with Lewy bodies (DLB) is based on an arbitrary distinction between the time of onset of motor and cognitive symptoms. These syndromes share many neurobiological similarities, but there are also differences. Deposition of beta-amyloid protein is more marked and more closely related to cognitive impairment in DLB than PDD, possibly contributing to dementia at onset. The relatively more severe executive impairment in DLB than PDD may relate to the loss of frontohippocampal projections in DLB. Visual hallucinations and delusions associate with more abundant Lewy body pathology in temporal cortex in DLB (D. Aarsland, Ballard, & Halliday, 2004 p.142).*

Today, in Victoria, Parkinson’s disease is defined as:

*a progressive, degenerative neurological condition. It primarily involves a disturbance in the co-ordination of movement and has three main symptoms: tremor, rigidity and bradykinesia (slowness of movement)(Parkinson's Victoria, 2007 p.2).*

PD is a common neurological condition in Australia with 8,900 people being diagnosed in 2005 (Access Economics, 2007). Currently it is estimated that 25 people are diagnosed every day of the year. PDD is the term used when, in the course of their
illness, people with PD develop dementia. This raises the question about whether some of these people have DLB. Using the Access Economics 2007 basic data and making the same extrapolations as with dementia to DLB (Table 3.1, 3.2) and allowing for the 20% of people with younger onset PD (YOPD) who, potentially, may not have Lewy body disease, it is possible that the number of potential people with DLB (in Australia) could grow significantly (see Table 3.5).

<table>
<thead>
<tr>
<th></th>
<th>Parkinson’s disease</th>
<th>Less 20% for YOPD</th>
<th>5% DLB</th>
<th>20% DLB</th>
</tr>
</thead>
<tbody>
<tr>
<td>2005 Prevalence</td>
<td>54,700</td>
<td>43,760</td>
<td>2,188</td>
<td>8,752</td>
</tr>
<tr>
<td>2005 Incidence</td>
<td>8,900</td>
<td>7,120</td>
<td>356</td>
<td>1,424</td>
</tr>
</tbody>
</table>

*Table 3.5: Extrapolation of the prevalence & incidence of DLB in Australia from PD figures.*

In a newly released pamphlet entitled “Parkinson’s and Lewy Body Dementia” (Parkinson's Australia & Alzheimer's Australia, 2007), and in Parkinson’s other printed and electronic material, the definition of PD given above is consistent with the explanations of the underlying pathology; …*Lewy Bodies (sic) in the substantia nigra affecting the dopaminergic synaptic pathways.* The unswerving orientation of the literature is that of a motor disorder. Where non-motor symptoms are discussed an imbalance of medications is often offered as an explanation for them, for example Parkinson’s Victoria web based fact sheet (*http://www.parkinsonsvic.org.au/about-ps/documents/nonmotorsymptomfactsheet.pdf*) provides the following information:

> The exact cause of hallucinations is not known, but they may be related to Parkinson’s and/or medication ...

> Developing unusual behaviours that are out of character can also be a non-motor symptom. These are almost always associated with the use of Parkinson’s medications, specifically Dopaminergic medications.

An excellent description of DLB is provided in an article in the Signpost magazine, produced by the Parkinson’s Association, in which McConvey (2007 p.3) “sheds some light on the often overlooked, misunderstood and mis-diagnosed non-motor symptoms...”
associated with Parkinson’s”. Symptoms such as REM sleep behaviour disorder, hallucinations, autonomic nervous system failure and compulsive behaviour are discussed. Unfortunately, instead of the potential of a differential diagnosis of DLB being raised, the article concludes that non-motor symptoms are often poorly understood by general practitioners and other health care professionals.... This intent on preserving the Anglo mindset of PD as a disease of the motor system, and statements such as “similar to Alzheimer’s disease, one of the most common initial symptoms of DLB is impaired memory of recent events” (Parkinson’s Victoria, 2007 p.3) are problematic for carers and people with DLB: How do they interpret the processes used in dealing with the issues they encounter and how do relationships develop with support services staff?

Parkinson’s Victoria is not alone in this apparent reluctance to consider DLB as a primary diagnosis over PD or Parkinson’s disease dementia. Snyder and Adler (2007) from the Mayo Clinic and Noble (2007), a UK PD nurse specialist, offer similar articles to that of McConvey. The Mayo Clinic researchers also suggest that the cognitive fluctuations may be associated with the standard medication regimes used in PD associated with dopamine regulation. It is well established that dopamine is one of the neurotransmitters active in the areas of the brain (substantia nigra and basal ganglia) vulnerable to Lewy bodies (Francis, Perry, Piggott, & Duda, 2006) and that the basal ganglia have a role in cognitive function (Gabrieli, 1998; Witt et al., 2002). This prompts the question: is it the disease process or the medications that produce the symptoms? Dopamine dysregulation and the basal ganglia are also implicated in studies that investigate impaired decision making and skills and habit learning associated with PD (Gallagher, O’Sullivan, Evans, Lees, & Schrag, 2007; Mimura, Oeda, & Kawamura, 2006; Witt et al., 2002).

Mimura and colleagues (2006) cite several studies that support their findings that impaired decision making does not correlate with low scores on the MMSE, yet it does correlate with the ability to read, or attribute internal mental state in, other people. In a study that assessed driving skills and included 21 “non-demented people” with mild to moderate PD, the mean MMSE score for safe drivers (n=11) was 28.07 (SD 1.64) and for unsafe drivers (n=7) was 28.14 (SD 1.57) (3 withdrew). Testing indicated that
“driving performance was related to memory retrieval performance, a type of memory impairment that is characteristic of subcortical compromise” (Grace et al., 2005 p.773).

Another study (Tolosa, Compta, & Gaig, 2007) suggests that there is a pre-motor phase of PD consisting of constipation, loss of smell and REM sleep behaviour disorder. All of these symptoms may inform a differential diagnosis of DLB but certainly suggest the presence of Lewy body pathology. A further study found that 45% of hallucinating non-demented people diagnosed with PD developed dementia within the twelve month period between their initial and subsequent assessments (Ramirez-Ruis, Junque, Martí, Valldeoriola, & Tolosa, 2007) and another study (Mott, Kenrick, Dixon, & Bird, 2005b) reports that 73.5% (of people with PD, N = 444) have sexual limitations with the researchers suggesting that erectile dysfunction can be an early and presenting symptom of PD.

The DLB, PD, PDD conundrum appears to lie in the definition of dementia. Taking the Consortium’s (McKeith et al., 2005) view that dementia is a progressive cognitive decline of sufficient magnitude to interfere with normal social or occupational function it could be argued that sleep disorders, loss of driving skill or impaired decision making might be considered dementia. Even when exclusion criteria are applied, for both DLB and PPD, cognitive impairment can be measured in newly diagnosed populations of people with PD (Foltynie, Brayne, Robbins, & Barker, 2004). It appears that the α-synucleinopathies constitute one disease which is most commonly recognized as PD. If 70% of people with PD develop dementia in the course of their illness (D. Aarsland et al., 2004; Burton, McKeith, Burn, Williams, & O’Brien, 2004) then perhaps it is a semantic argument rather than a diagnostic one which may be settled through greater acknowledgement of the spectrum of Lewy body disease.

With the increasing sophistication of neuroimaging, the ability to identify the areas of the brain affected in all of these disease entities is improving but not necessarily assisting in the differential diagnoses. MRI (magnetic resonance imaging) has shown no discernible pattern of difference in DLB and PPD (Burton et al., 2004) and in PET scans loss of dopamine transporter is seen in both DLB and PDD (O’Brien & Colloby, 2006). Immuno-staining of post mortem specimens provides valuable information for
researchers as they strive to unravel the complexities, and much work is being done to correlate ante and post mortem findings (see Dickson, 2006; Harding et al., 2002; Jellinger, 2004).

Genetic research is providing new directions in understanding the pathogenesis of these diseases (Goker-Alpan et al., 2006; Masters, 2007). For example, recent research has established that there is a familial form of younger onset PD that is predominantly a motor behaviour disorder which results from a mutation of the parkin gene PARK2 and hence is sometimes referred to as Parkin disease. It is not an α-synucleinopathy (Khan et al., 2003; Lucking et al., 2000). However with the ongoing research there is much discussion as to the genetics of PD. One view is that mutations in PD genes explain only up to 20% of early onset cases and up to 3% of late onset PD (Bentivoglio, 2007) and another is that mutations of the α-synuclein gene are responsible for only a tiny fraction of familial cases of PD (Nicholl et al., 2002). McKeith provides this insight into the genetic research of PD and DLB:

There are recent reports that triplication of the alpha-synuclein gene (SNCA) can cause DLB, PD and PDD whereas gene duplication is associated only with motor PD suggesting a gene dose effect. However, SCNA multiplication is not found in most Lewy body disease patients. Continued clinical, pathological and genetic evaluation of familial cases of DLB and AD is therefore an important and potential highly informative area for continued research (McKeith, 2006 p.420).

This does not assist those caring for and living with these diseases today. Those who support the concept of a spectrum of Lewy body disease are in general agreement that the one-year rule of the DLB Consortium (McKeith et al., 2005) should apply both in research and clinical practice. That rule suggests DLB should be diagnosed if a person presents with dementia before or with parkinsonism, and PDD should be diagnosed if dementia occurs a year or later after parkinsonism. In the Victorian environment, where general practitioner understanding of DLB may be lacking and specialist referral is
often well into the course of the illness and usually based on symptomology, that is, people with PD are usually referred to neurologists, and people with dementia to geriatricians or CDAMS clinics (Ames, 2007), the one-year rule may be academic.

3.4 Summary

In this chapter I have looked at the differing definitions of dementia, the relationship between AD and DLB and the more confusing relationship between DLB, PD and PDD. If there is so much confusion within academia and the health professions, then it is not surprising that people who are faced with the daunting task of confronting any of these diseases (either as a person with cognitive changes or parkinsonism or as a carer) could readily misinterpret what is being said to them or feel that the information that they are being given is not relevant to their particular situation. There is a developing trend in the literature to classify dementia as either cortical or subcortical (Collerton, Burn, McKeith, & O’Brien, 2003; Montoya, Price, Menear, & Lepage, 2006). Cortical dementia is that typically seen in AD in association with amnesia, apraxia, aphasias and agnosias, whereas subcortical dementia is characterized by a slowing of information processing (attentional/executive and visual-perceptual deficits), apathy, decreased motivation, depression and personality changes (Montoya et al., 2006). This is typical of the dementia seen in the Lewy body disorders and it may be useful to promote this distinction to a wider audience.

The significant publicity, attached to high profile people with AD like Hazel Hawke, wife of a former prime minister (Pieters-Hawke & Flynn, 2005) and mass media and awareness campaigns associated with organizations such as Alzheimer’s Australia, has resulted in a public awareness of AD. Although the onset of the dementias being considered in this study is insidious, a person’s short term memory loss is a prominent and easily discernible feature in social interaction. There is no evidence to suggest that there is an easily discernible feature in DLB - on the contrary, it is suggested that the fluctuations in cognition, the nature of the deficits and the ability of the person to ‘rise to the occasion’ in social situations masks many of the early features. Therefore, it may be possible that the discernible features of parkinsonism lead to misdiagnosis.
There are indications that the medical profession is as baffled as this researcher, Parkinson’s Victoria and others. Several years ago there was a report on a task force established to deliberate on clinical diagnostic criteria for parkinsonian disorders (Litvan et al., 2003) and reports are now emerging of a consortium for the clinical diagnostic criteria for dementia associated with Parkinson’s disease (Emre et al., 2007). In his concluding remarks in the Alzforum webinair (2009) one of McKeith’s wishes was that the DLB lobby could communicate successfully with the dementia and PD communities. To that end his voice (McKeith, 2007) and others can be heard stimulating debate within academia (Lippa et al., 2007; O'Brien, 2009) and in professional newsletters in Europe and America (J. E. Galvin et al., 2008; Jellinger, 2009).

In the next chapter I review literature on the impact of dementia and Parkinson’s disease on carers.
Chapter 4  Caring: Costs, Benefits and Experiences

In a critical review of informal care giving to ageing family members in America, Walker, Pratt and Eddy (1995) contended that much of the literature contained ambiguities associated with definitional and contextual constructs. They reviewed over 150 articles in an attempt to clarify the nature of care giving, its outcomes and the relationships between informal and formal caring. Current Australasian reviewers (Goodhead & McDonald, 2007; Savage & Bailey, 2004) indicate that psychosocial researchers are still grappling with these questions including questions of terminology associated with the person providing care. Although much of the literature assigns the appellation as “caregiver”, “carer” is heard more frequently in practice. In this study “carer” is the preferred term and is used to describe the participants; “caregiver” and “care giver” are used interchangeably to reflect other authors’ use. Some ambiguities have been resolved although there is still considerable flexibility and individualism in interpretation. For example, Goodhead and McDonald (2007 p.16) offer six alternatives (from New Zealand, Australia and U.S.A.) for the definition of an informal caregiver. That proposed by Savage and Bailey addresses the definitional issues raised in the 1995 review (Walker et al., 1995) pertaining to the distinction between instrumental activities of daily living (IADLs) such as shopping, bill paying and house cleaning, and activities of daily living (ADLs) of a more personal nature like grooming, toileting and eating by the inclusion of a simple all:

A relative, friend or neighbour who provides practical, day-to-day unpaid support for a person unable to complete all of the tasks of daily living (Savage & Bailey, 2004 p.111).

This is an acceptable definition of a caregiver for this study as it provides scope for a relative to reflect on the transition of their spouse from an autonomous individual, completing all of the tasks relevant to their autonomy within the relationship, to a care recipient.

The notion of autonomy and the context of care giving vis-à-vis the relationship between caregiver and care recipient, the gender of the caregiver and the stage of the care giving process are thematic foci of these reviews and, as they are relevant to this
study, they are explored in this chapter. Another theme central to the reviews and much of the published literature concerns the impact of care giving, both positive and negative, on the caregiver. Although much of the current material is generic there is a body of work that relates impact to the care recipient’s disability, and salient work is cited.

In addition two other themes are explored: the caregiver as informant and carers’ narratives, found within the context of published works and carer support networks – Alzheimer’s Australia and Parkinson’s Australia.

The research literature was sourced primarily utilising the ‘breadth studies’ and medical databases available through The University of Melbourne’s library internet search facilities. Terms searched included various combinations of ‘carer’, ‘caregiver’, ‘informal care’, ‘dementia’, ‘Alzheimer’s disease’, ‘dementia with Lewy bodies’, and ‘Parkinson’s disease’. Demographic and review papers that provided generalized information were retained, however papers that specifically addressed issues of caring for the younger person with a disability, pathologies other than dementia and Parkinson’s disease, and specified dementias such as frontotemporal dementia or dementia associated with Down syndrome, were all rejected as DLB is a neurodegenerative disease of ageing. Library holdings of the University, Alzheimer’s Australia, Alzheimer’s Victoria and Parkinson’s Victoria were also accessed and workers in the field provided information about carers as informants.

4.1 Facts and Figures

There has been a plethora of economic, productivity and health reports commissioned in Australia since 2000. These are associated with the ageing of the baby boomers, a slowing birth rate and increases in life expectancy (see Access Economics, 2001; Australian Bureau of Statistics (ABS), 2003, 2005a, 2005b, 2007; Australian Institute of Health and Welfare (AIHW), 2003, 2004). In drawing the information together from this “complex arrangement in respect of the range and number of data and information sources” (Goodspeed, Goss, & Barac, 2004 p.106), Hugo contends that:

- population ageing is one of the most important processes
- which will influence Australia over the next three
decades... (as) almost all of the growth in Australia’s population is going to occur in the older ages (Hugo, 2007 p.170).

Currently the majority (83%) of people over 60 who have a disability live at home and in most instances are cared for by informal carers, 92% of whom are family (Hugo, 2007). The Australian Bureau of Statistics (ABS) makes a distinction between primary or main and non-primary carers in its data collection and reporting associated with place of residence (home or facility based) and hours of care. The ABS and others collating and reporting on the data, report that there are 2.3 million Australians providing assistance within the home to those who need help because of disability or age. About 20% of these carers, some 460,000 people identified themselves as primary carers, 43% of whom are spouses, more wives than husbands, generally not working (59%) and just over half relying on some financial support from the government (Access Economics, 2005c; Australian Bureau of Statistics (ABS), 2005a; Hugo, 2007).

Not only are carers a significant proportion of the population, but they also make a significant contribution to the community in providing care to their relatives. Access Economics (2005c) estimated the annual value of informal care in Australia to be $4.9 billion (based on the amount carers could earn by being in the work force) or $30.5 billion (based on the cost of employing someone to do the caring work instead) per annum.

Access Economics have undertaken commissioned reports on the social and financial implications of a range of health issues including reports for Alzheimer’s Australia (Access Economics, 2003, 2005b, 2006) and Parkinson’s Australia (Access Economics, 2007). From those reports we have gained some insight into the demographics of the carer population potentially impacted by DLB and the financial implications of care.

The 2003 report for Alzheimer’s Australia was commissioned prior to the release of data from the 2003 Survey of Disability, Ageing and Carers (SDAC) (Australian Bureau of Statistics (ABS), 2003) yet it is reported that 41% of people living with dementia relied on a spouse / partner as the informal caregiver and that in 2002 the value of that care, were it to be replaced by paid care was over $1.7 billion. From its calculations and
projections there is a projected increase in the total real financial costs (direct and indirect) from 0.77% of Gross Domestic Product (GDP) in 2002-3 to an astounding 3.3% of GDP by 2051 (Access Economics, 2003).

Using SDAC figures, Access Economics (2007) estimate that people with Parkinson’s disease living at home in 2005 had about 7,300 primary carers, most of whom were similarly aged spouses, 83% of whom were retired. This is a significant deviation from figures given in the report commissioned by Carers’ Australia (Access Economics, 2005c) where it was reported that 78% of primary carers were of workforce age even though 58% were not working because of their care giving. This reflects the Parkinson’s disease affected population where 82% of the people are retired (Fyffe & McCubbery, 2007).

From the data available it seems reasonable to suggest that there is a population of retired, spousal, primary carers of people with DLB to inform this study. As it is a retrospective study, in that participants will be asked to reflect back on the early stages of their spouses’ illnesses, it is pertinent to explore the impact of care giving. Access Economics provides the following succinct summation:

Informal (voluntary) families and carers - the supportive invisible multi-billion dollar workforce – provide a huge contribution, which often may take a heavy toll on their own health, wellbeing and income (Access Economics, 2003 p.40).

4.2 The Burden of Care Giving

Over the past seven years a collaborative study of wellbeing, defined as a stable state of being well and contented, has been undertaken by Australian Unity and Deakin University (http://www.deakin.edu.au/research/acqol/index_wellbeing/index.htm). To date 21 surveys have been conducted and the analyses have resulted in a measure called the ‘subjective wellbeing homeostasis score’ or the Personal Wellbeing Index (PWI) which is 75, described by Cummins as:

the first level deconstruction of ‘Life as a Whole’. It comprises seven questions relating to satisfaction with life
domains; health, personal relationships, safety, standard of living, achieving in life, community connectedness and future security. Each question is answered on a 0-10 scale of satisfaction. The scores are then combined across the seven domains to yield an overall Index score, which is adjusted to have a range of 0-100 (Cummins et al., 2007 p.1).

In May 2009, the latest survey reported, the index for ‘Life as a Whole’ in the general population as 78.2. Some of the analyses have targeted specific groups such as the unemployed (PWI 66.6), the unemployed with an income less than $15,000 p.a. (PWI 61.3) and the unemployed who live alone (PWI 60) which are all lower than the homeostasis PWI score of 75 and the 2009 score of 78.2.

In July 2007 the collaboration and Carers’ Australia (Cummins et al., 2007) conducted and reported on a special survey of carers (N=3,766). It found that carers have the lowest collective wellbeing index of any group so far studied in the surveys, with the PWI of 3,049 people who live with person for whom they care (83% of sample) calculated at 58.4. The study also used two sub scales from the Depression, Anxiety and Stress Scale and reported that 56% of carers were moderately depressed and 50% were experiencing moderate levels of stress. With increasing age the differences between carers and people in the normal range are not as pronounced, however there is still a 10 point difference in the wellbeing index in the older (76+) range. The least affected carers were those living with and caring for their spouse (N=1,584, PWI 60.8) and the authors of the report surmise that this can be explained in terms of caring in the context of a long-term relationship – typical of the carers of late onset dementia and Parkinson’s disease.

If wellbeing is a stable state of being well and contented, then what is care giver burden – a term often found in the research literature and how is it measured? An early definition, proffered by Zarit and Zarit, described burden “as the extent to which care givers perceive that their health, social life and financial status are suffering because of their caring experience” (Zarit, Todd, & Zarit, 1986 p.261) and a frequently cited instrument for measuring burden, the Zarit Caregiver Burden Scale (ZCBS) bears their
name. It is a self administered 22-item questionnaire which explores the caregiver/patient relationship, the caregiver's health, psychological well-being, finances, and social life. Although originally designed for caregivers of children the instrument now has global currency and a short 12 item and a 4 item screening form have recently been validated, against the original, for use in geriatric settings (Bedard et al., 2001). Other definitions of care giver burden are an extension of the Zarit definition, the most encompassing being that used by Goodhead and McDonald (2007 p.42) who define burden as the strain caused by physical, psychological, emotional, societal and financial stressors associated with care giving.

With the semantic interplay between burden, strain and stress(or) and the broad parameters offered for investigation, it is not surprising that there are some 2,700 plus articles that appear on the PsychInfo database to the queries ‘caregiver’ and ‘burden’. There are also laments on the inconsistencies in methods and results in the research (Bedard, Pedlar, Martin, Malott, & Stones, 2005; Goodhead & McDonald, 2007; Savage & Bailey, 2004). Focusing on dementia, predominately of the Alzheimer’s type and PD and with the criteria for the diagnosis of DLB in mind, I have chosen a cross section of studies that illustrate how manifestations of the care recipients’ illnesses can contribute to carer burden.

In a review and meta analysis of 30 cross sectional and 12 longitudinal studies, Black and Almeida (2004) concluded that the behavioural and psychological symptoms of dementia (BPSD) are predictors of burden, psychological distress and depression in carers. These findings reinforce those from earlier studies which found that the mental symptoms of PD were the most consistent and powerful predictors of carer distress (D. Aarsland, Larsen, Karlsen, Lim, & Tandberg, 1999), and the severity of behavioural disturbances in people with DLB was significantly associated with carer depression (Lowery et al., 2000). They also support more recent studies showing that reduced awareness of executive deficits are robust predictors of distress for carers of people with AD (Bonney et al., 2007), and apathy, disinhibition and hallucinations contribute to carer burden in PD and AD (Lippy, Gerstenhaber, Williams, Bassett, & Marsh, 2006; Neil & Bowie, 2008). Physical ill health is also a caring outcome of significance
These studies alone suggest that there is evidence to support a negative impact for carers of people with DLB who may well exhibit many of these symptoms. However further studies investigating other non-motor symptoms of PD such as sleep disturbance (Grace, Walker, & McKeith, 2000; Pal et al., 2004), lack of intimacy (Mott et al., 2005b; Svetlik, Dooley, Weiner, Williamson, & Walters, 2005) and difficulties with communication (Cifu et al., 2006; Tremont, Davis, & Bishop, 2006) also impact negatively on carer wellbeing and, again, are symptoms which are predictive of an alternative diagnosis of DLB.

A number of studies focus on the relationship between the caregiver and care recipient exploring domains that embrace the psychological, emotional and societal aspects of caregiving. Gender is offered as a determinant of burden in some studies but with inconsistent results. However, the Wellbeing of Australians Report (Cummins et al., 2007) indicates that women caregivers have a PWI which is 3.4 points lower than their male counterparts suggesting women experience higher burden and stress. This finding is supported in the Parkinson’s disease population in New South Wales (N=303) where female carers reported higher burden in the psychosocial domains than the male carers (Mott, Kenrick, Dixon, & Bird, 2005a). In a study that compared the impact of caring for people with PD without cognitive decline (N=84) and people with AD (N=88) the authors conclude:

*Ultimately the meaning of caregiving is constructed in the relationships and contexts within which the care recipients and the caregivers interact.....women appeared to be no worse off than men in spousal caregiving relationships unless the impairment was cognitive (Hooker, Manoogian-O'Dell, Monahan, Frazier, & Shifren, 2000 p.572).*

Not surprisingly, the quality of the premorbid relationship is cited consistently as significant in predicting burden and influencing the attributes or style that one partner assumes in their caring role (N. E. Edwards & Scheetz, 2002; Hodgson, Garcia,
Tyndall, 2004; Lewis, Hepburn, Narayan, & Kirk, 2005; Papastavrou, Kalokerinou, Papacostas, Tsangari, & Sourtzi, 2007; Steadman, Tremont, & Davis, 2007). Lack of family support (Hales, 2007; Neufeld & Harrison, 2003; Tremont et al., 2006) and restrictions on holidays and social life (Schrag, Hovris, Morley, Quinn, & Jahanshahi, 2006; Thommessen et al., 2002) are also cited as contributing to carer burden regardless of diagnosis. In a recent large (N= 1002) Australian telephone survey of family carers of people with a disability, lack of social opportunity and social isolation (coupled with financial hardship) were found to be negative impacts of caring and carers’ wellbeing (B. Edwards, Higgins, & Zmijewski, 2007). These studies support Brodaty’s (2007) contention that carer outcomes are influenced by many variables. A large American study (Schulz et al., 2004) which investigated depression and anxiety in carers of people with AD found that the transition to institutional care is particularly difficult for spouses, almost half of whom visit the patient daily and continue to provide help with physical care during their visits (Schulz et al., 2004). An intensifier was concern about the quality of care that their spouse was receiving.

The majority of the papers discussed previously provide generalizations drawn from statistical analysis of rating tools. There is a growing body of research that employs physiological indicators to measure stress quantitatively in care givers. In a meta-review of much of that work the authors state:

*We searched published and unpublished reports over a 38-year period and found 23 studies that compared physical health indicators in family caregivers of persons with dementia to health indicators in non caregivers who were generally matched on age and sex. Care givers had a 23% higher level of stress hormones and a 15% lower level of antibody responses than did non care givers. Whereas these observational data do not allow us to infer definitively that caregiving is hazardous to one’s health, such potential added risks are noteworthy because they may have clinical implications for millions of care givers (Vitaliano, Zhang, & Scanlan, 2003 p.966).*
Chronic stress is now known to also impact physiological functioning at the genetic level (Blackburn, 2010).

There is also a growing body of work that explores these themes, particularly those associated with spousal/partner relationships and illness, from a qualitative perspective. They consider both the carer and the care recipient (for example Chesla, Martinson, & Muwaswes, 1994; K. Galvin, Todres, & Richardson, 2005; Gates, 2000; Hodgson et al., 2004; Kaplan, 2001; Karner & Bobbitt-Zeher, 2006; Lyons, Stewart, Archbold, Carter, & Perrin, 2004).

An early and comprehensive post doctoral study (Wright, 1993) used the Meadian perspectives of “defining the situation” and “taking the attitude of the other” to explore aspects of marriage with 30 couples where one partner had a diagnosis of (early) Alzheimer’s disease matched against 15 well couples. Wright underpinned the study with two assumptions:

*Couples have a shared history that has shaped the emotional and instrumental roles that partners carry out toward each other and their present relationship forms the basis of expectations for future emotional and instrumental caring (Wright, 1993 p.7).*

Wright examined attitudes to household tasks, tension, companionship, affection, sexuality and commitment by having all participants complete a number of rating scales and an interview. The conclusions are revealing. Of the well group Wright argues that:

*The capacity to “take the attitude of the other” is the hallmark of their relationship, and with the passing of time, spouses increasingly value each other as unique persons. The overall development outcome for well couples in a concordant relationship (Wright, 1993 p.111).*

In contrast there is a marked difference in the findings within relationships that are impacted by Alzheimer’s disease. Of these carers Wright claims that:

*Caregiver spouses carry major household responsibilities alone, they often use tension control and displacement as*
a means of dealing with emotional strains, they have a need for substitute companionship, and they either accept or are frustrated over the lost sexual relationships or are resentful of excessive sexual demands. Most caregivers retain the capacity to take the attitude of the afflicted (sic) spouse and this contributes to their commitment to stay in the relationship ........it is a commitment dependent relationship that spans outcomes of adaptation and control, as well as distortion and disorder (Wright, 1993 p. 112).

A number of other studies address this psychological processing of the relationships as the disease (AD) progresses, analyzing them thematically. From interviews over an extended period with 15 spousal and 15 child carers, Chesla and colleagues (1994 p.3) suggest that relationships can be viewed as either “continuous, continuous but transformed or radically discontinuous”. Two studies using symbolic interactionism as a framework offer insights into meaning making in caring relationships.

In the first study, Kaplan (2001), analyzes how 68 spouses view their relationship with a partner after relinquishing the carer role and discusses how relationships can be expressed as to death do us part, we but, husbandless/wifeless, becoming an I or unmarried marrieds. The second study by Karner and Bobbitt-Zeher (2006) gives an interpretation consistent with Wright’s (1993) in that they express the caregivers’ journeys as morality tales of transformation from order to disorder, from havoc to meaningful interaction where the caregivers:

construct value in their struggles to negotiate the disorder of illness and recreate meaningful and affirming selves and relationships (Karner & Bobbitt-Zeher, 2006 p.556).

Other researchers have studied dyads where PD is present, finding that “PD had an impact on the physical, psychological and social worlds not only of the patient but also of the partner” (Hodgson et al., 2004 p.345). This view is also supported by Davey and colleagues (2004) in a study which focuses on the carers’ perceptions of risk associated with falls. In providing an interpretation of the PD journey of six couples Birgersson
and Edberg (2004 p.621) write that there are different patterns from “unity towards unity, unity towards distance or distance towards unity”. These patterns are similar to the experiences of relationships impacted by AD.

A final study (Sherman & Boss, 2007) worth commenting on is one which addresses issues faced by wives as care givers where there are adult step children, a situation that is likely to become more frequent in the Australian experience of aged care because of the increasing divorce rate. The researchers conducted in-depth interviews with nine women identified as having a late-life remarriage. Pre-morbid relationships in the broader familial context influenced the care-giving experience most of which were negatively impacted because as:

...step children ‘opted-out’ of providing care giving assistance, they ‘opted-in’ to challenge caregivers about decisions and finances (Sherman & Boss, 2007 p.253).

4.3 Positive Aspects of Care Giving

In contrast to the concept that to care is to be burdened, and that the experience is one of loss, futility, hopelessness and loneliness (Svanstrom & Dahlberg, 2004), there is a small but significant body of work that supports the notion that to care is a rewarding and positive expression of a relationship, particularly a spousal relationship. This is expressed in the interpretations of relationships as continuous (Chesla et al., 1994) and to death do us part (Kaplan, 2001), as well as in a number of studies cited previously that explore the premorbid quality of spousal relationships and their influence on carers’ expressions of burden. Sorrell (2006 p.158) found there is a “beauty that often lies hidden” in caring relationships associated with AD.

In viewing both dementia and PD as relational rather than person centred, the contribution and voice of the spouse becomes evident, and it is argued that sustaining couplehood is more pertinent to attaining positive care outcomes. Brooker (2004) in commenting on the late Kitwood’s intentions posits that he too saw the carer/partner as an integral component of his concept of person centred care and it has been suggested that:
to frame caring relationships primarily in terms of stress and burden does indeed represent a simplistic reduction of the experience that manifestly fails to capture the dynamics of couplehood in dementia (Hellstrom, Lundh, & Nolan, 2007 p.32).

In focussing on the early stages of caring pertinent to this study, a single case study provides some interesting insights. In this study two researchers (K. Galvin et al., 2005) accepted a carer’s invitation to explore the transition of his relationship. Thematic analysis provided three themes: something is wrong; being the carer; and advocacy. In their discussion of the first theme the authors enumerate four sub clusters:
1. the dilemma of acknowledging something was wrong;
2. mourning their previous life together;
3. the challenges of changes in social relationships with the outside world; and
4. the importance of ‘small joys’.

They propose that “as carers find new strategies of caring and coping in a positive way, new meanings of existence are generated” (K. Galvin et al., 2005 p.9).

4.4 Carers’ Narratives

Galvin’s (2005) study guides us to another genre of inquiry – that of the published carer narrative. This idiom is as diverse and as individual as the presentations and courses of the illnesses themselves. It would appear that in some instances a public profile, mixed with journalism and media savvy, is a motivating force to publish. This can be seen in the profiling of the journeys of Hazel Hawke (Pieters-Hawke & Flynn, 2005), Iris Murdoch (Bayley, 1998), Muhammad Ali (Ali-Walsh, 2005) and Michael J. Fox (Fox, 2002). In an interview with Bayley, two or so years after Murdoch’s death in the context of his recent remarriage, the reporter discusses the exposing of intimacies thus:

In death even, it seems, he was grateful that his wife had given him this gift. In a way, it is the best thing you can possibly leave to a writer: a wonderful subject. Partly for this reason, Bayley has no qualms, he says, about having
turned the intimacies he shared with his late wife into something so very public, an industry almost (Adams, 2001).

There are numerous less highly profiled narratives as well, many of which have their genesis in articles written for support organization magazines. In the compilation entitled “In memory of memories” (Breckman, 2003), several contributors provide vignettes of the early stages of their spouses’ illnesses in later life and the impact this had on them. One carer states “in a few short months she changed from being a loving wife, partner and helpmate into a difficult, unreliable, incompetent individual” (Fountain, 2003 p.13). This carer contemplated divorce until words spoken by his wife triggered a wave of love and compassion.

Another carer speaks of cycles of grieving as her husband loses the ability to relate emotionally, regains it with the introduction of medication and then, as the effectiveness of the cholinesterase inhibitors abates, again no longer relates. Johnston reflects:

'It is difficult to explain such feelings to people. In the face of his great losses it seems petty to say you are sad because there is no emotional support for you. But this has been the bedrock of our relationship (Johnston, 2003 p.33).

I read three narratives which I would like to discuss in more detail: “A matter of timing” (A. Brown, 1998), “Daddyboy; A Memoir” (Wolfe-Konek, 1991) and “The Long Good Night; My Father’s Journey into Alzheimer’s.” (Simpkins, 2003). In these narratives three female academics explore the experience of Alzheimer’s disease in the context of family life. Each writes with poignancy and insight into the emotional toll that physical caring for a person exacts, and all are recommended by the endorsements on the dust jackets of the books as providing valuable insights for carers of people with AD.

A mantra espoused by support service and health professionals is that everyone experiences illness, especially chronic and progressive illness in their own way. Holland posits that the same can be said for carers:
It is important to recognize that no two carers share identical experiences. Carers like people they care for and like other members of society, are unique individuals. This means that each carer will understand their experience of caring and the experiences of carers generally in different ways (Holland, 2008 p.58).

In previous chapters I have reviewed the literature that indicates there are features in the clinical presentations of the dementias and Parkinson’s disease that can suggest, to some degree, the course a person’s illness can take. Brown as the carer of her husband Stan, who was diagnosed with AD at the age of 57, gives a cogent picture of the insidious onset of this disease. Her husband’s enforced redundancy triggers her to heed her intuition of being certain that something was very wrong. Stan’s confusion, loss of short term memory, loss of learnt skills, getting lost and wandering off would resonate with many carers of people with AD as would Brown’s enforced early retirement and her lament that she would need to take control and keep going. Brown chronicles the progression of Stan’s illness by highlighting the good times of holidays and family whilst providing insight into the difficult decisions pertaining to relinquishing care, incontinence and the difficulties of hospitalizing a person without autonomy. Of her own grief and healing, she writes:

*I am aware that for many years I have been living a sort of bereavement but I have no idea at all about how I will cope with a real one. Everything that lies ahead is unknown and all I can do is what I have been doing for so many years – live a day at a time and fill every minute as usefully and pleasantly as I can. I cannot help my emotions – bitterness, despair, anger, remorse, guilt, self-pity. They are awful, negative ones. But there must be room for happy thoughts – I try to brush aside the sadness and think of making every moment as happy as possible (A. Brown, 1998 p.134).*

Both Simpkins (2003) and Wolfe-Konek (1991) present their stories as daughters of ailing fathers. They differ in the philosophical undercurrent of their journeys – Simpkins
explores her belief system and the deep spiritual comfort it offers, whilst Wolfe-Konek and her family contemplate issues surrounding the meaning of the quality of life and euthanasia. Although the dust jackets of both books highlight AD as the focus of the narratives, consideration of the presentation and course of the fathers’ journeys suggest, in light of current understanding, DLB rather than AD. An explanation could be that interpreting the texts from a chronological perspective provides insights into the difficulties of diagnosing and understanding a disease that has poor recognition today, and was not even available for consideration at the time of Wolfe-Konek’s publishing.

Leonard Konek was diagnosed with Parkinson’s disease, and subsequently Parkinson’s disease dementia syndrome, in 1980. The diagnosis was sought because of Leonard’s cognitive difficulties (he recognized he was no longer confident that he could successfully negotiate in business), his parkinsonism and his wife’s expressed concern about his active nightmares:

He frightened me last night as he has never frightened me before. He let out a scream, stood up and charged across the bed, and went to the corner where he was kicking the sliding glass door……he told me later he was protecting me from a tiger…… I’m afraid to sleep with him. Ever since he kicked me in his sleep a few months ago, I’ve been afraid (Wolfe-Konek, 1991 p.6).

Within the text, but not specifically dated, the author mentions her father’s hallucinations, fluctuations, incontinence, delusions and aggression. Wolfe-Konek states that the progression of the disease is not steady writing that Leonard is at times lucid, able to speak in meaningful sentences and able to recognize people, pain and pleasure; the latter in the last days or weeks of his life. She muses that each day brings new confirmation of the bleak prognosis of Alzheimer’s disease. She structures images of isolation, denial, guilt, loss of personhood, rejection, acceptance and moving on through conversations shared with her mother and others at two Alzheimer’s carer support meetings. Within this context the merits and process of organ donation is discussed, so it is not surprising to find in the concluding pages that Leonard’s autopsy result in 1985 showed that he had both AD and PD.
Similarly, the progress of Jerry Simpkins’ illness can be extrapolated from the narrative. In his early 1950s he experienced episodes of cardiac arrhythmia. Simpkins describes a decade of episodes of her father’s paranoid delusions of kidnapping, loss and robbery, inattention and dizzy spells. The extended family is alienated because of his suspicious behaviour and delusions.

Simpkins also intimates that her mother was coping with a significant yet unshared burden. When recounting an hallucinatory episode she writes that her mother’s reaction was to sigh and comment that he needed a lot of attention. After describing how she felt that her husband’s demanding childlike behaviour, possessiveness and aggressiveness were jealous reactions to the attention paid to his grandchild, Simpkins chronicles this exchange:

‘Mother, what do you think is wrong with Daddy?’ I asked.

‘Ain’t nothing wrong with your daddy that killing him wouldn’t fix’ Mother said loudly. He interpreted that comment as flirting. Mother looked at Daddy as if he were a stranger (Simpkins, 2003 p.85).

In the subsequent chapter Simpkins writes of the sudden death of her mother whilst her father, accompanied by her uncle, was seeing a neurologist. His reaction to her death – denial, confabulation and hallucinations, resulted in a psychiatric assessment. Jerry was admitted to hospital for psychotropic drug treatment to which he had a severed adverse reaction. Then, after some weeks in the clinic (probably in the late 1990s) he was formally diagnosed with depression and AD and was discharged home to the care of his daughter (the author), who became his full time carer until his death, at home.

Simpkins indicates that her father’s palliation, initiated because of his inability to swallow was brief, yet prior to those last days he was still ambulant, at times lucid and articulate as illustrated by the following vignette:

*Three weeks ago we found him unconscious on the floor. By ambulance we took him to hospital. While the nurse and I were appraising him in his semi conscious state, his*
clothes soiled, bruises surfacing on his face from having landed on it when he fell, and she was asking me if I wanted extraordinary measures employed to keep him alive, I replied, “this man can get up and walk out of here any time he wants.”

I was the only person who thought that ending was possible. Everyone else was predicting the end of his life. I stood in front of Daddy, immobile in his hospital bed, and I asked, ’are you ready to go home?’ He got right up. People backed away from the mystery of his return to life by simply being offered the refuge of home (Simpkins, 2003 p.178).

Leonard Konek’s autopsy report suggests an alternative diagnosis of DLB and from the information provided, Jerry Simpkins’ adverse drug reaction, together with many other symptoms, also points in that direction. Yet in both narratives the carers identify with others and make meaning of their fathers’ illnesses through association with others dealing with AD and PD in their own families. In Konek’s case the medical diagnosis was PD /PDD but the alternate diagnosis of AD appears to be adopted by the family because of their engagement with the increasing recognition and profile of that disease in medical circles, in the media and emerging carer support networks:

I attend (sic) a conference sponsored by the College of Health-Related Professionals for helping professionals who have Alzheimer’s patients in their charge. The conference, designed for fifty professional participants, draws more than four hundred, some of whom are family members of Alzheimer’s victims (sic) (Wolfe-Konek, 1991 p.21).

Simpkins’ quest for information following her father’s diagnosis is illuminating:

It was a time of reading books that were supposed to describe what it is like to take care for a man with
Alzheimer’s – only the books didn’t really tell the whole truth (Simpkins, 2003 p.137).

One feature of both of these narratives that caught my attention was that Leonard and Jerry are presented as existing in the world – the Heideggerian concept of Dasein or Being (D. Davis, 2004). This is a concept that I have only started to consider since immersing myself in this study. The experience of caring for a person who retains a sense of personhood – “a standing or status that is bestowed on one human being, by another, in the context of relationship and social being” (Kitwood, 1997 p.8), to which the carer can relate to and recognize, well into the course of the disease, contrasts significantly with my own personal experience of loss in the presence of AD. That loss is eloquently expressed by Brown:

It was 1983 when our journey began. Just my husband and I and a long, lonely journey through Alzheimer’s disease. A journey that still continues. There are still two of us, but for many years I have been the only one aware of getting closer and closer to the journey’s end……………….. He is now in a nursing home, well cared for by a devoted and caring staff. Somewhere along the journey, probably many years ago, I lost him…. He registers no recognition when I visit him. There are no remaining memories (A. Brown, 1998 pp.139-141).

This dichotomy of loss and connectedness is a key issue explored in the research interviews for this study.

4.5 Caring and DLB

The research literature on carers of people with dementia, usually classified as either AD or “dementia” and PD is diverse, predominately quantitative and rarely targeting carers of people with DLB. The few studies that do target the DLB population retain that diversity. Other than a recent thesis (Bradshaw, 2007), and papers derived from it, that investigated attentional differences in people with DLB and AD, only three papers were found in this review. There is a single case study that reports on the use of family
therapy following a diagnosis of DLB (Rogerson, 2006), a quantitative study of carers of people with DLB (N=25) and AD (N=75) that reports “the severity of behavioural disturbance was significantly associated with depression in the DLB carers” (Lowery et al., 2000 p.61), and a mixed methods study of communication strategies in 12 spousal dyads where one partner had a diagnosis of idiopathic PD (Whitworth, Lesser, & McKeith, 1999). One aim of this latter study was to ascertain if conversational profiling could provide a differential diagnosis of PD or DLB. The results indicated that people classified as being in the DLB group showed a propensity to discuss their hallucinations, had more communication difficulties because of their fluctuations and had difficulties with comprehension.

Carer narratives are also scant. Contained within “In Memory of Memories” (Breckman, 2003), Carr provides a succinct enumeration of her husband’s DLB criteria starting with non threatening hallucinations. These are followed by increasing confusion that fluctuates, conversation blocks, decreased spatial awareness, parkinsonism and incontinence. Four years into his illness, and in care because of her inability to handle his behavioural symptoms, Carr asserts that her husband still knows her and remains “his affectionate cuddly self” (Carr, 2003 p.25) – a further example of this connectedness.

This is also evident in the final narrative for discussion - Taylor’s (2007) “Take Me Home: Parkinson’s, My Father, Myself.” It would be reasonable to question whether this is again an inconsistent title or wrongly placed in this discussion. It is a retrospective narrative that spans 18 years of care commencing in 1983 when the author, John Taylor’s son was nine. In 1988, 60 year old John’s parkinsonism, poor driving skills, nightmares, hallucinations and depression were diagnosed as PD.

Taylor’s narrative is multifaceted. It is the story of his life through which he chronicles his father’s illness, the increasing burden of care and its impact on the immediate family. It is also a quest to discover meaning in his father’s symptoms, specifically John’s delusion that his son is someone else – someone to fear and reject – his nemesis in his decision to retire early.
Like Jerry and Leonard in the previously discussed narratives, John was still ambulant in early 2001, the year of his death, a year complicated in March by bowel surgery, time in an intensive care unit, and a lengthy convalescence during which time he was able to communicate lucidly, albeit briefly, with his son about Mahler. Taylor writes that after a difficult and demeaning convalescence his mother took his father home and was later to write to him recalling the last weeks of his father’s life in November:

_In those last days, we were close. He was loving again._

*He caught hold of my arm one afternoon and ‘proposed’. At least what he actually said was ‘I want us to be married’. It is a special memory._

*I asked him where he would like to go if I took him out. He wanted to go shopping...he enjoyed a big cream cake in the café and wanted to buy some Christmas cards. This was his last outing._

*He seemed to be so well that last week.........On Friday morning he stood up twice and looked intently out of the window. He was so well...Saturday night he was sick – and Sunday - I miss him so much (J. Taylor, 2007 p.232)._ 

Later, Taylor gained access to the medical records and, through these he reconstructed his father’s medical history. He indicates that an assessment by a neuropsychiatrist in 1994 and a research paper written on a study of John in 1995 both concluded that he had DLB and much of the correspondence relates to his pharmacological management. Taylor’s rationale for publishing using the Parkinson’s label is simple. In email correspondence with me on 18 May 2008 he said: _I went with the Parkinson’s label because that was the label we, as a family, were given all along_ and he acknowledged that his understanding of DLB, as an entity in itself, is emergent.

In these narratives the authors take on the role of informant, surrogate respondent or proxy respondent depending on which appellation is preferred. In current practice the carer as informant paradigm is open to discussion.
4.6 Carers as Informants

The major dilemma of the role, value and inclusion of carers as informants appears to centre on the ‘is it dementia?’ versus ‘is it PD?’ conundrum.

In the dementia field, there is a significant body of literature associated with development and validation of informant rating scales (Brodaty, Low, Gibson, & Burns, 2006; Jorm, 2004; Jorm, Scott, & Jacomb, 1989; Randhawa et al., 2007) and studies indicating that the use of these instruments, together with testing of the person of concern (POC), result in more accurate diagnostic outcomes (Isella et al., 2006; Kemp, Brodaty, Pond, & Luscombe, 2002; Mackinnon et al., 2003). In an editorial Jorm states:

pooled data from 10 studies showed that informant scales had a sensitivity of 86% and a specificity of 80%, compared with a sensitivity of 79% and specificity of 80% for brief cognitive tests (Jorm, 2003 p.881).

There are also studies that correlate informants’ and POCs’ self evaluations of quality of life (QoL) and cognitive functioning (F Boström, Jönsson, Minthon, & Londos, 2007a; Kolanowski, Hoffman, & Hofer, 2007; Medical Research Council Cognitive Function and Ageing Study, 2000). It is acknowledged that the parameters of the studies impact on the results. One significant finding is that people with DLB have significantly lower QoL than people with AD, regardless of the rating instrument used or whether the POC or informant responses are used (F Boström et al., 2007a). An Italian study indicates that the informant information is helpful but not always reliable when depression is considered with AD (Scocco, Fantoni, & Caon, 2006) and not surprisingly, in one study the correlations between informant and POC were found to change as a factor of the severity of the dementia (Novella et al., 2001).

In Victoria the Cognitive, Dementia and Memory Service (CDAMS) – the statewide assessment service - has a common model of service delivery in each of the 13 clinics. The model includes contact with an informant and the clinics actively pursue a carer should a person present alone. The carer (informant) is interviewed but not all clinics ask that they complete rating scales.
In comparison, the Parkinson’s literature promotes the autonomy of the person with PD and champions the person’s rights in a Charter to *take part in managing the illness* (European Parkinson's Disease Association, 1997). Most patient literature supports the confidentiality of the patient doctor relationship; a stance that is reinforced through the legislation such as the Health Records Act 2001 in Victoria. Nevertheless, the Parkinson’s Victoria help sheet associated with medical treatment of PD suggests that people take a family member or support person with them to doctor’s appointments (Parkinson's Victoria, 2008b).

### 4.7 Summary

Caring takes its toll. Although there is a paucity of research on caring in the presence of DLB it seems reasonable, through extrapolation, to assume that the carers in this study may exhibit both the positive and negative impacts of care giving.

Many of the studies reviewed are quantitative using a plethora of rating instruments to determine correlations between perceptions, relationships and the discriminators under investigation. Others, including the narratives, explore concepts of the dynamics of relationships as they confront and endure the impact of living with a degenerative disease. Immersing myself in the caring literature awakened me to new possibilities, particularly in relation to concepts of Being and connectedness, as I explored the caring relationships and experiences of my research participants. I detail my engagement with them in the next chapter.
Chapter 5  Methodology

In this chapter, having, at the outset, established symbolic interactionism as the philosophical or analytical framework for the study (refer page 7), I develop the argument that this research is heuristic in its methodology and discuss the methods through which I illuminated my topic.

5.1 On Being a Qualitative Researcher

For researchers like myself schooled in the evidenced based quantitative approaches to research, qualitative research presents a plethora of options, opportunities and obstacles, not least of which is the conceptual terminology – an excellent example being Patton’s (2002 p.98) summation of a constructivist’s perspective as being “ontologically relativist, epistemologically subjective and methodologically hermeneutic and dialectic”!

Schwandt (2007) provides a succinct explication of some critical aspects of qualitative inquiry that initially confounded me:

Methodology is a particular social scientific discourse (a way of acting, thinking and speaking) that occupies a middle ground between discussions of method (procedures, techniques) and discussions of issues in the philosophy of social science.... There is no direct, unbroken, logically necessary link between various positions on issues in the philosophies of social science, methodologies and methods (Schwandt, 2007 p.193).

The ‘lack of link’ stance is reinforced by others (Hurworth, 2008; Patton, 2002; Snape & Spencer, 2004) who posit that there are no rules in constructing qualitative research, however they espouse that a ‘lack of link’ in no way obfuscates the demand for discipline, rigour and a systematic approach; the central tenet of qualitative inquiry.

My chosen philosophical framework, offered by the symbolic interactionists, and expressed as a paraphrase of Wallace and Wolf’s (2006) work is about meaning making; that is, how I and others understand, act towards ourselves, each other,
individually and collectively, and interpret constructions of illness, specifically in this study, DLB.

I am confident that this framework provides ample structure through which to discuss the findings from my research question which I initially stated as: *What is the experience of caring for a person with DLB?*

I had thought to answer this question through the exploration of a number of questions that embraced my presuppositions – questions of differential diagnosis, changing relationships, knowledge, or more pertinently lack of knowledge, and the role of carer support services. As I approached the point where I was recruiting participants, these questions still resonated as well as they did when I first considered this study, but to some extent they have become blurred within the central question. I have also been challenged, through my review of carer narratives, with questions of ‘being’ and ‘connectedness’ particularly in the latter stages of the disease progression. I found that I was continually reflecting on my own family’s experience of letting go and I dwelt on the ontological arguments proffered by Davis and their relevance to caring for a person with DLB.

...... the end point of the dementing process is an essential rending of Dasein’s way of being. This is a bleak conclusion indeed for the sufferer (sic), but the consequences of enlisting relatives to the retrieving of a person long since gone is no less so. While it is imperative that the sufferer (sic) is treated with dignity until the close of their life, the relatives would do better to be removed from this final process. For then they might be allowed to determine with courage that there is nothing left of their past together in a way that grants them an opportunity to mourn (D. Davis, 2004 p.378).

Consequently, I questioned the appropriateness of exploring how carers’ perceive and experience the changes in their relationship with the person being cared for and with
others from the onset of change until diagnosis, and I sensed that the phrase “from the onset of change until diagnosis” was redundant.

I stated in my introduction that the notion of exploring DLB and specifically the impact early stages of the disease has on carers, became, and continues to be, consuming. I am immersed in a self-directed or heuristic search to find meaning in both the disease and the experience of caring in its presence.

5.2 Heuristic Methodology

While the origins of heuristic methodology are discussed in Chapter 1, this section focuses on how I interpreted the methodology to address my research question.

Moustakas (1990) details six phases of heuristic research: initial engagement, immersion, incubation, illumination, explication, and culmination in a creative synthesis. In adopting this methodology I acknowledge there is debate in its use and interpretation (Douglass & Moustakas, 1985; Moustakas, 1990; Patton, 2002; Sela-Smith, 2002). Moutsakas’s stance is that heuristic research is “I” centric and its purpose is to be self transformational. Sela-Smith, in a critical analysis of Moustakas’ work, states:

*Though self-search, in my opinion, is the objective of this method, even in Moustakas’s (1990) self-report of his process, there was a shift in his focus from the self who is experiencing the problem to the experience that the self is having with the problem. In this shift, though it might appear that he or she is attempting to understand an experience being felt, in reality, the experience becomes the focus and there is no return to the I-who-feels. Feeling is disconnected from the research and self-transformation does not occur. The tacit dimension is not entered, and the internal structures remain intact (Sela-Smith, 2002 p.71).*

In a review of 25 of 28 studies purporting to employ the methodology, Sela-Smith contends that this tacit dimension was ignored, the use of co-participants was counter
intuitive to self transformation and artificial (academic) constraints impeded each stage of the process. However, on further reflection the author posits:

Moustakas shifts from experience being used as a verb that is connected to the internal self search to experience as a noun that is connected to observation and thoughts related to the observation of an event or an experience ........ I contend that heuristic inquiry that results in self transformation and the creation of a story that generates potential for transformation in others and in society is the strength of the self inquiry method (Sela Smith, 2002 p.72 & 82).

This interpretation has resonance with the generally accepted interpretation of heuristic research, that is:

What is my experience of this phenomenon and the essential experience of others who also experience this phenomenon intensely? (Patton, 2002 p.107)

In other words, it is inquiry that emphasizes connectedness and relationships, leads to depictions of essential meanings and portrayal of the intrigue and personal significance that imbue the search to know, and concludes with a creative synthesis that demands the voice (intuition and tacit knowledge) of the researcher and the representation of the co researchers or research participants as whole persons (Douglass & Moustakas, 1985).

Being cognizant of adopting a stance that is ‘of the experience’ rather than ‘in the experience’, if one takes a pedagogical view of the six phases of heuristic research as described by Moustakas, then I am engaged and immersed. The engagement came per chance in that a casual request to review a lecture left me with many more questions than answers, and the immersion (the process through which I have developed a deeper understanding of the nature of DLB and the caring experience) has stimulated me to keep probing and questioning.

I would argue that the academic process facilitated incubation, the third phase of the process, in that confirmation of candidature and ethics approval made me “retreat from
the intense, concentrated focus on the question” (Moustakas, 1990 p.28). In addressing these peripheral requirements and being challenged by others to justify the research, I found clarity in my understanding of the issues I want to explore.

The illumination phase, in Moustakas’s terms, is “the awakening to new constituents of the experience, thus adding to new knowledge” (1990 p.29). This can be viewed as the data collection phase, the explication phase as the analysis of that data and the creative synthesis as the resulting discussion. However, Moustakas cautions that the processes of discovery always have at their core the frame of reference of the discoverers, so that of necessity, my creative synthesis (culmination phase) of the experience of caring for a person with DLB is dependent on my ability to be empathic and open with my co-researchers.

Although the pedagogical approach has validity from an academic perspective, I have found that each phase of the heuristic process has relevance to every word read and every discussion entered into so far and, indeed, to each component of the whole. As I approached the interaction with my research participants this phasic process was re-emphasised in that Moustakas (1990) is prescriptive in the methods that the researcher should employ in preparation, data collection, organizing and synthesising data, as well as the analysis of the data. Those guidelines underpin the process utilized in this study.

5.3 Methods

Qualitative research methods have a long association with educational research, but it has only been in the past two decades that they have gained favour in the health professions (see B. S. Black & Rabins, 2007; Byng, Norman, & Redfern, 2005; Hansen, 2006; Patton, 2002). Patton (2002) posits the challenge is to match methods to questions, so consequently the methods I employed were both quantitative (questionnaire) and qualitative (interviews and focus groups) approaches. The quantitative data were used to inform rather than to generate statistically analyzable results because of the small sample size.

I conceptualized the study as having two stages; the first stage centred on my interactions with the carers of people with DLB, whom I represent as my research
participants, and a second later stage, involved a focus group or focused discussion with geriatricians and psychiatrists.

The first stage, my interactions with the carers of people with DLB, involved a number of contacts; and replicated the heuristic cycle of initial engagement, immersion, incubation immersion, incubation and then explication with each research participant. This can be aligned to the stances of other qualitative researchers, particularly in the health field (see Grbich, 1999; Hansen, 2006; Seidman, 1998), who argue that planning for unstructured interviews necessitates up to three contacts with the interviewee. The study design facilitated the heuristic cycle in that once the initial engagement had been made a questionnaire was completed by telephone and then followed by a face-to-face interview. The research participants were then offered the opportunity some months later to participate in a focus group. Further opportunities for engagement arose through the debriefing session, where the research participants were encouraged to attend with family members and, finally, 12 months after the initial contact we came together again so that I could inform the research participants of my findings and show them the creative synthesis. In heuristic inquiry the synthesis is synonymous with the findings as it is my interpretation of the experience of caring for a person with DLB. However, mindful of representing the other, I wanted the research participants to member check the synthesis to ensure that it “constituted credible evidence” from their perspectives (Patton, 2002 p.572).

5.3.1 The Questionnaire

Countless questionnaires associated with dementia have been validated and some are routinely used by assessment services and private practitioners in Australia. These include the Mini Mental State Examination (Folstein, Folstein, & McHugh, 1975), the informant questionnaire to measure cognitive decline in the elderly: IQCODE (Jorm et al., 1989), the Cambridge examination for mental disorders of the elderly: CAMDEX (Roth, Huppert, Tym, & Mountjoy, 1988), and the dysfunctional behaviour rating scale: DBRI (Molloy, McIlroy, Guyatt, & Lever, 1991). From general inquiry I ascertained that, within the CDAMS clinics in Victoria, there is no standardization of the preferred rating scales in use, and in some instances rating scales are not used at all. Consequently, to garner informant data the most common instruments used are a
generic informant questionnaire and face-to-face interview. Most CDAMS clinics also rated frontal behaviour, using the Frontal Behaviour Inventory: FBI (Kertesz, Davidson, & Fox, 1997) and depression, using the Geriatric Depression Scale: GDS (Yesavage et al., 1983).

The British Geriatric Society (2007) among others, promotes the following for the assessment of PD: Unified Parkinson's Disease Rating Scale: UPDRS (Fahn, Elton, & UPDRS Development Committee, 1987) for motor assessment, MMSE for cognitive assessment, and the GDS and Parkinson’s Disease Questionnaire: PDQ39 (Jenkinson, Fitzpatrick, & Peto, 1998) which assess quality of life issues. All of these instruments are completed by the person with the disease. The Parkinson’s Disease Society of the UK (2006) also promote the Non Motor Symptoms Questionnaire: NMS Quest, which they recommend for people being assessed, however they limit a ‘yes’ response to a symptom that was experienced within the previous month.

As no single tool specifically met my requirements for the questionnaire for this study, a review of these instruments did provide a broad base from which to draw. I conceived a number of aims for the questionnaire (Appendix 1) which I administered using the telephone.

Whilst the use of the telephone as a contact medium is ubiquitous in market research, Hurworth (2005) suggests that there is scant evidence to support its use in qualitative research. However, in exploring the tensions between face-to-face and telephone interviews, Novick (2008 p.391) suggests that “telephones may allow respondents to feel relaxed and able to disclose sensitive information” both aims I wanted to achieve prior to the face-to-contact. The questionnaire allowed me to gather some very basic demographic data as well as gain an overview of the timeline and assessment processes undertaken. Questions to that end thus formed the first part of the survey.

My primary interest was to gain an appreciation of the early signs that carers noticed and align them with the criteria for DLB (McKeith et al., 2005) regardless of the diagnoses. In order to do that I devised a series of dichotomous questions relating to motor signs, senses, autonomic function, memory and behaviour. In a number of instances they aligned closely to those on established questions such as the NMS Quest
but were reworded to be applicable to the carer. For example, NMS Quest question 13 ‘have you experienced in the last month a loss of interest in what is happening around you or in doing things?’ was re-presented as ‘did … lose interest in your life together?’ and ‘did … lose interest in your family’s life and doings?’. Questions that anticipated a ‘no’ response such as ‘did you notice a difference in ……’s ability to hold a glass, cup or mug steady?’ and ‘did …. ask the same question repeatedly?’ were also included.

At the end of the questionnaire I included two questions relating to medical management; specifically, whether AD or PD medication had been prescribed, and three questions about the inclusion of the carer in the assessment process.

The sequencing of the questionnaire conforms to accepted design principles (Cohen, Manion, & Morrison, 2000), however contrary to another principle (Oppenheim, 1992) the questionnaire was not subjected to piloting. Pretesting was not undertaken primarily due to the lack of subjects however a draft of the questionnaire was given to several carers of people with dementia who were not participants in the study. They found it straightforward to complete, logical in its sequencing and able to be completed within the allocated time. That group identified a number of redundant questions and consequently they raised questions about the purpose of the research. This was anticipated as none of the test subjects were carers of people with DLB.

5.3.2 The Interviews

Once the questionnaire was completed and I had an understanding of each carer’s situation, the purpose of the interview was to gain insights into the caring experience. From my experience as a health professional and telephone helpline counsellor, I expected that these interviews would be dictated not only by the experiences of those being interviewed, but also by their immediate concerns about their partner and their understanding of DLB. I also expected that, to some degree, there would be general information sharing and to facilitate that, whilst remaining focused on the topic, I was conscious of the need to consider the form of the interview.

Kvale (2007 p.11-14) enumerates twelve characteristics that define qualitative research interviewing. Some are self evident; the interviews are qualitative, have a descriptive focus and have specificity, that is they focus on a specified topic, in this instance caring
for a person with DLB. As this study did not require inter-subjectively reproducible data, further characteristics associated with sensitivity were redundant. However seven of the characteristics provided a framework for the interviews in this study and are discussed below.

**Lifeworld:** where the interview should capture the everyday. In my interviews this notion could have subsumed many interviews. Often the research participants had burning issues which were the immediate focus of their lifeworlds. This was especially evident in the opening minutes where they were consumed by the ‘today’ or ‘last night’ of their experiences or that of their spouses.

**Meaning:** particularly of central themes. The necessity of interpreting what was said, as well as what was implied, by intonation, gesture and pregnant pause, was critical to interpreting the experiences. Someone being fabulous, kind or wonderful did not always equate with the worth of the information of assistance given by them, so it was often necessary in the words of Kvale to:

> seek to formulate the implicit message, ‘send it back’ to
> the subject, and obtain an immediate confirmation or
> disconfirmation of the interpretation of what the
> interviewee is saying (2007 p.11).

**Qualified naïveté:** I found this to be a critical component of my listening skills. It was impossible to approach the interviews without some preconceived ideas, however I was always ready to explore new territory or listen to different interpretations on themes that had been canvassed previously. In some ways this characteristic could be construed as being counter intuitive to that of focus, however the focus, DLB, was patent; how people experience it is an individual and unique experience.

**Ambiguity and change** are characteristics that I found shared common ground in many of the interviews. This related to the participants’ poor understanding of the medical construct of DLB and their interactions with those living in the AD and PD lifeworlds. I found that Kvale’s final two characteristics both compounded and ameliorated some of the participants’ reflections on their own situations. These characteristics are-

**Interpersonal situation:** where the interaction between the person being interviewed and
me was always influenced by my knowledge of the topic. Several of the above characteristics that I brought to the interviews enabled me to create, as much as possible, equality in the power relationship of the interaction (see Cohen et al., 2000; Kvale, 2007; Seidman, 1998). In most situations I had disclosed my family history with AD in my first contact with the participants or during the telephone survey and my age was an advantage. I also accepted hospitality when it was offered including at the beginning or in the middle of the interview to give the participants control. In several interviews the participants chose when to terminate the interview. Although at times I felt it to be inopportune I did not object. The structure of the study design allowed me to talk about the next data gathering activity – this reassured the participants of an ongoing relationship and I always gave the participants the opportunity to continue the interaction once the tape had been turned off. Although not everyone availed themselves of that opportunity, it did result in several garden tours, numerous coffees and a few long chats and, hopefully, the last of Kvale’s characteristics – positive experiences.

Adherence to these characteristics was possible within my chosen interview style - the conversational or in-depth unstructured interview which can be described as:

\[ a \text{ method where researchers want to understand the} \]
\[ \text{meanings people give to their experiences, to study stories} \]
\[ \text{they tell and to place these in context (Hansen et al., 2008 p.101).} \]

Although Patton (2002) suggests that interviews of this type can be difficult to pull together and analyze, the topic was patent and some areas of interest were identified as a result of the telephone questionnaires.

Rather than have an interview guide I chose to commence each interview in a standard manner with a prefatory statement (Patton, 2002) referring to the information provided in the questionnaire and then suggesting that the purpose of the interview was to explore the participants’ experiences. I then directed, if necessary, the participants to areas of interest with transition announcements such as “did you find it difficult to go away?” and “am I right in thinking that you go to a Parkinson’s support group?”
5.3.3 Focus Groups

Although widely used and accepted in market research and advertising, focus groups are gaining currency in social aspects of medical research (Hansen, 2006). In a broad sense, this approach was adopted in two phases of this study as the literature suggests that focus groups are useful for clarifying potential options and recommending courses of action (Krueger & Casey, 2000; Stewart, Shamdasani, & Rook, 2007). The first focus group with the carers, who came together after the interview phase, was targeted to elicit options for support and education. The purpose of the second focus group was to gain consensus (Hurworth, 2008) from a divergent group of specialist medical practitioners on some of the issues identified from the analysis of the data and to hear their views on a way forward. Obviously, the perspectives of the two groups were very different in that the carers’ group was struggling to comprehend the nuances of DLB, whilst the specialist medical group, familiar with the guidelines for diagnosing DLB, was an unknown with respect to each member’s understanding and experience in dealing with the psycho-social aspects of caring and DLB. It is argued that the intention of focus groups should be to allow for free ranging communication between group participants whilst they are led by the facilitator to address a predetermined focal point (Hurworth, 2008; Patton, 2002; Putcha & Potter, 2004). In both groups the general principles of conducting a focus group were followed, although rather than focusing specifically on one issue in the second group, several themes of interest (Stewart et al., 2007) were pursued and it could be argued that it was a focused discussion rather than a focus group.

The Carers’ Focus Group

Although an integral component of the study, I expected that some participants, particularly those caring at home, would not be able to attend the carers’ focus group even though the details of it were mailed to all participants. The focus group was incorporated into a DLB ‘discovery’ day. Seven carers attended the day which commenced with a presentation from me on the history of and research into DLB and its relationship with AD and PD. There was also an opportunity to ask questions of me and Professor David Ames, my topic specialist supervisor. The focus group was convened
after the participants had time to meet and talk informally over lunch so that there was some established rapport. The focus group plan is appended (Appendix 2).

5.4 Ethics Approval

The University of Melbourne’s Human Research Ethics Committee (Ethics ID 0721488), granted approval (Appendix 3) for this research in June 2008. Once the interviews with carers were completed I realized that holding a focus group with general medical practitioners, which had been my intention, would not enhance the study and after discussion with my supervisors, an Ethics Amendment was lodged. This allowed me to run the focus group with specialist medical practitioners whose practices routinely included people with DLB. The Ethics Amendment was approved in February 2009.

5.5 Recruitment and Informed Consent

Having explored the DLB / AD and DLB / PD conundrums at length in my review of the literature, I was keen to have a sample that was neither homogenous or of maximum variability, but was one which provided sufficient data for the exploration of both pathways to diagnosis. Although it was anticipated the recruitment process may provide some challenges in achieving a balanced sample, I was fortunate that it was straightforward. Through the memory clinic networks the study came to the attention of a researcher involved in a large dementia project with a Melbourne based hub. That researcher brought my study to the notice of carers of people with DLB in that project. An article about the research was also featured in a Parkinson’s newsletter. When people interested in participating in the study contacted me I sent them the plain language statement and consent form (Appendix 4).

Of the seventeen people who requested plain language statements, thirteen spousal carers of people with a confirmed diagnosis of dementia with Lewy bodies, joined the study. Informed consent was given by all participants prior to them undertaking the first stage of data collection, that is, completing the questionnaire, and they were asked at each subsequent stage of data collection if there had been any changes in their circumstances where that consent was no longer valid.
The demographics of the participants are discussed in the next chapter but the sampling demands of the study were satisfied in that it was a purposive sample with two criteria of importance (Hansen, 2006; Patton, 2002): (1) spousal carers and (2) a DLB diagnosis. It was also balanced as the participants were recruited through memory clinics (N=5), Alzheimer’s Australia - Victoria (N=1), Parkinson’s Australia (N=6) and a carer support group (N=1).

I convened the specialists’ focus group well into the analytical phase as it formed a separate stage of the study. I have already discussed its purpose but not the recruitment of participants which was through my subject matter supervisor’s networks of psychiatrists, geriatricians and neurologists. The nine specialists each signed an informed consent and participated in lively interaction. I ensured that all research data presented was de-identified as I knew some of the participants were the treating specialists of spouses of the research participants. A synopsis of the discussion is appended (Appendix 7).

5.6 Ethical Dilemmas and Risk Management

From its inception, this heuristic journey has had one purpose – to understand the experience of caring for a person with DLB. Yet, like all journeys, there are innumerable routes one can take. In preparation for a critical part of my journey - interaction with others - I had attended to all the preliminary stages, was confident in the choices I had made and thought I was on the right route. Unfortunately, that view was not shared by the University’s Ethics Committee to whom I applied in January 2008. It requested that, rather than recruiting people with a diagnosis of AD or PD and using the questionnaire to identify carers whose spouse may have been misdiagnosed, I restrict my recruitment to carers of people with a confirmed diagnosis of DLB.

Although the excruciating details of those negotiations and the delay in commencement of data collection are largely forgotten, they made a significant contribution to my personal understanding of symbolic interactionism. ‘I’ waged war with ‘me’ over the impact it would have on my study design route, the appropriateness of the methods to which I had already committed and, finally, the requirement to disclose. The changes imposed meant I had to change my recruitment strategy. More significantly, the changes
challenged my rationale for including a quantitative method, the questionnaire, into what had transformed into a qualitative study. On reflection, I consider that the use of the questionnaire and the data that it generated enhanced the study.

I was confronted with some ethical dilemmas during the recruitment and interview stages of the study. During recruitment a potential candidate approached me for information about the study because she believed her spouse had DLB but he would not accept her intervention in his medical management. I resolved this dilemma by explaining the criteria for participant recruitment and suggested that she discuss her concerns with her local doctor. I also informed my supervisors of the conversation.

The interviews presented several ethical challenges in relation to informed consent of third parties, namely spouses and children. When arranging the interview I suggested that it would be more comfortable for everyone if it could be scheduled at a time and place that would ensure privacy and enable us to speak freely. Where the person’s spouse still lived at home it was suggested that a respite day would be the most suitable. The majority of the interviews were consequently conducted in private spaces. In one situation, where the interview was held in a communal area of a retirement village, the participant’s spouse and professional carer joined us towards the end of the interview. The tape recorder was discretely removed and the interview formally concluded by phone the following day.

Three other situations were more difficult. One interview was conducted in the participant’s lounge room with her spouse sitting in her line of sight in the next room. I was not able to see her spouse but it was obvious that he could hear the conversation because at times the participant lowered her voice to a whisper. I turned the tape off when the carer asked me to move into the next room so that we could continue our conversation whilst she assisted her spouse with his afternoon tea. I was not given an opportunity to reconvene the interview.

The second dilemma came about when the participant actively engaged both her spouse and son in the interview. The interview was conducted at a time when the participant was severely sleep deprived and very stressed. I gave her a number of opportunities to abort or reschedule the interview but she was adamant that we should continue. When
transcribing the interview I included interactions from her husband and son but only directly quoted the participant in the analysis.

The final scenario resulted in the interview being conducted by telephone after it was obvious that the participant’s spouse was actively involved in the questionnaire responses and that the participant was adamant they would both be present during the interview. Although a passive participant, the spouse’s presence was palpable during the interview and this impeded an open discussion.

As part of my risk management strategy the presentation used to facilitate discussion prior to the carer’s focus group was repeated a month after the focus group as a debriefing session. All of the research participants were given the opportunity to attend and invite their families and friends. About 20 people attended the session including participants and the children of several carers who had not been able to attend the focus group. Although several children shared previously unheard anecdotes about their parents with me on that occasion no subsequent reference to those data were made.

The debriefing session and the final gathering of the research participants highlighted the progressive nature of the disease under consideration. I recognized that personal situations could change rapidly so, as well as sending out written information about each stage of the study I telephoned the research participants a few days before the event to confirm ongoing consent and their availability. It was during these calls that I learnt of the deaths of two of the spouses and established how the carers wished me to deal with the information. On both occasions we acknowledged the deaths within the groups which led to considerable interaction and information sharing. Another carer expressed so much distress during one of these calls that, with her consent, I made a referral to the counselling services at Alzheimer’s Australia Victoria.

5.7 Data Analysis

Hansen (2006) makes the observation that researchers can expand their analysis of qualitative data by reading widely and approaching their data with open minds. Although confident I had read widely, I was conscious of some emerging expectations. Consequently I recognized the need to manage my data so that my biases and pre-
conceptions were patent and the analysis and reflection occurred on those data and the experiences of the research participants. This required several approaches.

### 5.7.1 Data from the Questionnaire

A hard copy of the questionnaire was available for each interaction and the responses plus elaborations were noted. At the conclusion of each call I immediately reviewed the responses and wrote a dot point summary of any material that I interpreted as being significant for the carer, or for me, in preparation for the subsequent interview.

I transposed the responses into an Excel spreadsheet and then exported the demographic data to a data file in the student version of the Statistical Package for the Social Sciences (SPSS) and mean and standard deviation analyses were done. As is evident in Chapter 6, the quantitative data presented are minimal and merely demonstrate the coherence of the cohort and the consistency with which their spouses’ symptoms aligned with the diagnostic criteria for DLB. However, in other papers and presentations related to my emergent study, it has been useful to provide demographic data summaries using the accepted quantitative approach.

The demographic information from the questionnaires was invaluable in providing insights into the spouses’ profiles and subsequently for framing the interviews. I reviewed the questionnaire prior to each interview and also had it available for reference. It enabled me to acknowledge the carer’s spouse and the journey that each couple had taken without having to seek explanation and clarification. It also allowed me to concentrate on the carers’ experiences and ask questions relevant to those experiences in a timely manner. The questionnaires provided rich detail from which I was able to construct the profiles of the dyads in Chapter 6.

### 5.7.2 Transcribing

The interviews and focus groups were audio recorded and a scribe was also present at both groups. Whenever feasible I scheduled the interviews so that each interview, transcription and verification was completed as a unit. The audio file was uploaded onto my personal computer and I then listened to the complete file. I then transcribed the file adding emotion in brackets (laughter) or capitals for intensity (NEVER). I transcribed
all ‘you knows’ ‘ums’ and grammatical errors as I found they were a valuable aid in
connecting with the carer when I was subsequently immersed in their story. After each
transcription was finished I listened again to the audio file whilst reading the interview
transcript. I fully concur with Hansen’s assessment that “transcription is painstaking
work and takes a lot longer than you might expect” (Hansen, 2006, p.113) and I found
that I was selectively omitting my repeated explanations of some aspects of DLB.
Where this occurred I notated the transcript and placed a time marker next to the
notation so that I could review the audio file quickly if I was in doubt about either the
context or the continuing conversation.

I used the same process for the focus group with the carers and appended the scribe’s
notes. As I had used a Powerpoint presentation to raise the issues I wanted discussed by
the specialists, I used that as the basis of my transcription of that focus group and listed
bullet points on the notes page of each slide. However when I came to incorporate their
comments into my writing, I quickly realized the value of a verbatim transcription.
Therefore, within the transcription I assigned a new row to each voice but, with the
exception of my own voice, I made no attempt to denote any identifiers. This precluded
individual identification of the speaker, by voice or opinion, whilst it provided me with
consensus and divergent views on the issues raised.

5.7.3 Coding

To a significant degree my analytical framework of symbolic interactionism dictated the
themes I wanted to explore – the carers’ meaning making of DLB and their
relationships with themselves and others in its presence. Faced with a vast collection of
data I identified quickly with Seidman (1998, p.108) who wrote “it is foolish for me to
edit on screen, because I invariably miss issues that are easily evident to me when I
work with a paper copy”. After innumerable readings of the transcripts and heartened
by the concept that there is no definitive articulation of the correct way of proceeding
(Hansen, 2006; Hurworth, 2008; Kvale, 2007; Patton, 2002) I started with six codes,
namely:

1. Interaction with doctors
2. Understanding DLB / AD / PD
3. Service providers
4. Self – knowledge, coping, life
5. Relationship with spouse
6. Friends and family.

This set of codes proved useful for my first interrogation of the data as I started to develop the themes and present the voices of the carers but I realized quickly that my simplistic code was insufficient for finding the thick description and identifying alternative viewpoints. I finally adopted the categorization approach articulated by Kvale (2007) although I reduced strengths of opinion from the suggested seven point scale to a positive and negative paradigm.

This approach resulted in a truncation of major themes into relationships, DLB and carer issues. Each theme was then expanded and, when appropriate, positive and negative interactions coded. Table 5.1 illustrates the header of the grid for the Relationships – Carers and Medical Profession category and illustrates how I expanded each major theme into its component categories. Obviously not all components had a positive (+VE) or negative (-VE) association and in some instances ‘positive’ assumed an ‘accurate’ connotation in that the opinion expressed by the carer was a correct interpretation of the topic being coded.

<table>
<thead>
<tr>
<th>CARER</th>
<th>GP +VE</th>
<th>GP −VE</th>
<th>HOSPITAL +VE</th>
<th>HOSPITAL −VE</th>
<th>SPECIALIST +VE</th>
<th>SPECIALIST −VE</th>
<th>DRUGS +VE</th>
<th>DRUGS −VE</th>
<th>EXPRESSED LACK SUPPORT</th>
</tr>
</thead>
</table>

Table 5.1: Grid Header: Relationships - Carers & Medical Profession

In order to code and present the data I ordered the research participants by age and then assigned pseudonyms to their initials and first names and to their spouses’ first names (see Table 5.2: Code for Participants & Spouses). This master code, which contains the participants’ initials, is held with the original tapes and files.

The transcripts were then reprinted substituting all identifiers. Footers contained the substituted identifiers and page numbers and the text was presented in columns so that it was evident who was talking. A blank column was used for coding and notation. Codes and, subsequently, quotes in the analysis were assigned a number, page number and row
number. See Appendix 5 for the coded analyses, together with a section of one de-
idified transcript (provided as an example). This format was also applied when quoting from the specialist’s focus group (SFG), with the SFG identifier, page number and row number assigned to quotes.

<table>
<thead>
<tr>
<th>Carer</th>
<th>Initials</th>
<th>Carer first name</th>
<th>Spouse first name</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>YM</td>
<td>Yvonne</td>
<td>Tony</td>
</tr>
<tr>
<td>2</td>
<td>RH</td>
<td>Ruth</td>
<td>Simon</td>
</tr>
<tr>
<td>3</td>
<td>FS</td>
<td>Fran</td>
<td>Keith</td>
</tr>
<tr>
<td>4</td>
<td>WJ</td>
<td>Wendy</td>
<td>Alex</td>
</tr>
<tr>
<td>5</td>
<td>SC</td>
<td>Sara</td>
<td>Barry</td>
</tr>
<tr>
<td>6</td>
<td>GB</td>
<td>Glenys</td>
<td>Frank</td>
</tr>
<tr>
<td>7</td>
<td>OV</td>
<td>Olive</td>
<td>Harry</td>
</tr>
<tr>
<td>8</td>
<td>TL</td>
<td>Trudy</td>
<td>Colin</td>
</tr>
<tr>
<td>9</td>
<td>BM</td>
<td>Betty</td>
<td>Jeff</td>
</tr>
<tr>
<td>10</td>
<td>KS</td>
<td>Kerrie</td>
<td>Brian</td>
</tr>
<tr>
<td>11</td>
<td>NK</td>
<td>Norman</td>
<td>Mary</td>
</tr>
<tr>
<td>12</td>
<td>JV</td>
<td>Janet</td>
<td>Leon</td>
</tr>
<tr>
<td>13</td>
<td>LV</td>
<td>Lucy</td>
<td>Murray</td>
</tr>
</tbody>
</table>

Table 5.2: Code for Participants & Spouses

5.7.4 Presentation of the Data

I have presented the data in three chapters as separate data stories. In Chapter 6 after quantifying and, at times, reflecting on the demographics and questionnaire responses, there is a profile of each research participant. The profiles pivot on the research question – the experience of caring for a spouse with DLB using information gleaned from the questionnaires and the interviews. While they are my interpretations and impressions of each person, I have integrated their words to give voice to their individual situations.
Chapter 7 draws my understandings of the topic, the research as presented in the previous chapters, and the research participants’ experiences together through thematic analysis. I have immersed myself in the data to look for and present emic perspectives of each theme. In these two chapters I have used some editorial discretion to present quotes in a readable manner. I have indicated when significant paraphrasing was necessary.

In the third data analysis chapter I have integrated my understandings of DLB, developed from the literature, and my interpretations of the issues of caring for a person with DLB, as presented through the voices of the research participants, and taken the role of the other (Blumer, 1969; Griffin, 2008; Wallace & Wolf, 2006). In so doing I unite the frameworks underpinning this study in that the symbolic interactionist makes new meaning through dialogue with oneself and others and the heuristic process demands that the interpretations of that new meaning are expressed as a creative synthesis. In taking the role of the other - that of a carer of a spouse with DLB, I explore my findings as a DVD role play. The DVD and further discussion about the creative synthesis is in Chapter 8.

By using these three approaches to presenting the data, I have endeavoured to present an authentic, credible and trustworthy or valid account of caring for a person with DLB.

5.8 Validity

Validity is a thorny issue yet a concept fundamental to quantitative research. It has undergone much iteration in the promotion of alternative paradigms of methodological innovation. In exploring its translation from the quantitative to qualitative milieu, Lincoln and Guba (1985; 1986) argue that the qualitative researcher must demonstrate rigour, or trustworthiness and authenticity, in any study. In grappling with establishing criteria through which rigour can be demonstrated the authors comment “the reader should regard our discussion as speculative and, we hope, heuristic” (Lincoln & Guba, 1986, p.78) and suggest the following authenticity criteria: fairness, ontological, educative, catalytic and tactical authentication, terms not readily found in current literature. Denzin contends that the defining feature and goal of qualitative research is the “quest for the authentic voice of the other...”, a goal that is “fraught with problems”
(Denzin, 1995, p.313). From the symbolic interactionist perspective of meaning making this immediately raises problems where the “other” is twofold; it can be the language, and its recording, transcription, coding and reporting, of an “other”, or the “I” “me” dialogue when one takes the role of the “other”. By using both strategies in my data analysis and presentation, I have sought to give authenticity to the study. I have also employed some of the earlier criteria through the engagement with the research participants in the DLB “discovery day” where their understandings of DLB were enriched (ontological authentication) and they were exposed to and discussed my and each others’ perspectives (educative authentication). Catalytic and tactical authentication, the remaining authenticity criteria espoused by Lincoln and Guba (1986), are more easily recognized in current debate as knowledge translation (Draper, Low, Withall, Vickland, & Ward, 2009) and are discussed in Chapter 8.

From an heuristic perspective Moustakas (1990, p.32) posits that “the question of validity is one of meaning – [a] judgement [that] is made by the primary researcher”. Although it is tempting to adopt this view and move on, Black and Rabins argue that:

\[\text{the success of qualitative inquiry depends on [the researcher] understanding the principles and methods on which this approach is founded and skillfully executing the techniques used for collecting and analyzing data and reporting findings in a credible manner} \ (B. S. Black \\ & Rabins, 2007 p.170).\]

It is generally accepted that rigour has four components: credibility, confirmability, dependability, and transferability and these criteria are cited as the standards for valid qualitative research (Nuttall, 2006; Whittemore, Chase, & Mandle, 2001; Wu et al., 2007).

Credibility is demonstrated through my efforts to interpret the data accurately so that they reflect the lifeworlds of the participants. To this end I have used a number of techniques to give them voice. At times I have let the carer tell their story in thick rich description. Elsewhere I have captured their adjectives or phrases to emphasise emotion or points of view. When there was significant concordance I gave each voice a bullet point. Through these differing presentations I have tried to represent their journeys
sensitively, vividly, thoroughly and explicitly. These attributes are considered secondary criteria for validity (Whittemore et al., 2001) and, with regard to explicitness, auditing is recommended (Lincoln & Guba, 1986). Consequently, I have subjected my analysis and records to external auditing, the details of which follow. I have also exposed my research to peer review through conference presentations and papers. The specialist’s focus group provided a further feedback mechanism.

Confirmability acts as a safeguard against researcher bias and preconception, attributes which I have already acknowledged. Thus, throughout the analysis I brought multiple voices to each theme and issue. Where there was a lone voice I supported it through reference to the research literature. In both the creative synthesis and the concluding chapters, where I argue for change in the medical understanding of DLB, in the systems that support people with neurodegenerative illnesses and in society itself, I do so by confirming that my voice is bolstered by numerous sources, be they a number of the research participants, the supporting literature, or the opinions of the focus groups. Input was also welcomed from colleagues in the support services, whose practices may be impacted by my findings.

Dependability is at the core of my decision to apply the academic rigour of a dissertation to my research question. My initial exposure to caring and DLB alerted that unsettled, wondering, challenged mindset that I spoke of in the introduction. I now welcome being challenged because I have the knowledge and understanding to argue for future carers of people with DLB, together with a critical self-appraisal that reminds me that it is not primarily my journey.

The final criterion for validity is transferability which Nuttall explains as the researcher’s responsibility “to present the research findings in a way that enables others to apply the knowledge or insights in other situations” (Nuttall, 2006, p.438). This criterion has its roots in the quantitative notion of generalizability, which is the ability to apply results “to the wider population from whom the trial sample was drawn” (Gibson, Timlin, Curran, & Wattis, 2004, p.422). It is a point of contention between qualitative and quantitative researchers (Lincoln & Guba, 1985; Patton, 2002) and is usually argued as a factor of sample size and selection with the general consensus
being that the purpose of qualitative research is to provide a depth of insight into a phenomenon (Hansen, 2006; Hurworth, 2008; Patton, 2002). Denzin (1995 p.313) proffers “the desire to present the voice of the other in the qualitative text is a desirable goal, the defining feature of qualitative research”. As the creative synthesis and transferability are intricately intertwined I continue further discussion on aspects of validity pertinent to the synthesis in Chapter 8.

5.8.1 Auditing

As a peripheral activity by an independent reviewer, auditing also underpins dependability and confirmability in qualitative research (Lincoln & Guba, 1986). I engaged a competent, disinterested colleague to audit this thesis at the conclusion of the research.

The brief was multi-layered to establish both adherence to process, particularly the protection of my research participants and their anonymity and the consistency of the coding, and product or the manner in which I used the data to construct my discussion and the creative synthesis. The auditor was provided with full access to the tapes, transcripts and the thesis from which she could select any of my reported research data randomly and authenticate my use of it from the original material. This involved:

1. Audio tape to transcript;
2. Transcript to reference in any chapter;
3. Verification of the DVD audit; and
4. Contextual inference from the focussed discussion with specialists.

The reviewer’s attestation to rigour is appended. (Appendix 6).

5.9 Summary

In this chapter I have documented the processes and intellectual activity that underpins this study. The study was conceived from an egocentric perspective in that I wanted to explore the experience of caring for a person with DLB. It evolved quickly into an altruistic endeavour to improve the lives of people who find themselves faced with caring in the presence of this debilitating disease. Its evolution occurred because of the
rigours imposed by the academic process, the need to comprehend my own role in the journey and the research participants whose journeys I was privileged to share.

Kvale, in speaking of interacting with research participants reflects:

interviewing has provided me with a deeper understanding of the issues, structures, processes, and policies that imbue participants’ stories. It has also given me a fuller appreciation of the complexities and difficulties of change. Most important and almost always, interviewing continues me to respect the participants, to relish the understanding I gain from them, and to take pleasure in sharing their stories (Kvale, 2007, p.112).

That has certainly been my experience and I trust that through the stages of heuristic inquiry their stories are represented with honesty, integrity and a sense of the respect that they imbue in me. The following chapters embrace the explication and culmination phases of the study commencing with insights into the lives of people confronted with DLB.
Chapter 6  Something is Wrong- the Beginning of the Caring Journey

This chapter presents the research participants and their recollections of their emergent selves as carers. In presenting the data and recounting from the carers’ perspectives the awakenings to the subtle changes that acknowledging and accepting progressive illness in a spouse demands, I am also seeking to understand and interpret the journey of caring for a person with DLB. This is consistent with both the heuristic and the symbolic interactionistic paradigms underpinning this study. Consequently, as I report the data, in this and the following chapters, I find myself in self-dialogue, reflecting on the literature and, on occasions, musing over the rationale for the circumstances in which the carers were placed.

It seems inevitable that tables are the most efficacious way of providing an overview of the research participants and information about their spouses and their illnesses, however, at the same time I am mindful of the emphasis by Moustakas on the individuality of experience (1990). That individuality is a composite significantly influenced by the individual’s relationship with the person for whom they care and their social circumstances, yet the collective data illustrate and give credence to my ensuing arguments. So I will continue my hyphen sitting and present the initial analysis using both quantitative and qualitative paradigms.

6.1 Demographics and Dates

Table 6.1 provides the basic information about the research participants and their spouses at the conclusion of the interviews in November 2008.

All participants are over 60 years of age in long term relationships and the homogeneity of the cohort provides a consistent platform for the thematic analyses. The initial diagnosis, the date of that diagnosis and the years between the first diagnosis and the diagnosis of DLB was provided by the carers as they understood the information provided to them. It has not been validated in any way.
<table>
<thead>
<tr>
<th>Carer</th>
<th>Spouse Age</th>
<th>Years married</th>
<th>Residence of spouse</th>
<th>1st diagnosis of spouse</th>
<th>DLB diagnosis Date</th>
<th>Years to DLB diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yvonne</td>
<td>61</td>
<td>38</td>
<td>home</td>
<td>Early dem.</td>
<td>2004</td>
<td>3</td>
</tr>
<tr>
<td>Ruth</td>
<td>62</td>
<td>39</td>
<td>NH</td>
<td>PD</td>
<td>1993</td>
<td>15</td>
</tr>
<tr>
<td>Fran</td>
<td>65</td>
<td>48</td>
<td>home</td>
<td>AD</td>
<td>2000</td>
<td>7</td>
</tr>
<tr>
<td>Wendy</td>
<td>66</td>
<td>47</td>
<td>home</td>
<td>Nothing</td>
<td>1998</td>
<td>5</td>
</tr>
<tr>
<td>Sara</td>
<td>67</td>
<td>45</td>
<td>home</td>
<td>MCI</td>
<td>2006</td>
<td>2</td>
</tr>
<tr>
<td>Glenda</td>
<td>67</td>
<td>38</td>
<td>died 2008</td>
<td>AD</td>
<td>2003</td>
<td>2</td>
</tr>
<tr>
<td>Olive</td>
<td>70</td>
<td>44</td>
<td>NH</td>
<td>Depression</td>
<td>1995</td>
<td>9</td>
</tr>
<tr>
<td>Trudy</td>
<td>71</td>
<td>52</td>
<td>NH</td>
<td>Just age</td>
<td>2001</td>
<td>4</td>
</tr>
<tr>
<td>Betty</td>
<td>74</td>
<td>53</td>
<td>home</td>
<td>Too complex</td>
<td>2005</td>
<td>1</td>
</tr>
<tr>
<td>Kerrie</td>
<td>75</td>
<td>54</td>
<td>NH</td>
<td>PD</td>
<td>2000</td>
<td>7</td>
</tr>
<tr>
<td>Norman</td>
<td>79</td>
<td>56</td>
<td>home</td>
<td>PD</td>
<td>2007</td>
<td>1</td>
</tr>
<tr>
<td>Janet</td>
<td>80</td>
<td>61</td>
<td>home</td>
<td>AD</td>
<td>2001</td>
<td>5</td>
</tr>
<tr>
<td>Lucy</td>
<td>87</td>
<td>55</td>
<td>NH</td>
<td>PD</td>
<td>2000</td>
<td>6</td>
</tr>
</tbody>
</table>

Table 6.1: Demographic information for research participants

If one were to apply the one year rule for differentially diagnosing DLB, PD and PDD (McKeith et al., 2005), the obvious conclusion that could be made from the information provided is that three people (spouses of Ruth, Kerrie and Fran) who were diagnosed initially with PD and subsequently with DLB years later could or should be “labelled” as people with Parkinson’s disease dementia (PDD). A criterion for inclusion in the study was that the carers’ spouses must have a given diagnosis of DLB regardless of how, when or why that diagnosis was made. One can only speculate, however I suspect that the DLB diagnosis was given to the spouses of Kerrie and Fran on informed reflection as they both reported early awareness of dementia and visual hallucinations. Ruth’s spouse was given the DLB label because of an adverse drug reaction in 2008 however she also reported apathy, visuo perceptual deficits and vivid and terrifying visual hallucinations as early as 2000. The data serve to illustrate the confusion about this diagnosis, and Table 6.2 further illustrates this point, in that reassessments and secondary diagnoses were often given.


<table>
<thead>
<tr>
<th>Name</th>
<th>1st year of change</th>
<th>Year of 1st diagnosis</th>
<th>1st diagnosis</th>
<th>Year 2nd diagnosis</th>
<th>2nd diagnosis</th>
<th>Year DLB diagnosed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ruth</td>
<td>1990</td>
<td>1993</td>
<td>PD</td>
<td></td>
<td></td>
<td>2008</td>
</tr>
<tr>
<td>Sara</td>
<td>2005</td>
<td>2006</td>
<td>MCI</td>
<td></td>
<td></td>
<td>2008</td>
</tr>
<tr>
<td>Glenda</td>
<td>2003</td>
<td>2003</td>
<td>AD</td>
<td>2005</td>
<td>PD</td>
<td>2005</td>
</tr>
<tr>
<td>Olive</td>
<td>1995</td>
<td>1997</td>
<td>depression</td>
<td>2000</td>
<td>PD</td>
<td>2004</td>
</tr>
<tr>
<td>Trudy</td>
<td>2000</td>
<td>2001</td>
<td>Just age</td>
<td>2002</td>
<td>PD</td>
<td>2005</td>
</tr>
<tr>
<td>Betty</td>
<td>2002</td>
<td>2005</td>
<td>Too complex</td>
<td></td>
<td></td>
<td>2006</td>
</tr>
<tr>
<td>Norman</td>
<td>2006</td>
<td>2007</td>
<td>PD</td>
<td></td>
<td></td>
<td>2007</td>
</tr>
<tr>
<td>Lucy</td>
<td>1997</td>
<td>2000</td>
<td>PD</td>
<td></td>
<td></td>
<td>2006</td>
</tr>
</tbody>
</table>

**Table 6.2: Carers’ reports of diagnoses**

It is difficult to resist the temptation to generalize from such a small cohort but Table 6.3 illustrates clearly that the carers were aware that their spouses exhibited many problems which match with the now established criteria for the diagnosis of DLB. When the research participants were given the questionnaire they were asked to think back to the first things that they noticed their spouses were having difficulty with and Table 6.3 is drawn from those responses.

Driving, fixing things and being apathetic and or withdrawn are all characteristics of sub cortical dementia and questions relating to spousal difficulties in these areas consistently drew positive responses. Fluctuations, parkinsonism (PD) and visual
hallucinations (VH) are features that, with dementia, are the criteria that raise the potential for a diagnosis of DLB (McKeith et al., 2005). It was noted that during the interviews Wendy and Sara mentioned that their spouses were experiencing motor problems (PD) and visual hallucinations although these questions drew negative responses on the questionnaire.

<table>
<thead>
<tr>
<th></th>
<th>Driving</th>
<th>Fixing things</th>
<th>Withdrawn apathetic</th>
<th>Fluctuations</th>
<th>PD</th>
<th>VH</th>
<th>RBD</th>
<th>LOS</th>
<th>Autonomic changes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yvonne</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Ruth</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Fran</td>
<td>Yes</td>
<td>?</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Wendy</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>?</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Sara</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>?</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Glenda</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Olive</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Trudy</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Betty</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Kerrie</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Norman</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Janet</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Lucy</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
</tr>
</tbody>
</table>

PD: parkinsonism, VH: visual hallucinations, RBD: REM sleep behaviour disorder, LOS: loss of smell

Table 6.3: Carers' perceptions of spouses' early problems

Consistent with the research (Boeve et al., 2007; Terzaghi et al., 2007), REM sleep behaviour disorder (RBD) was an early issue for a number of couples. The LOS column indicates a positive response when the carer was asked if their spouse had reported that their sense of smell had gone. Some carers commented that it was the first change that they could recall. A number of researchers (Khan et al., 2004; Miyamoto et al., 2009;
Olichney et al., 2005) are investigating the relationships between RBD, olfaction and DLB/PD. The diagnostic specificity of these indicators may be significant as those relationships are better understood and quantified.

All participants reported some early autonomic dysfunction from a change in bowel habit to impotence, common complaints of older men. Autonomic dysfunction is only a supportive feature according to the DLB Consortium (McKeith et al., 2005) yet its impact on the carers was obvious from the interviews and will be considered in depth in the thematic analyses.

6.2 The Carers

Although Moustakas suggests that two or three exemplary individual portraits should be presented (1990) he also argues for the retention of each individual in the research.

The aim of the research is to explore the caring experience in the presence of DLB. What is the “exemplary depiction”? Each experience was so rich and added to the overall experience that it is impossible to ascertain the components which make the “exemplary depiction”. If it is the situation where DLB is the primary diagnosis then, in this particular sample there is no example, although Wendy’s experience is the closest as she endured five years of knowing something was wrong before the initial diagnosis of DLB was made.

Consequently, I have chosen to acknowledge each carer, their relationships and the salient features of their personal experiences and their perceptions of self, as they were given to me in the latter months of 2008. In doing so I am mindful of Seidman’s contention that “crafting a profile is an act of analysis” (Seidman, 1998, p 110) and that this is my interpretation of those experiences and the meaning that each person made of them.

6.2.1 Yvonne

Yvonne is a 61 year old woman living with her husband of 38 years in country Victoria. He, Tony, is 15 years her senior. He retired from a professional career in his early 50s and, with their two young sons, bought a farm which they ran until Tony’s care needs became such that Yvonne decided to sell. This was a difficult decision: huge a big big
thing and I suppose that was two and a half years ago and I am only just getting over it. That was a big big step (1:7.5). Yvonne took a 54/11 retirement package as part of their plan for her to spend more time working on the farm. However that decision was taken in part because she recognized that Tony: was getting old. He was getting old, getting harder to manage and he was getting tireder and I needed to take over doing things that he had done previously (1:1.3) - a view reinforced by her sons’ acceptance of their father’s behaviour.

Admitting to being a bit of a workaholic (1:2.1) Yvonne settled into farming whilst still working part time but was concerned about Tony’s deteriorating health. He had RBD: the restless nights he would have dreams about fighting his father and he would be punching me in his dreams (1.3.3), was diagnosed with atrial fibrillation and had a colonoscopy for an upset belly (1:3.4), prior to his diagnosis with PD in 2004. That assessment was instigated by Yvonne when Tony sustained a fracture: when (the doctor) came in and said ‘what do you think is going on?’ I said I reckon he is a Parkie (1:5.3).

As Tony’s care needs increased and her sons left home, Yvonne and Tony moved to a country town closer to Melbourne with increased services, which they now access. Yvonne thinks her status has probably changed more to carer now than wife (1:10.2).

She rues not being able to be spontaneous about anything. Tony’s illness:

---

1 54/11 retirement package was an Australian Government incentive to encourage people to maximize their superannuation benefits by retiring early.
has had a very big impact on my future..... I had to leave work, leave all my work mates, leave the community, the Landcare group, I mean the whole lot (1:18.4).

Yet she is not reneging on the partnership. Asked if she has considered alternative care for Tony she murmured: Aahh not really, because I think you know he wants to be at home and ... not really I think, (1:11.3) however she does have some trepidation:

I suppose my main issue for me now is given this information, at this point, is there a way that I can predict the future and plan for that? (1:20.5)

Even through tears, Yvonne displayed a sense of humour - in the early stages we had a menopausal woman, Tony and kids doing VCE, so there was a lot of stress (1:15.1) - perhaps the biggest understatement of our interview. An intelligent, capable woman, she revealed that, during her husband’s early stages, they also had to deal with their youngest son being diagnosed with a serious illness, and that in 2007 she was diagnosed with moderate depression.

6.2.2 Ruth

Ruth is an active self-employed 62 year old woman living in a suburban town house. Simon, her husband of 39 years, lived with her until June of 2008 when he was admitted to hospital and, subsequently, to a nursing home. They have two children whose understanding of Ruth’s predicament is at odds:

He said to me: ‘Mum when are you going to retire and look after Dad full time?’ You see that was the way he thought it should work, but my daughter on the other hand said [to him]: ‘Mum is not that sort of person. She can’t do that like you think she should do it.’ He felt that was my duty (2.13.3).

Ruth relies heavily on the support of her daughter: because of her nursing background [she] can cope with it beautifully (2:27.2), but feels that although her son still has unrealistic expectations at times, (he) has come to terms with [the situation that] Dad is going to have to spend the rest of his life there (2:31.3).
Ruth feels that Simon’s cognitive problems started as far back as 2000 and possibly earlier – a feeling echoed by his brother in law: *he said you know I reckon Simon’s had a problem for a lot longer than we realize* (2:3.3), but she felt powerless to have her opinion heard by his specialist:

> I would say to the doctor but he is doing this and that and something else and he must have looked at me and thought ‘well I do not know what you are on about, he looks alright to me, we won’t change his medication, he looks fine’ (2:6.5).

The transition from managing at home to high care has been a traumatic time for the family. Simon had been diagnosed with PD some 15 years previously, but they were managing well:

> the good days would be fine, we would go out to dinner or off to the movies. We would do all the normal things people do and other days we would just do nothing. No motivation, nothing (2:5.2).

The family were aware of his increasing care needs, particularly in regard to regulating his medication and facilitating his independent outings: *we were working towards a plan* (2:11.1) when the specialist admitted Simon to hospital for a review of his medications. From hospital he was admitted to high care.

Although the nursing home is geographically closer to her daughter than to Ruth, a routine is slowly evolving where Ruth is able to manage her business, enjoy her tennis and visit Simon. Ruth accepts her situation and recognizes that, with the full support of her daughter, she took the necessary steps: *to balance my life out (so) that I then had enough energy to come home and deal with Simon. I don’t think I could have done it any other way* (2:9.2).

Ruth is a person acutely aware of her own short comings, particularly her inability to assume the carer role, her need for independence within her relationship and the conflict that initially caused with her son.
6.2.3 Fran

Fran is a 65 year old woman living with her 74 year old husband Keith in a large two storey outer suburban home. Although in rehabilitation at the time of the interview, Fran’s 88 year old mother also lives with her and demands considerable care. They have two children both of whom live in the inner suburbs and reject their parent’s plan that they ultimately make Keith’s home their own:

He built this house 35 years ago. We thought that the house would be something that my daughter could move in to. We have got a little granny flat so we thought, oh well, we will move in there, you know a family home. We thought it would really go on, you know, but it is not like that at all. They come here and say: ‘God it is such a big house, what in the hell are you talking about’ (3:21.1).

Fran and Keith own a manufacturing business that Keith ran whilst his wife looked after the home and all of his needs. The business was damaged by fire eight years ago and at that time Keith found he was having trouble concentrating in meetings and he lacked the ability to re-establish the business. Although some of his issues were attributed to the trauma of the fire and depression, he was diagnosed with AD. Following neuro-imaging studies, Keith was diagnosed with DLB in 2007.

Since the DLB diagnosis Fran and Keith have travelled to Europe: we got over there, he wasn’t too bad but on the way back, you know, he has been no good since, then he has got worse (3:30.3), and had a holiday interstate with friends:

to me it was the longest two weeks of my life. I was on pins and needles the whole time I was just dying to get home.... So I said that was the last time. We are not going anywhere any more so that’s a decision I made (3:31.1-32.3).

In contrast to the way she presented at the time of the interview, and after a very disturbed night because of Keith’s nocturnal polyuria, Fran felt that she was coping but he is also frightened that the evolution of their relationship has contributed to Keith’s
dependency – a fear reinforced by her children’s and friends’ attitudes: am I making matters worse by doing things for him? (3:23.1)

Fran is aware that she is neglecting her own needs: I am not doing anything and I need to do something (3: 40.1). Ideally, to cope with their immediate problems, she would like a night carer but she also recognizes the need for some day respite. She feels that it is essential to find something appropriate and, at the time of the interview, was in the process of organizing an aged care assessment to facilitate this. Fran is familiar with the system as she accesses culturally appropriate respite services for her mother, but she is of the opinion that the same option would not be right for her husband: I wouldn’t send him [there]. You know Keith is so proud I couldn’t, he wouldn’t, he knows what is going on (3:44.3).

Fran’s expectations and desires for her life are the continuation of two pivotal roles that define her: (1) the homemaker: anyway I clean the house on a Thursdays…. No I feel good Thursday(s) (3:43.5); and (2) the nurturer of her husband: I am not sending him to any respite or anything like that (3.16.3) and family, particularly now her grandchildren: they are just gorgeous they both are. Now I miss that too because I can’t do that any more with Keith. They used to come up here and I used to look after them for two days (3:20.1).

2 At the time of the interview S was getting up about 20 times a night to urinate (nocturnal polyuria). Changes to his medication regime in subsequent weeks resolved this situation
6.2.4 Wendy

Wendy is a 66 year old woman living with her 68 year old husband (Alex) of 47 years in suburban Melbourne. They have a son who lives with them and Wendy’s mother also lived them prior to her death from cancer in 2007. She is well supported by their GP, whom she refers to by first name, and is herself in good health.

Wendy reports that she became aware that Alex was sort of going down hill a bit in 1998 (4:1.1). She consulted the GP who referred them to a specialist but was told that there was nothing there (4:1.1). At that time Wendy reports that Alex had diabetes and acted out his dreams: I said to my sister buy me a crash helmet for Christmas (4: 13.4).

Concerned that Alex was getting worse, Wendy requested a further assessment in 2003 at which time a PET scan was done and a diagnosis of DLB was made. Alex remains under the care of the specialist: he said I will see him one more time, well that’s about four times ago, (4:10.1) and the GP. He is taking AD medication with positive results, he is not too bad. Really we can’t complain (4:10.4) and has had two cardiac stents, a recent, successful cataract operation and another planned for October 2009. At the time of the DLB diagnosis Wendy and Alex were referred to AAV where they engaged in both social programs and educational courses, and Alex now attends a day respite program one day a week.

Wendy reluctantly stopped work in 2004 because she realized that Alex and her mother were not coping at home without her. She struggled with that decision over a nine month period because she loved work, the people and being involved. As a couple Wendy and Alex continue to go out for lunches, visit and stay with family and go on holidays with their son who lives with them and is very supportive. His presence allows Wendy to continue her outings to the local club, a pastime that she still enjoys, it is my escape; they are like family down there (4:6.4).

Asked if she sees herself as a wife or a carer, Wendy’s considered response was: I would say probably more a carer, yeah cos he just doesn’t function on his own, (4:7.6) however she is optimistic yet philosophical about her future:

because I am one of these people that I take one day at a time. So I know what is down the track and I probably just
don’t want to know. I just take one day at a time and we just enjoy ourselves while we can and we are lucky in that way that you know what you are facing so you can do things while he can (4:3.4).

Life still has more good days than bad (4:11.2). Although much of her energy is spent on attending to Alex’s needs, both in activities of daily living and in his access within the community, she doesn’t consider that her own life has been sidelined (4:6.1). She gave the impression that she would return to work if she could. She pushes Alex to participate in family and community activities, whilst respecting his dignity and refusing invitations at the last minute if it is a bad day. She still makes time for herself. Wendy acknowledges that her son’s involvement makes her very lucky (4:6.2).

6.2.5 Sara

Sara is a 67 year old woman living with her 69 year old husband (Barry) in a self contained unit in a suburban retirement complex. Married for 45 years, they have a very supportive daughter and son and another son who lives in the country. She is very close to and well supported by her sister, and for some time has volunteered at a local aged care facility. Apart from some arthritis and a bad back, she is in good health.

Sara had a comfortable, happy and socially active life that she anticipated would continue with Barry’s retirement in 2005. When reflecting on the changes that her husband’s health had demanded she mused:

nothing like this, nothing like this – travelling, socializing.
He would be playing bowls, I would be going to yoga and water aerobics nothing like this (5:2:2).

But Barry’s lack of motivation and apathy caused her concern. Sara discussed this concern with her sister who has relatives working in the cognitive sciences. Under their guidance Barry was referred to a specialist who diagnosed mild cognitive impairment in 2006, and subsequently DLB in 2008.

Whilst Barry was in hospital with an injured shoulder following a fall in early 2008, Sara moved them into the retirement complex - for her an excellent move – if we had been at home I couldn’t have managed I don’t think (5:15:8), but she feels Barry is
much worse since his fall. She is not sure whether his disorientation is a worsening of his condition or the move: he is disorientated but he might have been like that in the other house (5:16:2), as she related episodes of disorientation going back several years. Overall Sara feels that Barry is settling in. Talking of the communal area she remarked:

\[
\text{when he gets in here he knows it and, to a lot of people,}
\]
\[
\text{they would think he was fine. Knock on the door he is}
\]
\[
\text{cheery and you wouldn’t know anything was wrong}
\]

(5:16:3).

Sara confided quietly that she saw herself as a carer absolutely (5:4:4) and that she is constantly worried and frightened, I am sort of on edge the whole time (5:8:1). Although on a rare good night Barry sleeps well, most nights he is constantly disturbing her and she finds those nights draining: I wake up and I think I don’t think I have been to sleep all night (5:11.4). Sara thinks she is coping at present (5:17:2) as Barry has respite care Wednesday mornings and Thursdays. She perceives that will be enough (5:17:2) although she is aware that her own life is hampered by her caring role:

\[
\text{so no I can’t do any of the nice things like going to water}
\]
\[
\text{aerobics or yoga and so friends will say, ‘well you are}
\]
\[
\text{having a rough time I will take you out for coffee’, but I}
\]
\[
\text{will say no it doesn’t work like that. I can’t do anything, I}
\]
\[
\text{can’t slip up to the shops to get some cotton if I want to}
\]
\[
\text{do some machining. I can’t, no (5:5:1).}
\]

When asked what challenges she saw in the future Sara pondered:

\[
\text{I think how long will I cope at home. I think that. It is like}
\]
\[
\text{as long as possible I want him here at present. If they}
\]
\[
\text{were all days and nights like his baddies then I would}
\]
\[
\text{have to say yes, I will have to let him go but there are}
\]
\[
\text{good days. But how do you know when it is going to be a}
\]
\[
\text{good day? (5:12:6)}
\]
Barry was admitted to care several months after the interview because of increasing physical disabilities. He died in March 2009 and his autopsy confirmed DLB with some amyloid plaques and tangles.

### 6.2.6 Glenda

Glenda is a 67 year old woman grieving the recent death of Frank, her husband of 38 years. At the time of his death, some eight to ten weeks after his admission to a nursing home, Glenda’s daughter was living close by and although her son lived interstate he visited regularly. Frank was admitted to care because of his increasing needs and Glenda’s own health problems.

Glenda describes Frank’s condition as a mysterious and confronting illness (6: 1.3) which was initially diagnosed as AD in 2003 after Glenda recognized that Frank couldn’t get oriented and couldn’t follow through on sequential things. He was writing a book and couldn’t find the pages (6:2.4). Frank’s diagnosis with DLB came about two years later [when] he developed a tremor in his right hand. We went back to the specialist and the minute we showed him that he said: ‘oh I can diagnose it now, it is DLB’ (6:3.4).

After the initial AD diagnosis, which shattered (6:4.3) Frank, they shared a special time and travelled overseas to catch up with friends and tell them what was happening (6:4.3). However, their subsequent reactions to Frank’s death and letters expressing sentiments such as: ‘Oh it must be a huge relief’ (6:30.3), have reinforced Glenda’s belief that:

the community should be educated about DLB: I know that I make a point always with people, even when I am writing now about his death, that he did not have AD. I want people to know that he never ever really became stupid – away with the fairies, he never had a personality change (6:5.2).
Over the course of Frank’s illness they:

tried to live life up to the full together. You have to realize
that you have to think ahead and do all the packing and
plan everything but he understood. We would have people
in a lot, and music and the theatre, and he was so fit in
fact he walked a lot (6:5.3).

This enjoyment of their relationship and life together continued even after his admission to the nursing home: every week I took him out to a little restaurant where we had lunch together and went for a walk (6:19.3). Glenda is being well supported by family and friends as she grieves.

6.2.7 Olive

Olive is a 70 year old woman living in a suburban villa unit. Harry, her 71 year old husband of 44 years, was accepted into high care in January 2008 and moved to a nearby facility in May 2008. Olive knows the facility and many of the staff and residents well as her mother lived there for a number of years prior to her death in 2006, just after her 100th birthday. They are supported by their daughter, three sons and their families. Olive has established a close rapport with Harry’s treating specialist.

There is a strong familial history of PD on Harry’s side of the family, and for many years Olive and her sons were in contact with their local GP suggesting that Harry be assessed for that disease:

I would ring, the boys would ring, our three sons all rang
him and said: ‘we think Dad has got Parkinson’s because
he is like his father’. Harry went and the doctor said’ oh I
have had a phone call from the family - they think you’ve
got Parkinson’s’. But he said: ‘do this, do that – Nah you
haven’t got Parkinson’s you definitely haven’t got
Parkinson’s’. Harry would come home and say: ‘what’s
this about you thinking I have got Parkinson’s?’ (7:2.4)

Finally about eight years ago, Olive’s daughter, on her return from living overseas, demanded a second opinion. Harry was referred to a specialist who diagnosed PD.
Although devastated, this satisfied the family: *I was pleased as far as Harry was concerned, he could know that yes I have got a problem* (7:5.4) and Harry attended Parkinson’s support groups whilst Olive continued with her social activities and care of her mother.

DLB was diagnosed in 2004, initially by their daughter and subsequently, formally, after the family sought a review from a specialist who was treating an extended family member. In retrospect Olive believes Harry’s cognitive signs were evident years earlier:

> Well a lot of people didn’t pick up with Harry until they saw him physically, but looking back, there were other things that came first, absolutely...... 15 years ago. I was taking over more and more things, like I did all the bills...... he just wasn’t right, he couldn’t grasp things and he would be shuffling papers, oh it was just weird (7:4.3).

Although Olive continues to take Harry to appointments, visits to their children’s homes and frequently to their own home, she admits to finding this increasing difficult particularly in dealing with Harry’s incontinence: *I can honestly say I am not very good and Harry wouldn’t be very good with me doing things for him too - he is a very proud sort of man* (7:15.4), and his increasing physical disability.

Olive gains considerable strength from a group of close friends and her family. She is active in community work, involved with a carer support group and makes time for the gym twice a week. She is concerned about the familial aspects of Harry’s condition and the implications that may have for her sons.

### 6.2.8 Trudy

Trudy is a 71 year old woman living in a self contained unit in a retirement village. Trudy met Colin when she was 15, married when she was 19, and shares a close relationship with her husband who is now 75:

> you think as one and sort of our whole life has been doing things together. I mean he was never one to go off and do what he wanted and the same with me too (8:12.2).
Colin has been cared for in a high level care facility since January 2008: the worse decision of my life, I still find it difficult (8:11.3). They have two very supportive married sons.

Trudy first thought Colin had a memory problem (8:2.1) in his late 60s and became increasing frustrated because she was told: it is just his age early in the piece (8:2.1). In 2002, at her family’s insistence, Trudy requested a referral to a specialist who diagnosed PD and reassured her that, with medication, Colin’s condition would remain static for five years. Since then they have consulted a number of practitioners obtaining a diagnosis of DLB in 2005.

Trudy is self educated in her understanding of DLB and eager to learn. After our interview we chatted for a further hour about the relationship between DLB and PD. Her caring is an extension of her life long relationship and she now laments:

well now I don’t consider myself as much as a carer as I
did when he was home. I think when you are caring you
do just consider yourself as a carer. I am still the main
person in Colin’s life, I know that and he is still the main
person in my life (8:13.5).

With this understandable attitude Trudy is finding it difficult to establish a life of her own. She gave the impression of a person who is trying to make sense of a number of dilemmas in her life, but because there is no clarity, she finds herself becalmed in a sea of thoughts and questions. She admits that she is doing not much actually (8:22.4). She is aware that her situation is akin to when people are left widows (8:12.1) and says:

hopefully next year I can start to socialise a little bit more
go off and get into something because I found now, with
my boys, that’s all I talk about you know. Dad did this
and Dad, you know, but that’s all my life is (8:25.1).

Saddened by the feeling: that I have lost him, he is still there in body, but the person I knew has gone (8:12.3), Trudy continues to take pleasure in her time spent with Colin: he will sit there and say something and just grin at me (8:32.4).
6.2.9 Betty

Betty is a 74 year old lady caring for her 75 year old husband (Jeff) in a suburban home. They have been married for 53 years and have three very supportive married daughters.

In their early retirement Betty and Jeff were “grey nomads” thoroughly enjoying life. Jeff had a few health issues and was seeing a range of medical specialists, including a neurologist for restless legs (9:2.5), although Betty’s questionnaire response indicated that perhaps it was RBD rather than restless legs. On one of their trips (which was to be their last in the caravan) Jeff recognized his difficulties with driving although Betty reports that this episode was perhaps two years before the diagnosis (9:2.3) (of DLB in 2006) and, looking back, there were little things that I didn’t pick up on because I didn’t want to (9:2.1). Betty struggles to accept Jeff’s failing health and the changes it has brought to their relationship:

he knows who I am and he loves me but things change
and it is not the same. It is not the same any more. No. No
but I accept all that, I accept that I still love him (9:6.1).

Whilst she is fiercely protective of his rights and dignity: anything that might upset him I don’t talk about (9:1.1), Betty is conscious of the demands made on her and her family’s concern for her. That said, she is grateful for the support of her family and understands that they are concerned for her. Although they provide some respite, Betty ensures it is of a social nature, to protect Jeff’s dignity, and he also attends an activities group once a week. Betty acknowledges that she may have to consider alternative care but even the idea of facility based respite is, at this point, too overwhelming:

No I am not ready for that. I am not, no I am not. And I
don’t think he is either. (9:23.6).... I have been going to
make enquiries but I just can’t. I know the girls will be
supportive and come and look (9:35.3).

Betty’s life centres around her care of Jeff. She recognizes the need to have a day for me (9:17.1), but misses the long conversations we use to have. We used to drive and talk about every mortal thing (9:5.2). Betty is adamant that she should not be perceived as the one who is suffering (9:5.3), however she portrays a sense of isolation and loneliness.
6.2.10 Kerrie

Kerrie is a 75 year old woman who has lived and worked in a small, relatively isolated country town for 54 years - all of her married life. Still active in her community, she has lived alone since August 2007 and supports her 80 year old husband, Brian, who now resides in the local care facility. Kerrie remains active in Brian’s care within the home by visiting regularly, assisting with some of his care needs and maintaining his links in the wider community. Although their three children are supportive, they do not live locally.

Kerrie reports that Brian was diagnosed with Parkinson’s disease in 2000: when the local doctor saw him walking down the street he picked it straight away (10:1.2). Determined to find out about it and do something about it (10:2.1), Kerrie galvanised Brian and they opted to stay within the community but move to a purpose built home on a flat block of land closer to the centre of town. There was an inkling of some loss of planning skills at the time of the move:

I suppose I have always been a real organized sort of person and then I like to organize him and I was horrified at how some things got thrown in and I thought well I have done my bit (10:3.2).

Kerrie’s recall is that the first obvious signs of symptoms other than Brian’s stooped posture came a couple of years later. Faced with his assertion that she had arrived home too late to greet a room full of Canadian backpackers (10:4.1), Kerrie commented: I just dismissed it and then I thought there is something funny going on but I didn’t know that it was dementia (10:4.2). In recollecting that time Kerrie continued:

I would go and say the silly things that Brian was doing, you know, and somebody said: ‘how can you talk about him and tell us about these silly things?’ I said well something has got to be done, you know, and I said God help me I don’t know and then he would go off to bowls (10:4.3).
Kerrie and Brian continued to enjoy their retirement travelling: *but we didn’t take the caravan, he was getting that way that the caravan was a bit of a hassle* (10:13.2), and being involved in community life until Brian’s care needs increased. His failing health isolated him from the community, a situation that still saddens and perplexes Kerrie: *the fellows won’t go and see him or anything* (10:5.1). Kerrie considers herself a fairly strong sort of person although she:

> finds the hardest part is making decisions for two people when there are two people still here and one isn’t able to help you out. If it were just me then I would think it is only going to affect me isn’t it, but the decisions I am making are affecting him and me (10:23.1).

She recognizes that she has *to take each day as it comes* (10:17.6), but when speaking of the difficulties of caring for Brian at home, Kerrie made light of a number of incidences which must have caused her considerable stress and pain. She indicated that she had little support in dealing with them and gave the impression of an isolated person struggling to cope with her situation and Brian’s illness:

> I have always had a lot to do with the community and always joined in everything, you know, and I have always been a part of it, but I think that because, well my best friend she died of cancer, but I never ever had I haven’t really got ……………I have got a lot of associates…………. I haven’t got anybody who is really a close friend (10:27.1).

### 6.2.11 Norman

The one male carer, Norman is a 79 year old who, with his 78 year old wife Mary, lives in a seaside community two hours from Melbourne. Norman opted for a telephone interview because of distance and the desire to have Mary present. They have been married 56 years and have four children. In their retirement Norman and Mary maintained traditional gender roles: *I have always left running the house to her and I have looked after the financial matters and the garden and that sort of thing* (11:1.5).
Their retirement has also included lots of fishing and travelling to their second property on the South Coast of NSW.

Norman provided a very succinct account of Mary’s medical history whilst completing the questionnaire. When Mary was undergoing cataract surgery in June 2006 he realized that she was dithery and unsteady on her feet. She was diagnosed with PD in early 2007 and DLB later the same year.

Norman recognizes that his role changed gradually and that he is now responsible for the running of the house: I am still learning how to do the cooking (11:2.2), and the more confronting issues of Mary’s personal hygiene and care:

\[
\text{I did [find it confronting] to start with, yes, but I am just beginning to accept that it has just got to be done. It has got gradually worse, if you know what I mean, it just wasn’t thrust on me, the whole lot of it, right from the start (11:2.4).}
\]

He does not begrudge this added responsibility: I look at it from the aspect that Mary looked after me for some 56 years and now it is about time I looked after her and that is my attitude (11:2.1). Nevertheless, he finds it tiring and is grateful for the (increasing) support of his family: even if they come down and cook a roast dinner it is nice you know it is a change (11:12.3).

Mary and Norman attend a Parkinson’s support group using it as an educational resource rather than for its social or support opportunities: well we are very interested when the people from PA come down and give a talk…. but the social events, we don’t go to those (11:3.5). They also access Council home help.

Norman reported that they had recently spent time at their holiday house, with their daughters. He said that it gave them some insight into their mother’s decline: I think they realized that it was quite severe, you know, the deterioration (11:4.2) and they also recognized the toll it was taking on him:

\[
\text{one daughter said to me that she would be prepared to sort of take unpaid leave to look after her mother. I said}
\]
no, not at this stage. It might be down the track but we will worry about that when we come to it (11:11.6).

Accepting his situation: I am prepared to accept that it is just one of the things that happens... I think that it is my obligation and you know you have to accept that. Wouldn’t want it any other way (11:15.1), Norman also acknowledged that he had let his own social activities and outside interests slide:

I used to do a lot of fishing. I had a boat in the marina here which I had for 35 years and I have sold it. I had to get rid of the boat because I couldn't maintain it and use it enough to warrant it and um I didn't have the time. So I have just run out of time (11:7.7).

6.2.12 Janet

Janet is an 80 year old woman who lives with her 83 year old husband Leon. They have been married for 61 years and have three children, one of whom has PD:

my oldest daughter she is under the specialist for many years and he said that is a different type to what Leon has. He has the old age PD but she has a different one so she has no dementia. She has got worse now - she can’t walk anymore (12:2.5).

Janet has a long history of spinal degeneration reporting that she now has four collapsed vertebrae and has recently been diagnosed with diabetes. She has a difficult relationship with her GP who, much to her chagrin, has expressed his views on Janet’s ability to care for Leon at home:

long ago he said put ‘him in a home’ and I said ‘didn’t you say for better or for worse to death us do part’.......I would I said if he really knows nobody any more but otherwise no (12:12.1,2).

That interaction embraces Janet’s view of her relationship, her husband and their commitment to each other: He was a wonderful man and he deserves anything and
everything I can give him (12:5.2). Those sentiments don’t negate the strain that caring for her husband exacts and, to compensate for that and have some rest, Janet reluctantly accepts out of house respite two nights a week, home help and personal care assistance for Leon.

She finds the financial aspects of caring for Leon very difficult and has, at times, refused services because of the cost. They now have an Extended Aged Care at Home – Dementia (EACH D) package³:

but even now, yeah I still struggle. You need taxis and you need everything else and the medication yeah but I don’t complain (12:11.5).

Socially, they regularly attend their Senior Citizen’s Club and various members of the family visit, however Janet is reluctant to accept invitations which could expose them or their family to embarrassment. Janet rues the loss of one service professional who, in her view, was compassionate and there for her: she was a lovely girl and she came all the time and she actually did everything (12:10.2). She contrasts this with the cold factual service delivery they receive for Leon and her tense relationship with his treating practitioners.

³ EACH-D packages are an Australian Commonwealth Government subsidy to assist people with dementia who wish to remain in their homes. The subsidy funds case management and appropriate services.
6.2.13 Lucy

Lucy, at 87 years, is the oldest carer of the cohort. She lives in an independent unit in a retirement complex close to one of her sons in the outer suburbs. Her 85 year old husband, Murray, lives in a nursing home. They have been married for 55 years and have another son in Melbourne and a daughter who lives interstate.

Murray retired in his late 70s. Several years prior to that Lucy had bilateral knee replacements and, with her increased mobility and his retirement, they undertook a sea change. Not long after, Murray’s health began to deteriorate. He had several severe bladder infections, became very restless at night, began hallucinating and underwent heart surgery. During one of his convalescent / rehabilitation occasions an allied health professional suggested that he was developing Parkinson’s disease (13:2.6). Although that suggestion had some resonance for Lucy, she states:

_I didn’t know a great deal about Parkinson’s at all, but watching him exercise he would get quite exhausted and he would get angry and I thought then there is something funny going on here, you know, I don’t quite know_ (13:3.2).

However, the possibility of PD was not fully explored.

With Murray’s health failing Lucy’s sense of isolation within the community and from her family grew, so she unilaterally decided to relocate to be closer to one of her sons even though Murray was resistant to change. Despite his objections and his refusal to be involved with the move on any level, once settled Lucy sensed that _he changed completely and he really enjoyed it and he was just settling down to really be happy here_ (13:7.4).

The change of environment exposed Murray’s lack of driving skills: _then the big blow came of course, we had to get rid of the car and men hate doing that_ (13:8.1). The frequency of his falls also increased:
he would go to get up out of the chair and his legs would just give way and I would think oh that’s funny. I was silly I didn’t even pick it up even then (13:10.2).

These changes ultimately resulted in his admission to an assessment unit. During that admission Murray was diagnosed with DLB, a condition that: I had never, nobody had ever heard of it that we knew (13:11.1).

Lucy managed with minimal assistance for several more months prior to Murray’s admission to care. Although placing Murray in care upset her: it was a relief and I felt as though a load had been lifted off my shoulders. I could feel it (13:23.11), she now visits him on a regular basis and continues to engage him in the life of their community into which she has settled well:

[it] has been a lovely move. The people here are just lovely. I am settled in and I don’t mind so much being on my own and that sort of thing. I read and do my crossword puzzles (13:19.3).

Whether being closer to family scrutiny would have exposed her transition from wife to carer earlier is difficult to establish. Lucy confessed that she has got to the stage that I do forget a bit too (13:13.5), and at times in the interview she appeared to confuse her time sequences.

6.3 Summary

All life transitions present challenges. The challenges faced by these carers, as they negotiated their transitions from spouses to carers, have a commonality with others in similar situations. There is a tacit knowledge of their life partners, developed over years of intimate relationships and the confronting of their intuitive sense that something was wrong. The data suggest however that in this particular cohort, discovering what that “something” was presented challenges that few others face.

Their insights into a world impacted by DLB enabled me to immerse myself completely. I was fortunate to engage with thirteen people who were so open and trusting in sharing their experiences with me that I can now fully appreciate Moustakas’s sentiments of his own experiences:
From the opening moments with this other person I immerse myself in his or her world. I become totally absorbed, curious, alert, open, ready to enter into each expression. I want to understand what this person is expressing not only from his or her frame of reference, but from the vantage point of my own experience. Eventually what is expressed by the other person mingles with my own knowledge and experience (Moustakas, 1990 p.106-7).

Each account is an individual journey, yet there are so many experiences that have common themes. Some of these themes are apparent from the synopses presented, for example the carers’ interactions with health and support services professionals. In the next chapter I develop a thematic structure from the depictions and, with reference to symbolic interactionism, my conceptual framework, I continue to explicate the experience of caring for a person with DLB.
Chapter 7  Meaning Making

The core of this thesis is a psycho-social study of carers – their perspectives, interactions with the cared for, their families, health professionals, those in support services and me, the researcher, as well as the meanings those carers make from their interactions. Meaning making is the essence of symbolic interactionism - a theory that addresses the social context of human actions. It is argued that social theory is concerned with “the ways in which we act and our beliefs are generated partly by social structure but also in communication between individuals and in social groups” (Willis et al., 2007 p.439). In my role as researcher I have communicated with the carers individually and then facilitated the genesis of a social support network, by bringing some of them together in the focus group. It was readily apparent that their common issue – a spouse with DLB, allowed them the freedom to share frustrations, experiences and expectations although, that connectedness had not been established at the time of the interviews. Nevertheless these interview data provide rich insights into caring for a person with DLB and how these carers have made meaning of their situations.

My developing understanding of the complexities of DLB, my analytical framework and the carers’ perspectives and interactions provided me with a priori categories for the analysis of the data – their relationships with their spouses, families and various service providers, and their understanding of DLB. Not surprisingly, the data revealed further categories associated with the issues faced by the carers in their caring roles. It could be argued that these issues are extensions of the a priori categories; however I consider that they raised sufficient concerns to be categorized and discussed separately in this and a later chapter.

So how have I interpreted the experiences of the carers? I am cognizant of Blumer’s caution: “interpretation should not be regarded as a mere autonomic application of established meanings but as a formative process in which meanings are used and revised as instruments for the guidance and formulation of action” (Blumer, 1969 p.5), a pertinent observation in the context of applying my chosen framework of symbolic interactionism to my analysis. I have already given some impressions of the carers and how I perceived their sense of self in the previous chapter but now, as I consider the
research cohort as a whole, I will start by providing some observations of the group, even though it is often said that each caring experience is unique.

This is a group of people who are all in long term stable marriages in which the caring for a spouse in need is a natural extension of that commitment. This is both a strength and limitation of the study in that it not only provided me with a cohesive, homogenous sample, but it raised the issue of what happens to people with DLB who do not have spousal support? This is a question that I explore in a Chapter 9. Another limitation is the gender bias. Gender was not a criterion for inclusion in the study however it must be acknowledged that even in a small sample one male voice may not be representative. Nevertheless, on analysis, Norman’s data did not present any discernable coding anomalies.

Their decisions to engage in the study were twofold; it may help us and it may help others. Recognizing that DLB is a disease of ageing, I made a conscious decision not to include demographics about levels of achieved education and work history in the data collection. However from the interview data it became obvious that these demographics influenced the carers’ perceptions of their relationships and illness significantly. Broadly speaking, the carers appear to present their experiences in one of two ways: One from a stereotypical gender / role perspective; the other from a partnership perspective with shared responsibility but greater autonomy. This may be a function of age or level of education and these factors were evident in the individual synopses. I do not intend to analyze this in any depth, but this dichotomy will become evident in my discussion as will the impact of the initial diagnosis.

7.1 Relationships

Relationships are at the core of the caring experience. It was evident from the interviews that the carers’ relationships with their spouses directed and influenced their lives. Doctors were a central point of discussion however families and friends came and went in the conversations. There are a number of perspectives from which I could address meaning making through relationships. The ones that I have chosen to explore are those that, in my view, significantly contribute to the specific issues of caring for a person
with DLB, as opposed to caring in the presence of other aged related degenerative illnesses.

7.1.1 Their Spouses

The spousal relationship, its impact on caregiving and the resultant burden have been explored at length in Chapter 4. I do not intend to analyze my findings with the aim of making comparisons with the studies discussed, but rather I aim to bring to the fore issues that I argue should be considered if there is to be a greater understanding of the carer experience.

The carers expressed their commitment to their spouses and marriages in different ways. The older carers were absolute about their commitment:

You know we are both over 80 he is 82 nearly 83. You expect that if you are still around you have good days and bad days.... One of these days one of us has to go and I pray every night that he goes first. He doesn’t want to go now and I would not want him to go now. I know everybody says I have got the best husband, a husband in a million but he was not one in a million, he was one in ten million (12:3.2,3).

I am prepared to accept that it (DLB) is just one of the things that happen. I am not unduly upset about that. I think that it is my obligation and you know you have to accept that. Wouldn’t want it any other way (11:15.1).

Similarly, some of the younger carers whose working lives had been closely connected to that of their spouses expressed parallel sentiments:

I went to work with him, so we have been married 48 years and we have always been together 24 hours a day and I have always done everything for him. He has never worried about the house, never worried about anything; I have always done everything for him (3:12.4).
Others were more circumspect, but had made adjustments to their lives to adapt to the circumstances in which they find themselves:

_I am still his wife, always will be, but to him the farm was a partnership, the kids were a partnership …. My plan was to stay at the farm and work on it until when I was about 65 then I thought I may be too old to manage. So having to decide to sell the farm was huge, a big big thing (1:10.2, 7.5)._

_….if you know how to help keep their love and companionship, keep that alive between you as long as you can, then you can negotiate much better (6:27.5)._

Regardless of how it was expressed, commitment is the underlying strength which permeates the experiences of these carers. It drives their desire to persist with obtaining a diagnosis (even when it was not the ultimate one of DLB) because I knew something was wrong but we couldn’t put our finger on it (4:2.2), adjust to accepting long term care: oh no oh I’m not putting him in you know and it is marvellous how you change your mind (8:10.2), and ultimately ensure appropriate palliation; he had periods where his breathing was hard but then he went through spells where he was completely peaceful (6 26.2).

The spousal relationship also provides a degree of protection for the partner with DLB, particularly in social situations and in the early stages of their illness:

_When I think about it now Harry was going to go round to Rotary clubs speaking but he couldn’t have done that and I am thinking he can’t do this ….it will be embarrassing (7:25.4)._

_We would socialise and we would be with people and we would be all talking and you know the women talk and the men talk and I was very conscious of it because I knew Colin couldn’t keep up with the conversation. I would be tuned into my talk and I would be tuned into what the men were saying. Friends would ask Colin something and you
might think, oh dear, you know he isn’t going to answer
so I would come in and answer so he wouldn’t be
embarrassed (8:8.5).

The ability to cope with the impacts of the disabilities that their spouses face is also
ameliorated by their commitment, although the nature of their relationship appears to
influence how the carers deal with their situations and portray them. The older carers
described their situations with the emotional connection to their spouse:

When we came home his pants were full, so I had to clean
him all up. So I would like to know how people can’t
understand that or [that] you get up six or seven times a
night but I am happy that I have still got him, don’t get me
wrong. I don’t know what to do without him but they
[others] don’t know what is involved (12:1.5).

I don’t really know [what I would complain about]. Oh I
might say he can’t do anything. It is a nuisance; what
ever he does I have got to do everything for him. So I
don’t. They know what I do but I don’t complain to
everybody about what I have to do. He is my
responsibility, I love him, and I will just do for him. I feel
that it is my place to do it (9:14.3).

In contrast the younger carers, especially those who expressed aspirations for
themselves within the caring role, spoke of the ways in which the disabilities had tested
their resolve. Speaking of her husband’s compulsive behaviour Yvonne recalled an
episode when, as parents, they needed to support their child who was ill:

Tony is saying well he can’t go unless we take all his
special food because he wouldn’t eat motel food and all
this sort of completely obsessive ridiculous behaviour. He
must have light bix with no fat milk and no, he couldn’t
eat the motel breakfast, so that sort of stuff put a lot of
strain on it [the relationship] and made me very angry
(1:8.5).
Ruth provided an insight into this view of the autonomous partner. Although at the time of the interview Ruth’s husband was in care, when she spoke of her difficulties in adapting to the caring role, she laughingly confided:

*If it had got worse at home I think I would have had trouble. That probably sounds selfish but I felt that if looking after Simon was going to become (such) a problem that I couldn’t lead some sort of a life of my own then I might have been more of a blubbing mess……I have always been independent right from when I left school and I have always done my own thing, gone where I wanted and done what I like. I mean that’s the way I am but I think a lot of our generation are like that whereas the older generation, perhaps they kind of stayed at home a bit more, they kind of thought that was what they had to do* (2:12.2-5).

The nuances of the relationships were also demonstrated by the carers’ comments on the necessity to accept changes in role responsibilities as part of the caring. Those who had predicated to gender / role responsibilities commented on the strain of assuming new challenges. The women spoke about financial obligations: *everything is my responsibility I have to make decisions – monetary decisions, he always looked after the finances but I find I have to do that now. (9:11.1-2) and if it were just me then I would think it is only going to affect me isn’t it? But the decisions I am making are going to affect him and me* (10:23.1). However, it was the cooking that challenged the sole male carer: *and when I say I am still learning how to do the cooking, they (the family) say you told us that twelve months ago!* (11:2.2)

The necessity to assume greater responsibility was also evident from discussion with the women who had greater autonomy, however they expressed it with less angst and more preparedness to negotiate and delegate:

*Things like the computer that he was finding difficult, they were easy for me because I had been using them so I was quite happy to take over doing the accounting. I mean he*
was a very pedantic and meticulous person so he would do all the accounts and I said why do all this? Let’s just pay an accountant and then we don’t have to worry as much (1:2.1).

I think I am a fairly self assertive person who has always carried a fair load as it happened. I have always done all the accounts and carried all that and Frank, well we discussed all that but if you are the meek wife….. [You have to] understand what is going on so that you can best cope with it yourself. That I think is the important thing (6:27.5).

We would have got by with the help of someone coming in. I would have been happy to pay someone [even] if I had to go to work to earn the money to pay someone to come in…because I felt that Simon wouldn’t want me under his feet 24 hours a day 7 days a week. I would have driven him mad and he would have driven me mad - that wouldn’t have worked (2:14.1).

**Communication**

Another significant component of relationships is communication. The impact DLB has on people’s ability to communicate is varied but none of the carers spoke of their partners as being “non verbal” a description often used within the AD lexicon. The interviews were all peppered with anecdotes of conversations within the context of day to day life, the impact of fluctuations and rational thought and dialogue. During the interview visits I was introduced to four of the spouses with DLB; all engaged in social conversation.

It was clearly evident that the spouses who display fluctuations, as a component of their dementia, pose particular challenges for their carers both in home care and facility based care:
Sometimes he will walk around the house with his eyes shut like a zombie and other times he is quite with it and quite able to express himself and other times he speaks absolute rubbish (1:9.4).

This was obviously distressing for Yvonne but she remarked that it also had significant implications for other care givers: he does fluctuate which makes it quite difficult because I think some people think that there is nothing wrong with him (1: 14.3).

Those with spouses in care, either in acute situations or in nursing homes, spoke of how they constantly wondered what each visit would bring:

I would sit there for ages and he wouldn’t say a word and I would think he doesn’t hardly know who I am. It hurt me. I thought he doesn’t seem to know or care if I am here or not, but then if I didn’t go or I missed a day then [he would say] ’where have you been?’ I said Oh you missed me did you? (13: 15.3,6)

We go in and you don’t know what you are going to get for the day. I was there one day last week, I went over and I was there for an hour and a half and I don’t think he said one sensible thing in the whole time that I was there. Just talked a whole lot of nonsense stuff and yet you go the next day; he is fine, chatting away asking about the grandchildren and things like that (2:18.2).

Nearly all of the carers gave accounts of conversations that demonstrated their spouses had insight into their situations: he had tears rolling down his cheeks and he said ’this is a bugger of a way to die isn’t it?’ (2:36.1) and had retained the ability to reason, often in the latter stages of their illnesses. It is worth depicting some of these because they have significant implications for care provision for people with DLB.

The first vignette concerns a call Wendy took from the day respite centre where the staff were concerned that Alex was not well:
Anyway I brought him home and he knocked off two big corn cobs and something else for lunch and if he was sick he wouldn’t have done that so that I knew that he wasn’t sick. Then he had tea and everything and he was fine and I thought yeah. I said to him: ‘did somebody upset you round there?’ . . . . Anyway I got it out of him and what had happened was there is a guy who wanders around all the time and he will wander up to the door and that and apparently he tried to get out when someone was coming in. Alex explained that the staff called out: ‘Come on NO you’ve gotta come back in’ and he said that he couldn’t get out and he was frightened [that] he, Alex, was going to be locked in. So I told the staff he wasn’t sick, I just think he thought he was going to get locked in and he couldn’t get out and you can understand [why that would upset him] (4:12.4).

The second vignette concerns a carer negotiating a weekend outing for her spouse from a nursing home. The previous outing had been marred by incontinence problems which created enormous stress for Olive both from a social perspective and because to her, her husband seemed oblivious to his own deficits: nothing seems to worry him. He has lost not the proudness but the ability (7:18.7) to be embarrassed by his incontinence:

After this debacle last week with the bowel and urine problem he said: ‘what’s happening at the weekend?’ and I said: ‘I haven’t even thought about the weekend Harry’. I said: ‘I will ring. I will let you know’ and he said: ‘I don’t want to sit here for the next 20 years!’ (7:41.4)

The final vignette comes from the carer whose husband died prior to our interview. A common theme expressed by Glenda was the need for space and time in communicating with a person with dementia. Her husband had initially been given a diagnosis of AD and her greatest fear was that friends overseas, who had seen them prior to his subsequent diagnosis of DLB, perceived his death as a relief to her: I make a point even when I am writing now about his death, that he did not have Alzheimer’s. I want people
to know that he never ever really became stupid (6:5.2). Glenda related the following with a lot of pain and tears and I have taken the liberty of some paraphrasing:

I also knew then that time was coming that I would have to [relinquish care] so I went, and as it happened that day they showed me round and a room had become vacant. It was very hard I didn’t want him to go to a nursing home. I got our daughter and I discussed it. I got her and Frank and I told him what had happened and I said that I felt ...the time had come.......and he went very, very silent. He finally looked at me and said ‘is it for ever?’ and I said: ‘Yes it is’.

It is very different from people with Alzheimer’s when they don’t know what is happening at all. He knew exactly. I suggested that we have a time of quiet after we discussed it. I said: ‘I want to know what you feel Frank’ and he certainly understood (6:18.3).

Later in the interview, when speaking of her husband’s death, she said: Frank actually said to our daughter about Saturday ‘I am dying’. He said that to her (6:24:5). Frank died on the Wednesday morning.

Loss

To analyze loss after the previous discussion seems somewhat paradoxical yet loss is the overwhelming emotion that was expressed. Patently, loss is experienced by any partner caring for a person with dementia, but these carers, like those in the narratives discussed in Chapter 4, often spoke of their personal intimate loss juxtaposed to the hope, joy or acknowledgement of their spouses’ connectedness:

The hardest part was losing the person I knew. This person that I had married back 39 years ago, this gorgeous bright, bubbly, full of personality, full of life.... This happy go lucky. To have lost that person and to feel that I was living with a vacant shell of a person, that to me was the hardest. I haven’t been able to accept that
very easily. (2:7.3). But it is still the same Simon isn’t it? It is still the same person? Is he going to be happy to see you? (2:19.1)

We don’t have the long conversations we used to have. We used to drive and talk about every mortal thing.... But just little contact things (Betty touched one arm with the other hand) that don’t happen now - that’s lost. The ......interest. I feel it. He knows who I am and he loves me but things change and it is not the same. It is not the same any more (9:5:2-6.1).

I feel that I have lost him. He is still there in body but the person I knew has gone. (8:12.3). I take our 4 year old grandson over of a Tuesday morning and we walk Colin round and he takes his hand and Colin’s eyes light up when he sees him. He knows them (the grandchildren) (8:16.2). Colin always had such a nice personality and even now I get so happy over there [at the nursing home]. They say: ‘Oh he is a lovely man’. .... We go for a walk and every staff member that walks past him (says): ‘Hello Colin how are you today?’ He just smiles, he doesn’t always answer, but it is surprising sometimes he will just come out with something quite normal which sort of takes you back at times. He always had a good sense of humour and now and again that little bit of humour will come through (8:21.5-22.3).

He wasn’t too bad at that time but it was there and [there was] just the no conversation all day long, no company,
nothing to say. You know he always loved me very much and was a real gentleman, but he changed so much and he got grumpy and cranky and irritable (13:15.1). I will rattle on and tell him everything that is going on around the place. I went yesterday and as soon as I walked in he said: ‘Did you go to Ben’s funeral? I would have liked to have been there’. I thought: ‘Oh you remembered that’ (13:16.3).

Even Kerrie, the one carer in my group whose spouse experienced Capgras syndrome, which is characterized by a delusional belief that a person (usually a spouse) has been replaced by an impostor (Josephs, 2007), related her loss with hope, humour and sadness:

*He never acknowledged me as his wife. I don’t know whether he does now or not or I am just that person that keeps coming into his life. As soon as I walk in [to the nursing home] and I speak, he will look around because he has got very acute hearing, different to mine, but for about two years before he left he would not have it that I was his wife. He knew that he was married to Kerrie L---- ----... [Kerrie’s maiden name] but I wasn’t that person. He had three other women I don’t know why he had to have three, but he used to insist there were three. Even though we slept in a double bed he would never touch me. He’d say: ‘I haven’t done the wrong thing have I?’ and I would say you haven’t done anything!*

(10:6.3)

The loss expressed by the carers was twofold; loss of the intimate connection with their life partner and loss of the expectation of their lives together. The loss associated with their partners was paramount but none of the carers had ‘let go’. Those who were caring at home spoke in dread of the day when they would not be able to cope. Janet
commented: *if he is a week away from me and they don’t give him food and watch that he gets cleaned up then that it is. I get nothing back. I am too scared to do that* (12:4.2). This sentiment was echoed by Betty: *it doesn’t really need to be that situation as yet because they won’t look after him like I do but I know one day it will happen* (9:9.2), and tearfully by Fran: *he upset me terribly yesterday. He upset me because he said ‘why don’t you just put me in a home’. I found that dreadful and I told him* (3:14.3).

Those who had succumbed to the demands of caring at home fared no better. Kerrie, who tries to visit Brian twice a day at meal times, commented: *it is like his eating now. I don’t know when the days I don’t go if he attempts to feed himself or not* (10:21.4) and this concerns her because of his weight loss. And Glenda’s distress at the presumption of nursing homes that people with dementia need space to “settle in” is obvious:

*I find this whole philosophy [of entry into nursing homes] when you put someone with dementia into a home and you don’t [or are asked not to] visit them for the first week and don’t take them home for two months, to me, especially someone with DLB, is cruel. He knew exactly what was happening and to me it just makes it look as if you don’t love them anymore and I couldn’t get over that. In the end he only ever came home for one meal. I needed help to get him into a car and out again but every week I took him out to a little restaurant where we had lunch together and went for a walk. I did it with others - just a simple meal* (6:18.5).

The carers voiced similar expectations of their projected lives. Many spoke of travelling, particularly in caravans, and time with grandchildren. They, like others in a caring role, shared the disappointments of having to accept that compromises had to be made, the grandchildren not staying over, the sale of the van, but many struggled comprehending and accepting some of the early signs of subcortical dementia – their spouse’s apathy and lack of motivation:
- **he was getting tired and so he retired and sat at home and wasn’t motivated** (5:1.5),
- **he needs to do something because he just sits in the chair all day and watches telly** (4:4.3),
- **in the early stages I wondered what was wrong with him and I used to tell him he was boring** (7:20.7),
- **he had no input into anything...we looked at places [to move to] and he just sat** (8:7.4),
- **and I said one day: ‘Look you can do the same there as you do now. You sit in that chair all day long and you don’t do anything’** (13:7.3).

Even so, the carers often attempted to continue with social outings, travel and holidays until they realized that at least, in their own environments, they could manage albeit with difficulty. When speaking of their attempts to maintain social contacts the carers often referred to the role family and friends played in their lives and the lives of their spouses.

### 7.1.2 Family and Friends

There are idiosyncrasies in every family and friendship circle and illness of any kind challenges people in differing ways. Some people are natural carers whilst others bury their heads in the proverbial sand. Other symbolic interactionists have concluded that by becoming caregivers of people with AD, primary carers have to recreate meaningful and affirming relationships (Karner & Bobbitt-Zeher, 2006). However the carers I interviewed gave the impression that in the main, family relationships remained constant with no more or less involvement than each person expected because of the established family dynamics. Friendship circles were likewise relatively constant. Nonetheless, the carers spoke of situations that can be interpreted as pertaining specifically to the impact DLB had on how people interpreted what was happening, maintained or lost contact and interacted. Some of those situations are worthy of exploration.
Early Signs

Discussing concerns about one family member with others within the family circle is a normal consequence of daily life or post-gathering chatter and this was reinforced in the interviews. Subtle changes in a person were either accepted as the norm because of increasing age or questioned because of familial history or work experience.

Increasing age provided rational explanations for apathy, increasing periods of sleepiness and general slowing down. In Yvonne’s situation, where her sons were still at home, they reinforced her early dismissal of any problems, other than increasing age, by their acceptance of their father’s behaviour:

‘Dad’s just getting old’, which was fair enough, he might come out and work for a couple of hours then he would come home and he would be back asleep in the chair.
Well, they were used to him going to sleep in the chair. I think they sort of normalized it and thought: ‘Oh well he is getting old, he can’t do it any more, he is tired’ (1:12.3).

Even in a situation where family visited a similar acceptance was voiced:

I just thought: ‘Oh he is slowing right down’, so many of the men do at about that age. They [the family] didn’t seem to notice I don’t think at all. I just said Dad is slowing down. When they would want to go out the back - we had a very large back garden and the kids would want to go and have a game of cricket or something, Dad didn’t want to go. So you know it never dawned on me (13: 4.2-5.1).

Family members with experience in health related fields often raised their concerns or encouraged interventions, both in the early stages and when the given diagnosis did not resonate:

My oldest, he’s got two sisters-in-law who are nurses and a couple of times we were always at parties and birthdays and that, he said to me: ‘Oh Mum you want to take Dad to
the doctors’ – they were saying there is a change in him and I would say: ‘Well I have taken him and all they say is he’s alright’. Then one year, at Christmas, we were there and they went for a walk and they came back and my son said: ‘Mum, you get Dad to the doctor this week.’ I went to the doctor and I asked [said] that I wanted to see a specialist (8:16.4-5).

I was in denial, I think, and I would discuss a few things with my sister and I would ask her a few questions because her son is in a chair of cognitive neuroscience and I would ask her a few things. He won’t tell you anything but I would find out little snippets. He says not my patient, he backs off [but] he gave me a list of doctors and he emails with general things (5:2.3, 19.6).

Family Interactions

In the experiences presented, families were portrayed as supportive and caring and often people moved to be closer to a child, yet most carers distanced their children from the responsibilities of care and rejected intervention on a day-to-day or even respite basis. One carer had the live-in support of her son brought about, in part, by his own ill health. Another carer, in relinquishing care, chose a nursing home closer to her daughter’s home than to her own because she is the caring one and is going to be working there next year (2:38.2). The rejection of support was based in the carer’s belief that they were coping with their situations, either within the home care scenario: one daughter said to me that she would be prepared to sort of take unpaid leave to look after her mother and I said no not at this stage (11:11.6), or after they had relinquished care: I don’t call on the children to do anything at all. I tell them: ‘Well the day I get stuck then I will call on you’, but when they come up here I haven’t got a list of jobs to do or anything, we just sort of have an outing (10:12.5).
Other carers felt that demands were too onerous:

*I just, you know, if I got sick or something he would just have to go somewhere. I couldn’t ask the family to help out because there are certain things I wouldn’t like my girls to have to do for him that I do. So yeah, he would have to go into [care] (9:23.6).*

Betty chose not to elaborate on the ‘certain things’, however for others continence issues, and the risk of falls were mentioned as limiters of day-to-day social interaction within the family. Several carers spoke of reluctance to attend significant family occasions because of the inability of spouses to cope in unfamiliar and crowded environments. Birthdays and the like are managed on the basis of *we will be there but on the day I say ‘no he is not having a good day we won’t be there’* (4:11.1). However more formal events are either refused because *I wouldn’t feel comfortable and neither would he* (12:9.3), or managed in such a way that limits the demands on everyone: *I have booked him into respite. There is no way he would cope with the wedding. He hates big restaurants and lots of noise so he is [only] coming to the church* (5:17.3).

**Friends**

As is to be expected, the carers reported a full breadth of positive and negative experiences within their own friendship circles from steadfastness: *I have a couple of friends, they call in [and] I go over to their place and we do jobs together* (11:8.1), to rejection: *they don’t want to know you* (9:4.1), and criticism: *he says ‘it is your fault you know’* (3:37.1). The carers’ frustrations and hurt emerged when speaking of the impact rejection and criticism had on their spouses:

*He was really hurt when the new president rang up and told him that they didn’t want him out at the club even though he is a life member. I don’t know whatever happened [at bowls] and the fellows will never say. They won’t go and see him or anything; they think that it is contagious and they always say to me ‘can I have a conversation with him?’ I say: ‘Well sometimes he will*
talk to you and sometimes he won’t, and I say: ‘I can’t say that he will’ so they don’t bother going (10: 4.3).

Simon did something that was inappropriate and she [a neighbour] flew into him and he got upset....he laughed instead of being sympathetic. He didn’t interpret her message properly, he just didn’t comprehend the severity of it. She is saying: ‘Bob nearly died and he is in hospital’ and Simon is saying: ‘that’s nice’. I remember Simon being quite taken aback and really upset and distressed that he hadn’t understood (1:19.1).

The carers also spoke of the differing perceptions that their families and friends had in relation to the awareness of their spouses. Some perceived nothing was wrong:

One of the guys here last night said [that] Harry was not confused or anything and the other said: ‘Oh yes he is Jack’ and Jack said: ‘Oh is he? Whenever I see him I think he is quite good’. And he can be on a one-to-one with some things (7:331).

I don’t really feel the son-in-law accepted that anything was wrong. Poor man, his mother has dementia and his father as well.... So he says: ‘Oh there is nothing wrong with him, he is alright’ and he sits and talks and he would, he can sit and talk unless you really realized (9:7.5).

Others felt or feared that they had lost connectedness to their friend:

I still get a lot of support from them but the men in that friendship find it very difficult to communicate with Colin. They are still there for me, for us. Our best friends - she
said to me one day: ‘Mac has just lost Colin’……he has just sort of lost that friendship now. I mean he is still there but… (8:15.3).

The concern that families (and friends) show continually for those in need and the barriers that they face is highlighted in the following excerpt from Olive. It provides a perfect segue into the fraught relationships that this group have with their doctors:

*Family and friends noticed. Friends were talking behind my back. I would ring the doctor, our boys would ring. I would say: ‘Well Harry I won’t be surprised if you have [Parkinson’s] - you are getting anxious over [nothing]. If we were going out at 3 o’clock he would get to 2 o’clock and he was sort of pacing the floor and he couldn’t think [about anything else – he] was just concerned about being out at 3 o’clock. So it wasn’t until about eight years ago that we had been up in Sydney visiting our daughter [who had returned from America]. She said: ‘Mum there is definitely something wrong with Dad’ and I said: ‘I know but I don’t know what to do’ (7:2.3+).*

The daughter’s intervention led to a referral to a specialist and a diagnosis of PD was made. Later in our conversation Olive explained how a subsequent diagnosis of DLB came about:

*How we got on to the Lewy bodies was the specialist had never mentioned it. Our daughter worked for a support service as a volunteer……. She is switched on. She said: ‘Dad’s got Lewy bodies ask the specialist about it’. I don’t think I ever did but my son and his wife had an uncle over from England who had a friend in NSW. He had been to see [a doctor] at the Caulfield place and our son said we should go. So we got an appointment and we went down and they said: ‘Yes, he’s got an element of the dementia with Lewy bodies.’ They referred us to a*
psychiatrist and that’s when he was put on the Aricept, it made a huge difference (7:6.3).

7.1.3 The Medical Profession.

Olive typifies the experiences of this group of carers. Overwhelmingly, their views on general practitioners are negative. Much of that negativity stems from the carers’ frustrations at the advice being given and their perceptions that the doctors did not really understand the situations and the disease. Trudy’s experience is similar to Olive’s:

One doctor, who we are very friendly with, he just said to Colin: ‘Oh that’s just men you know’. He said: ‘Oh they have got selective hearing and if the wife says something they only pick out what they want to hear’, and I thought ummm I wasn’t too happy with that (8:2.2).

Others spoke more dismissively, particularly of their doctors’ knowledge of DLB:

It was absolutely useless, absolutely and still is. I feel we should change doctors and I have tried two or three other doctors at the clinic. None of them seem to know very much about Lewy body dementia at all (5:7.1).

When we went up to see our local doctor some time ago, he is a very able man, he is head of the clinic up here, a very nice person, and I said Murray had been diagnosed with DLB and he looked at me and said: ‘What on earth is that?’ I took it [a printout] up and showed him and he was absolutely fascinated he knew nothing. He took a copy – he had no idea and yet he is a very able and competent man (13:12.5-6).

The carers also gave the impression that their local doctors’ lack of knowledge about DLB influences their ability to counsel them appropriately when they were in need:
What would have made a difference [would have been] to recognize what was happening so I wouldn’t have ended up in such a mess because I was frustrated. He [spouse] would say things that would hurt me that he obviously didn’t really mean in these times when he really wasn’t with it. He would be aggressive to me verbally, not physically, but he would be saying: ‘Oh you just want all the money, you just want the house. You don’t want me’.

If I had known [that] was something to look out for, then I would have. The doctors were saying: ‘Don’t take it personally, don’t take it personally’ but I would think how else can I? (1:18.2)

How come the doctor hasn’t told me that [urinary dysfunction being a symptom of DLB]? I am getting frustrated with the medical people. You see the doctor has given me a stronger sleeping tablet. Well I am scared to give him the stronger sleeping tablet because he is like a zombie the next day and I am scared. I have got stairs in this house [a huge sweeping staircase] you know what I mean? (3:11.5)

In defence of the local doctors Trudy reported that, in response to a comment concerning her husband’s memory, her doctor’s passing comment: ‘oh that’s the Lewy bodies – that’s the one with PD’ (8:29.4) was the first time that anyone had brought the possibility of DLB to her attention. Several others also reported incidents that inferred that whilst their relationships with their local doctors were both caring and supportive, on occasions the doctors’ advice offered was not well received:

Long ago he said: ‘Put him in a home’ and I said no. So he said one day: ‘You still haven’t put him in a home?’ and I said: ‘If you tell me that once more you are not my doctor anymore!’ (12:12.2)
Specialists on the whole were regarded as “very nice people”. The carers whose spouses were initially diagnosed with PD, and had treating neurologists, expressed more frustration in dealing with the medical profession than those who had been referred to geriatricians or memory clinics. They indicated that their spouses had greater autonomy when there was a perception that PD was the initial complaint, often attending appointments and support groups alone. However, from my conversations it was evident that in many situations communication was freely exchanged between the specialists and the carers. Occasionally carers voiced frustration at being excluded from consultations: *[the doctor] must have looked at me and thought: ‘Well I do not know what you are on about, he looks alright to me’* (2:6.3). They also reported frustration as a result of being perceived by doctors as interfering: *Leon looks at me so I have to answer and he [the doctor] doesn’t like that very much. It is like I am a busybody woman* (12:14.4). Some carers struggled with being told repeatedly that many of the problems being experienced by their spouses were related to medication mis-management, even when they (the carers) were adamant that the medications made no discernable difference: *even if he misses one [dose of PD medication] you don’t really notice. I don’t think we ever had on-off or I have never noticed on-off* (7:27.2).

The system also frustrated those who had experienced the geriatric assessment system. Whilst those referrals gave them a diagnosis, there was limited follow up:

*They were absolutely wonderful. They ran every test bar pregnancy! It was good but then again they don’t want to see us any more. You are diagnosed and that’s it. Not enough follow up to my way of thinking* (9:3.2).

In a number of situations, where the referrals had been made to specific specialists, recommended because of their expertise in the field, the reassurance of being able to speak to someone who understood their spouse’s condition was palpable, however ongoing reassurance remained, in some cases, an unmet need: *He [the specialist] said I don’t really need to come every six months to see him. ‘Just if you have any problems give me a ring’. So what do you do? I am in limbo now* (8:5.2).

Some of the carers verbalized situations where they felt isolated and unsupported by the medical profession. Several expressed concerns that a diagnosis of dementia had
excluded, or is excluding, their spouse from appropriate medical intervention both in life threatening situations and in routine management. Two carers spoke of situations where they perceived that hospital staff were making decisions for them against their wishes:

*The last fortnight was very bad; he was in hospital, he had pneumonia and they told me [that] his heart is very weak. The doctor said: ‘If it stops we will not resuscitate him, [because] we will only break his bones’ (12:3.3).*

*Frank had pneumonia two weeks after he went out [into care]. We insisted that he should be treated and they looked at us as if to say why? But he had been so fit and so much with it and they [the doctors] were astounded after a week when he recovered. It was so hard to convince the nurses and the doctor that that was what he had been like. I found that difficult. I kept saying to them he is not just a vegetable lying in a bed (6:9.3).*

Another carer was dismayed that, in her view, her husband was being denied appropriate treatment for pain relief because of his diagnosis:

*I get a little bit angry with doctors [who say]: ‘We won’t do anything because of his problems and anaesthetics could upset it more, and you wouldn’t be able to cope’. I wouldn’t be able to cope! Why not give us the options and give him a little bit better quality of life? I don’t feel that they should make that decision for us; it should be our decision as to whether he wants to go through with an operation [for painful adhesions following previous thoracic surgery]. Is an anaesthetic really going to upset them to that extent? It can affect anybody, even a normal person, just for a short period of time and you get over it. I just feel that if he is going to be a little more comfortable*
it should be our decision. I just feel that people with dementia are not looked after the same way. They could do something but they won’t because of his condition and that is what they have told us and I feel that that is wrong (9:21.3-4).

An over riding concern was the lack of appropriate information about DLB. Comments included:

- no we weren’t offered any information at all (2:24.2),
- a lot of it I found myself I got more satisfaction out of getting it from places and reading up on things than I did from the doctors (8:4.4),
- I sort of felt that the local doctor should have known (7:23.3).

### 7.2 Understanding DLB

As I stated in my introduction, wanting to understand DLB was my starting point for this research, but a starting point from an academic perspective rather than a personal one. When the problem is personal and health related we rely on our past experience to provide the answer, test our social perceptions and finally seek answers from any avenue available to us. This was the pathway for most of the carers. Sometimes intuition tells us that the problem we face is one which is a mysterious and confronting illness and that not many people have ever heard of it (6:1.3).

#### 7.2.1 Past Experiences and Social Perceptions

A number of the carers spoke of members within their families who had AD or PD and how that had influenced their thinking or the attitudes of other family members and friends. Some recounted extensive family histories of ageing, cardiovascular disease and PD whilst trying to rationalize their own situations. Lucy, whose husband was in his mid 70s when his health problems became an issue, expressed her early concerns as ‘just age’:

> I didn’t dream of any thing like Parkinson’s. I always thought with Parkinson’s you started shaking badly and
all that, but he hadn’t started that at all. So I just thought: ‘Oh he is slowing right down’ - so many of the men do at about that age. (13:4.2) I had seen it in my own family like with my Dad and all those and they had sort of slowed down at that stage. (13.5.4). My mother had Alzheimer’s and I had her with me for quite a long time and that was completely different (13:11.4).

In contrast Olive pushed their doctor for a diagnosis because of her experiences with her father in law: I feel as though I am married to his father (7:28.2), yet she acknowledged other contradictions that had puzzled her:

Well that makes sense because my cousin’s husband, who is very bad at the moment, he knows when he is running out and needs another Madopar [PD medication]. Harry has never noticed any difference and even if he misses one you don’t really notice (7:27.2).

Carers also spoke of how their extended families’ own experiences added to their confusion in understanding DLB:

I don’t really feel the son-in-law accepted that anything was wrong. I never, never complained to the girls about what went on here, and it was only after he was diagnosed that they have realized things have slowly got worse. I think perhaps that my son-in-law on the farm tells us there is nothing wrong (9:7.5).

My oldest daughter, she is under the specialist for many years and he said that [it] is a different type to what he has. He has the old age Parkinson’s but she has a different one so she has no dementia. (12:2.5). There was [a show] on TV once about PD. They talked about Madopar but they also talked about an extra tablet which could help stop the Parkinson’s, not cure it, but stop it.
thought, well that would be nice too, and I rang my
daughter and said do you know that and she said: ‘I have
that Mum and I thought Dad had it too’ and I said no
(12:14.2-3).

From a symbolic interactionist perspective, it is worth pausing to look at meaning in
relation to DLB and the social interaction of groups within the medical profession. It is
evident from the previous discussion that, in the main, general practitioners involved
with the carers interviewed had little, if any, exposure to, and understanding of, DLB.
For example, one carer reported:

None of them seem to know very much about Lewy body
dementia at all and he [the specialist] said possibly our
doctor might have seen one case in her life ... and yet
friends that have got husbands with Parkinson's get great
support from their doctors and they seem to know far
more about Parkinson's (5:7.2),

However, evidence from this study also suggests that some PD specialists are also
blinokered to the alternative diagnosis of DLB and this is explored further in Chapter 9.

7.2.2 The Diagnosis

The vignettes in Chapter 6 present the carers’ interpretations of the early stages of their
spouses’ illness and it is evident that, for many, the diagnostic process was protracted as
Table 6.1 on page 90 illustrates. Several of the carers recalled the circumstances of
being told of the diagnosis with considerable pain and ongoing confusion. In presenting
their interpretations of those times I acknowledge the complexities of the diagnostic
process and that I have not been privy to any medical information nor have I discussed
the course of any particular case with medical specialists.

The first vignette raises the DLB or PDD debate. Over time Ruth had concluded that the
routine PD medication was not particularly effective – a theory she tested, however she
was continually assured by Simon’s specialist that pharmacological management was
the key to maintaining Simon’s independence. Although he had been diagnosed with
PD many years previously, the last eight years had been complicated by fluctuations, visual hallucinations and episodes where he would have a bad period, almost like he would have a build up of medication, and then he would go completely wacko. We had to get him to hospital in a hurry (2:6.2). In 2008 Simon was admitted to hospital for a medication review and trial of a new drug. Ruth takes up the story:

> We don’t know to this day and I guess we never ever will know [what happened]. When he went in on the Monday he was fine. We had coffee in the café and chatted and watched TV and all that sort of thing. They tried it on the Tuesday and I think it was by about the Friday that was when he completely went off the planet. Then they had to try and make some adjustments then they took it off because they figured this isn’t working for Simon. He became extremely aggressive. On the Monday, a week later, they rang me at midnight and said: ‘Simon has had a turn and he is up in the critical care section ward but nothing to be concerned about’. We never ever really found out what was that ‘turn’. [He also had an infection] and he became aggressive something shocking. He was wanting to rip throats; he was wanting to pull ears off; he was wanting to shoot people. He was terrible, absolutely terrible, and for that they had to give him Serapax or something and they had to put him on different medications to keep him calm. He was a mess there for weeks; we didn’t know what was happening, it was awful going in every day. Some days he would be quite funny, he would be with it and he would be chatting away and he would be in good spirits, the next day he would want to kill us all (2:16.2).

Some months later, whilst still an inpatient, Simon had a neuropsychological assessment: On a Friday afternoon in September she [the psychologist] said to me: ‘We have diagnosed that he has got DLB’ (2:24.2) and Ruth reflected:
But when things went wrong, completely wrong for us, I think, to me there was like a sense of relief when they finally said Simon has got DLB and he is going to have to be assessed for nursing home care. It was a relief to have someone tell us what the major problem was instead of the doctor keep telling us: ‘it is just the medication’ (2:14.2).

Of all of the vignettes, this case is extreme.

In the other two situations in which PD was the only differential diagnosis offered, the DLB diagnosis was accepted with equanimity. In one situation the diagnosis was made through inpatient assessment:

... there were quite a lot of people suffering [sic] with dementia ... and I said to the doctor one day that I didn’t feel that it was the right place for Murray ... and that’s when they told me what he had. You tell somebody what he has got and they just look blankly at you and say: ‘What is that?’ and I say: ‘Oh it is a type of Parkinson’s’ and just pass it off that way (13:10.4-12.2).

The other diagnosis was made through outpatient assessment: I suppose I just accepted it and then I thought that I should have really picked it up but I didn’t (10:15.2).

Six carers came to the study through an association with a hospital where, since 2002, the specialists have had access to a PET scanner. Although this did not necessarily avoid the AD / PD / DLB scenario, as not everyone is routinely scanned on first assessment, these carers expressed gratitude that a definitive diagnosis was made:

He sort of gradually got a little bit worse and the doctor said: ‘Oh do you think it is time to get another review?’ I said definitely, and so we went back and he had another couple of CAT scans and nothing showed up and his IQ went down a little bit and the specialist said: ‘There is
one way we can determine and that’s a PET scan’. So we had that done and it showed up (4:2.1).

Nonetheless, the general consensus amongst carers was that, although the correct diagnosis helped, being given a diagnosis did not translate to their understanding of DLB.

7.2.3 Sourcing Information

The carers presented a diversity of opinions on DLB and their understanding of it. Those who are computer literate and have some connection with the caring professions had an advantage over those who relied solely on information and advice from their doctors and support services. However, even with those advantages, those carers still found it difficult to access the ‘right site’: it is confusing on the internet because you look up Lewy bodies and then it talks about Parkinson’s or Alzheimer’s (2:25.2), or pertinent information:

We raced out and bought books and looked up stuff on the internet…..probably the best book I got was one that was written for nurses…. There was a chapter on PD that was quite informative including Lewy body dementia, which I thought it could be. But Tony didn’t ever have the visual hallucinations, which, if he had have, I would have said I know what that is, but he only ever had the smell hallucinations (1:7.2-3).

A number of carers gave me their favourite pieces of written information; one had a print out from the Scottish Alzheimer’s site and another chose one commenting: I have a lot of literature; I have a drawer full and a lot of it I found myself. I got more satisfaction out of getting it from places and reading up on things than I did from the doctors (8:4.4).

In 2007 PA and AA launched an educational CD entitled “Parkinson’s and Lewy Body Dementia” (2007) and, when relevant, I asked in the interviews if the carers had seen it. These are the positive views:
Alzheimer’s sent me out this brochure on Parkinson’s and Lewy body dementia with a video inside and I rang them and said could I have more copies because I gave them to all my friends. I just wanted the brochures not the DVDs but that was good - the purple brochure - that is the best one and I go back to that all the time (5:10.3).

I think the little booklet was more useful than the actual DVD but I have had several copies of it. It is very good to give to, well I gave one to the kids, the carers who come to look after Tony I have been able to give them a copy or show them, and his sister in NSW, so, very helpful in terms of having something for them to have some understanding. (1:13.3).

Research has shown that people enrol in research projects to assist others and learn more themselves (Murphy et al., 2007). A number of carers commented on various aspects of our discussions and how that had assisted in their understanding of their individual situations. The consensus from the carer’s focus group was that by being involved in the research they had “learnt heaps”, and that an information session specifically on DLB would have assisted them and would assist others in the future. That consensus arose in part from their individual experiences with both Alzheimer’s Australia Victoria (AAV) and Parkinson’s Victoria (PV).

7.3 Support Services

Whether through direct referral from the doctors or through their own endeavours, the majority of carers accessed one or other of the major support services for people with degenerative illnesses. The service first accessed aligned to the initial diagnosis however, over time, some carers accessed AAV and PV, as well as a variety of other service providers and agencies such as local councils and the Aged Care Assessment Service (ACAS). A number of factors appear to have influenced how and when various
support services were utilized and how the carers responded to the support provided. These factors are:

1. the diagnosis;
2. the perceived autonomy of the spouse;
3. whether the carer was proactive or reactive;
4. the appropriateness of the information provided; and
5. the ability of the carer to process the implications of changing diagnoses.

From my perspective, neither AAV nor PV appear to have recognized the idiosyncrasies of DLB in that AAV focus on cortical dementia, that is memory loss, and PV on the motor and non motor aspects of PD, so I was interested to see how the carers utilized these services in particular.

### 7.3.1 Alzheimer’s Australia Victoria

Not all carers had utilized the services of AAV. One was adamant that they had not because it was not appropriate for them: *not at all we - didn’t have that problem* (2:34.3), another because they were not aware that AAV is the peak support service for all dementias: *are they? That’s interesting* (12:15.7). One couple *just knew they were available but couldn’t go* (13:13.3).

Several carers had utilized AAV services with good effect, however the benefits were always countered by a suggestion of needs not completely met. Betty’s contact with AAV was initiated by one of the assessment teams in an attempt to ameliorate her feeling of abandonment. Although she reported her contact as a positive interaction, took on their advice regarding power of attorney and found the service was *good it was helpful* (9:29.5), it appears to have reinforced her sense of there being: *not a lot known about Lewy bodies, therefore there is not the help out there directed just to that. I know you can go to Alzheimer’s, they tell you to go there which I did. I have done most things that I was advised to do. We had a psychologist lady come in (from AAV). A lovely lady, she wrote and she came to see us and she was going to get in*
contact but she hasn’t again. I guess if I needed her I could ring but I just don’t feel that there is the real support (9:36.3).

Earlier in our conversation Betty confided that not all of the advice provided by the AAV counsellor was prudent. When speaking of her joy at having the family over for dinner, she added: AAV said perhaps it is too much for him to have family here but that would upset him if the family didn’t come (9:9.3). Also, when talking about her spouse’s visuo-perceptual deficits she said: he was at one stage stepping over all these lines on the tiles. AAV suggested we put a run of carpet all the way but he would have tripped on that! (9:17.2). At the conclusion of the interview when I provided her follow up information including an AAV fridge magnet, Betty was adamant that she had never heard of the National Dementia Helpline (9:37.2).

Yvonne’s experience was more positive: after he was diagnosed we went to an information session and I went to their counsellor for several sessions as well (1:12.6). However, she had difficulty dealing with the situation at home and chose to see the counsellor elsewhere: she came to the house and saw both of us a few times and you know I couldn’t talk about Tony in front of Tony (1:12.6).

Unfortunately, Glenda’s first experience was not as positive:

I went myself even before I had the diagnosis because we lived near. I found it very confronting. I picked up quite a lot of the material, but I found it very… I talked to a social worker, it was very, very confronting at first and it is important that people always have a sense of hope (6:3.2).

That sense of confrontation meant that she never took Frank to AAV (6:30.2), choosing instead to use the internet to access information together. Glenda also had another negative experience in seeking support:

He [the specialist] told me to join a support group and I rang up AAV. They couldn’t tell me anywhere that I could
One carer, whose journey was through the dementia pathway, provides an illuminating insight into how people struggle to make sense of information that they either interpret incorrectly or try to assimilate when, for their particular situation, it is inadvertently misleading in its delivery. Wendy accurately identified her husband’s early signs, was proactive in pushing for reassessment and relieved to get a diagnosis. She expressed the opinion that Alex’s illness had not changed her life much because she:

... knows what is down the track and I probably just don’t want to know. I just take one day at a time and we just enjoy ourselves while we can. We are lucky in that way - that you know what you are facing so you can do things while he can (4:3.4).

For Wendy, much of that knowledge has come from AAV who, in her opinion, have been terrific. She and her husband have attended several seminars including one which ran for about five months and you go once a month - that was fantastic, very enlightening really (4:14.1). Their attendance at that seminar opened the opportunity for an ongoing relationship with AAV. However that has now lapsed because of Alex’s refusal to go. It is my impression through talking with Wendy that she is still waiting for situations discussed in the AAV course to become her reality. Her conversation was interspersed with that anticipation; talking to Alex of others at day respite: they are not as lucky as you (4:4.3); of friends who have stopped visiting: I don’t know why because he is not that bad I mean we can go out - we went out to lunch yesterday (4:4.5); and of asking for ongoing assistance to problem solve from AAV: I don’t sort of look at it as problems at the moment. When you see and hear of others... (4:6.6).

The clearest indication of this anticipation came when I asked about her understanding of DLB. Wendy commented:

Well with the hallucinations and all that he is a lot better off without dementia because I do know, with dementia, you lose everything don’t you, like long term and short
term - your mind, you don’t know who people are, whereas with the Alzheimer’s you can still remember way back but not short term (4:17.7).

Confusion about the subtleties of each condition, such as was evident in my discussion with Wendy, was also apparent in carers who have had exposure to the Parkinson’s Association.

### 7.3.2 Parkinson’s Victoria

Parkinson’s support groups, particularly in rural areas, were actively embraced by those whose spouses’ initial diagnosis was PD. People attended as couples, for social activity and support: *I took him along right until the end you know, I always took him even if he just sat down and went to sleep or something* (10:21.1), or for information: *we are very interested (in the talks), but the social events,... well we don’t go to those* (11:3.6). As well as attending PV groups for their own benefit, some carers viewed them as a respite option and an activity through which their spouses’ autonomy and independence could be maintained – a strategy that varied in its success:

*We have hardly been at all. Tony has only been once or twice, I think he has only been once. I’ve been several times. The aim of that was so he could go to it but he won’t go so there is no point, but the information from PV has been very helpful, very supportive and the local support group convenor has been very supportive too (1:12.5).*

*Harry got into some support groups with Parkinson’s. I used to take him and another guy would bring him home. I didn’t go with him. At that stage Mum was still well and truly alive and I just sort of felt to go to those and to go to Mum, I was just laden down with it all. I just needed some spare time with it all, so he went to support groups. I take him now and I go in and see them but I don’t stay (7:6.1).*
A number of carers made positive mention of the PV support worker whose paper on the non-motor signs of PD I discussed in Chapter 3. Although that information resonated, no one appeared to make the connection between the information provided and their own situations; rather, it was assimilated as pertaining to PD. Trudy, who recognized dementia as an early feature of her husband’s condition, demonstrated a rare insight into the complexities of DLB, which was incidentally diagnosed three years after an initial diagnosis of PD: *With Colin the dementia and the Parkinson’s was there right from the first diagnosis, and one of them said it is just which one you go to the doctor about and they look at first* (8:27.3). She provided a most articulate explanation of their dilemma:

> I knew there was definitively, that there was a dementia there and, you know, going to the Parkinson’s support group most of the people there whose husbands or wives had PD, not many of them have this dementia like Colin, they had more physical things (8:2.4) ……. It was sort of frustrating because the people I was mixing with at the carer’s (group), like a lot of their husbands, haven’t got the dementia and even now a lot of them, their husbands are getting worse with the Parkinson’s and Colin is on an even keel I suppose (8:30.3).

As the diagnosis changed several carers accessed services offered by both AAV and PV, as well as a number of other agencies including those offered through the ACAS and councils.

### 7.3.3 Other Services

The carers’ knowledge of the aged care system and the services available varied considerably. There was consensus that it is a difficult system to navigate. Yvonne, who has an allied health background and whose spouse has an EACH (D) package, articulated the complexity of the problem clearly:

> For me my biggest problem is having to deal with all the different agencies and trying to deal with all the different
acronyms and trying and find out who does what where. I think having the one service and the one contact person is a good thing but, in that if you get a dud case worker, you are stuck (1:17.4).

Ruth reinforced this view, but from an emotional perspective: Oh absolutely 100% daunting - overwhelming. It nearly drove me bats (2:39.1).

Two carers provided insights into the potential difficulties of information transfer within the private healthcare system. Both spouses were diagnosed through referral to specialists’ private practices. Olive was made aware of home respite and other support services to which she was entitled to access by chance when a neighbour, who is an aged care support worker, knocked on her door to inform her that the people next door had left a tap on and all the water was flowing through to her place (7:22.3). When she saw Harry’s physical state she asked: ‘What help have you got?’ and I said: ‘Oh none’ and she said: ‘Why not?’ and I said: ‘Well what help can we get?’ (7:22.3). Her involvement and the services provided subsequently were fantastic, absolutely fantastic (7:24.1). Without that support for the three years prior to Harry going into care Olive is adamant that:

Oh I would have been in a mental home or somewhere. I couldn’t have. I don’t know what would have happened. I hate to think because they were fantastic support (7:24.4).

In response to my questioning her lack of awareness of available services, she replied: no one told us. How are you supposed to know? No one tells you (7:22.4).

During my interview with Norman he suggested that he was beginning to have concerns about leaving Mary for any length of time and I asked whether he had considered in-home respite. He had no understanding of the services available or how to access them: what! Someone could come in if I wanted to go to Melbourne for the day?: Do you get that through the shire? Nor did he know about ACAS and its role in the system: Aged care assessment I don’t think so… Oh that might be a good idea (11:8.7-9.1). Norman also accepted details of AAV making this comment which embraces the meaning
making issues explored: so that’s Alzheimer’s helpline. No every morning I ask her who I am and she hasn’t got it wrong yet, so we are quite OK from that point! (11:16.2)

7.4 Issues of Significance

Charon’s (1989) third construct, that is, that the meanings of relationships and DLB are handled in, and modified through, an interpretative process used by people in dealing with the issues they encounter, is pertinent to my new or expanded understandings of three significant issues that people with DLB and their carers face; namely, driving, continence management and care options. These are three issues that have significance for any person or carer faced with a neurodegenerative illness. However, the carers in this study provided me with new insights into the impact that DLB has on these critical aspects of case management and carer support. My interpretations of their experiences are presented in the next section. The wider implications of these interpretations are discussed in Chapter 9.

7.4.1 Driving

After reviewing the literature that indicated a potential for driving errors in people with DLB, and understanding that driving is viewed as a problematic balance between autonomy and safety in both the dementia and PD communities, I included questions in my questionnaire about the carers’ perceptions of their spouses’ abilities to drive. Prefaced with the statement: ‘Let me ask you about ….’s memory and behaviour in the early stages’, I asked each carer whether they had noticed deterioration in their spouse’s ability to drive in unfamiliar places, drive around roundabouts, cross busy intersections and ‘read’ the traffic. One or all of these statements drew a positive response, and often a harrowing tale to illustrate the concerns, from every carer.

The majority of the carers returned to the theme in their interviews. They related episodes of accidents and incidents that had accelerated the decision that driving was no longer an option. In some situations the person with DLB had recognized that they were having problems well before they were diagnosed, but they were supported to keep driving. Betty recounted an incident two years before Jeff’s diagnosis: He got half way there and wanted to come home because he just felt he was a danger to himself, he said, and everybody else (9:2.2). She admitted that she supported him to continue driving at
that time but later, when he was diagnosed, she raised her concerns and was pleased that the doctor suggested to Jeff that he cease driving. Likewise, Yvonne’s spouse refused to drive with his children in the car some six years before he was diagnosed.

A number of carers spoke of how their decisions to stop their husbands driving provoked anger. In some cases that anger was a recurring issue: Kerrie stated: I took the licence off him which led to fights about the licence because he was really arrogant (10:19.2), and Ruth spoke of how Simon remonstrated with her about her lack of consultation in cancelling his licence:

> He got quite agitated about that, he said: ‘Where’s my driver’s licence?’.. We had to try and explain to him that we had to cancel the driver’s licence - well he couldn’t come to terms with that. Why wasn’t he asked about it being cancelled? ... ‘Where is it, why can’t I see it?’ and then he would get very agitated and that is where it is very hard to reason with him (2:23.3).

Others showed a significant degree of insight once the decision had been taken: Glenda’s spouse, after grating about his family wanting him to stop, finally expressed that is was a relief not to drive (6:13.2), and an escalating situation finally reached a climax for Janet, with an unexpected result:

> For a while I knew his driving was not good and I said we have to let it go and he wouldn’t and he was angry. Then one day we went out and there was the curb and there was this thing sticking up for people to go round and he went past it and scraped the car. I said if that would have been a child standing there standing on that footpath - that’s it, I am not going in that car any more with you. So he was very angry and he went to bed. Next morning he came out and said ‘you are right’ (12:6.4).

It would seem that both people with DLB and their carers recognize deteriorating driving skills but lack the capacity, or guidance, to proactively instigate early assessment.
7.4.2 Continence Management

Incontinence is a major stressor for carers of people with dementia. I had presumed that the issues faced by carers of people with DLB would fall neatly under the management strategies that are promoted by both the continence foundations and dementia support services. It was revealing therefore to hear how adamantly the concept of continence was defended by carers in the face of almost insurmountable difficulties. A number of carers reported that their husbands had consulted urologists and had been given various opinions from “worn out” bladders to prostate issues. It is beyond the scope of this study to investigate the medical history of the people with DLB, however two carers reported that their husbands had had prostate surgery which, from the carers’ perspectives, had made no difference.

The carers reported that urinary dysfunction presents as nocturnal frequency:

- **[Last night] he got up eight times for the toilet and I wake every time (5:1.2)**
  Saturday night last week it was 12 times. He got up every 25-30 minutes. He actually goes to the toilet, it is not a dementia thing, where he thinks he wants to go because I listen to him and I can lie there and I can see him in the en suite (5:12.6).

- **He is up and down, he has a bladder problem ...the best sleep [I get] is from when he settles down at about 6 am - you can sleep then (9:6.5).**

- **[Eight times a night] – oh that’s nothing, it is more like 20 times, every five minutes (3:2.2).**

The frequency is then complicated by the parkinsonian symptoms of the disease:

- **He would get out and then I would have to come around and push his legs in, things like that, so those things became more difficult as time went on (2:8.2).**

- **I would get him all settled down and I would have to lift his legs up because he couldn’t lift his legs up, and then I would get him all settled down nicely and by the time I would walk from here to there to get in my bed he was out again and this went on nearly all night (13:1.3).**

- **He couldn’t pull his pants down (8:31.3).**
• I would go out shopping and come home to find him sitting on that chair bare bum with his pants near his ankles – he couldn’t pull his pants up so he would get to the toilet and pull them down but he couldn’t pull them up (7:24.5).

Only two carers commented that their spouses were having difficulty orientating themselves and needing direction to find the toilet, however there were a number of comments about the added burden that their spouses’ visuospatial deficits created:

• But then I would have to get up and help him in the night time, you know, I would have a wet floor and I would have to wash the floor and I would think, oh well, in a couple of hours he will be up again and I don’t want him slipping over (10:7.2).

• We had the en suite all revamped and renovated so it is all non-slip floor and he puts a towel down if he wees all over the floor (1:12.1).

Disturbed sleep is cited as a significant stressor: it is just, you know, it is just destroying (3:2.2) and this was evident in many interviews. The carers had numerous strategies for managing, struggled to find avenues for information and assistance that helped with the nocturia, and had mixed results when they tried to implement the suggested strategies:

The continence people suggested that he wear a bag at night but we are not going to do that. I wish he would cooperate so we could get a good night’s sleep, the pair of us, but I guess it is hard for him…. We have a commode so we use that in the bedroom of a night but so he doesn’t have to walk because our toilet is way out round the back, but no, he is not incontinent (9:15.3).

Changing the pull-up things never work so the whole bed is wet in the morning and it might be like last night I put the pull-ups on him during the night and then he got up about another five or six times to actually go to the toilet and so I wake up and I think, I don’t think I have been to sleep all night! (5:11.4) I have done all that …we have
been to two [continence clinic sessions] and haven’t learnt anything (5:12.4).

In one dyad on the verge of collapse, respite that included intensive cognitive behavioural therapy provided a solution that has been sustainable and, to-date, has delayed the option of alternative care:

> It was hard and at the end of that three weeks I still wasn’t sleeping properly but the message came through from the counsellor, that is what you have to learn to do, so now it is pretty good. He’s learnt too. He can still get out of bed and he can still change his clothes - before he would be yelling out for me to come and help him. So he still understands that much, it took a bit. He would wake me up and I would make it clear that he is not to wake me. It took two or three months. I would be wide awake and listening for him anyway. I think I have learnt. I don’t hear him get up now - I would hear him if he crashed (1:11.4).

Urinary dysfunction also limited people’s options for travelling and holidays as Norman explained when speaking of a trip to their holiday home:

> We broke the journey and we found difficulty with the motel we selected because they did advertise in the RACV accommodation guide that it had facilities for handicapped people but the facilities weren’t adequate. It was a big job that night and I had to drive the next day about 300 kilometres. Anyway we got there, but we came straight home instead of stopping (11:5.1).

Glenda and Fran related similar stories of complete exhaustion dealing with the nocturnal activities whilst staying at friends’ homes. Fran commented that she was dying to get home (3:32.1) and make the decision that travelling was no longer an option, and Glenda’s experience left her more exhausted than being at home.
Although a progression to incontinence at night was acknowledged by some of the carers, and a couple also coped with the added burden of faecal incontinence, no one mentioned urinary dysfunction as a significant day time issue. Finding toilets in public spaces and providing assistance with dressing and hygiene were all mentioned, but most carers rejected their spouses being seen as incontinent. Some, however, feared that facility-based care would render them so:

> You know, I found that difficult because Frank was never incontinent but the minute he went to the home do you know what they did? They stuck a pad on him. I said he is NOT incontinent and I want you to keep that as long as you can but they only sort of tried for two weeks (6:28.2).

> Even now they have pads on him all the time but he knows when he wants to go to the toilet and he will say, but sometimes you take him and he has already started and during the night he is incontinent…. he can’t go to the toilet himself (8:30.5).

Managing autonomic dysfunction is a major issue for carers of people with DLB.

### 7.4.3 Care Options

Sourcing and accepting alternative care options is a stressful experience in all situations of caregiving and the carers interviewed expressed these difficulties eloquently. The constraints that two hours of home respite places on a carer trying to manage their own personal care and domestic affairs is a universal woe, as is the difficulty in negotiating a complex aged care system. There were a few factors, which I perceive as being integral to the deficits experienced by those with DLB that compounded the dilemmas for these carers.

**When ‘Dementia is not Dementia’**

The commonly held perception that one must have short term memory loss equals dementia is pervasive and created difficulties for both the carers and their spouses in adapting to the routine use of respite services.
They can’t offer anything until Keith is assessed [but] it is no use putting him in with people with dementia. We went to AAV, had a workshop and I could see the difference between Keith and the other people. That was for both of us, the carers were in one room and the others in another, but Keith said he didn’t want to go [back], he just felt, he felt worse (3:44.3).

So we took him around [to a respite group] and he wasn’t happy about going. Anyway they said: ‘we will try another group’, so they did and he’s settled in a lot better. He said today, when I asked if it was a good day, ‘Oh yeah, bundle of fun’. He talks to them and they don’t talk and I said Alex they can’t, they don’t know, they are not as lucky as you are (4:4.3).

One day she [the woman from the respite centre] rang me up and said: ‘Oh Colin was getting very agitated at lunch time [so] one of the ladies stood with him. Anyway he came home that day and he said: ‘Ohhh they wouldn’t leave me alone, some woman, she was there all the time - silly woman’ (8:32.5).

**Letting Go**

Several carers, who had contemplated alternative care and decided it was either premature or not a viable option for them, expressed fears that a lack of understanding of DLB may place their spouse at risk. Some spoke of the physical risks, particularly associated with swallowing, whilst others saw the fluctuations and apathy as barriers to appropriate care. Betty expressed her spouse’s lack of drive with this example: *My fear about him going into a home is that he would sit and if his meal didn’t come he*
wouldn’t complain. - I don’t get a drink, I won’t complain (9:34.4). However, Kerrie viewed it as an issue both at home and in care:

He could never work out his medication. I don’t know whether he was plain lazy and thought she will do it for me anyway. It is like his eating. I don’t know when the days I don’t go [twice a day to the nursing home to feed Brian] if he attempts to feed himself or not (10:21.4).

The majority of carers who had accepted alternative care had all found themselves in situations where that decision, enforced by ill health and exhaustion, was made by others. Adamant that their preference was for home care, they all expressed enormous relief once the decision was made. Against Murray’s wishes Lucy organized respite so that she could visit her family interstate and have a rest. On her return the staff convinced her to accept another two weeks and then counselled her that he should stay. Lucy elaborated: they made the decision and it was wonderful that they said that to me because I knew that I could not go through all that again (13:14.4). Other stories, like Olive’s, are similar even though they were the result of acute hospital admissions: the doctors said he needs full time care, so he was assessed as high care and that’s the way I wanted it to be. It was an easy way out. I didn’t have to make the decisions (7:12.1). Later in the interview Olive returned to that theme and mused: it was terribly, terribly sad and I was a bit of a wreck but, at the same time, I felt that a load had been lifted off my shoulders (7:37.3).

Knowing

Knowing, or retaining the ability to recognize and relate to family, is a feature of DLB that sets it apart from AD. Although placement is a difficult decision under any circumstance, opting for separation and accepting it is complicated by the carers’ awareness of that autonomy and personhood of their spouses. This was expressed as a reason for refusing or delaying respite usually to the carer’s detriment:

That’s what he wants [to stay at home]. He accepts, and so do I, that we do need to have respite for him every so often. He went in for three weeks early September last year and he didn’t like that, and I thought, well I will
Knowing also increased the stress of visiting and maintaining the relationships. Olive is active in Harry’s management taking him to appointments, having him home for the day and engaging him in family life. Reflecting on maintaining her relationship, which she perceives as being; hardly a wife, you know, you are just there (7:36.7), she mused that if Harry did not know her she would: meet it as it comes but I think if they don’t know you I probably wouldn’t go every day. I don’t know I will have to wait until that happens (7:20.5).

The Course of DLB

The final issue of significance related to the number of questions I was asked about the course of the illness. Some were subtle and probing and I answered gently allowing the carers to dictate the pace. My interchange with Norman started with: what I can’t understand or nobody has really told me, to what degree it can progress to? (11:12.4). After discussing the progressive nature of the disease I talked generally about some of the symptoms of DLB and the issues that could arise associated with a lack of mobility, continence, fluctuations and swallowing difficulties. Being relieved that the latter symptoms were not yet obvious, Norman reflected: it is handy to have some knowledge from the carer’s point of view as to what it can progress to (11.13.6). Others asked bluntly: does dementia kill you? (8:21.2), or with a sense of desperation: do they die earlier, do they, do you know? (9:37.6) suggesting that there is an unmet need in these carer’s understanding of the progression of DLB.

7.5 Reflection

As I reflect on what I have chosen to illustrate, and as I listened to the interviews and re-read the transcripts again, I wondered if it is possible to interpret the essence of another’s experience accurately. From my own experience, I understand that these are different journeys from that taken by my father when he was caring for my mother with AD. Many would contend that each journey has to be different, as they belong to each individual, but the essence of what I now recognize as the experience of caring for a
person with DLB emerged through each of the carers’ experiences. Connectedness, particularly to grandchildren, in the presence of intimate loss, knowing, planning and attentional deficits and autonomic dysfunction repeatedly featured in the carers’ depictions. Issues such as these, that are present as a direct consequence of the pathology, will not change. However, other issues such as ignorance of the disease, lack of information and support for the carers and better care options should be addressed so that the carers of people with DLB do not have the added burden. I explore some options for change in Chapter 9.

What I have come to appreciate is that the experience of caring for a person with DLB is different to that of caring for a person with AD and that those differences should be recognized. The next phase of my heuristic journey, where I create a synthesis, provides me with the opportunity to explore the experience of caring for a person with DLB further.
Chapter 8 The Caring Experience – A Creative Synthesis

Heuristic research is a journey of discovery. I have taken that journey, exploring every aspect of DLB from neuro-anatomy and pathology to the processes involved in arranging alternative care. Throughout the process of analyzing the experiences of those who care for people with DLB, I returned to the incubation phase as I pondered the challenge of developing my creative synthesis – the culmination of an heuristic journey. I wanted to integrate an understanding of DLB, developed from my reading, with the carers’ experiences into a cohesive, believable synthesis that demonstrated Moustakas’s intent:

*The creative synthesis is an original integration of the material that reflects the researcher’s intuition, imagination, and personal knowledge of meanings and essences of the experience (Moustakas, 1990 p.50).*

As I reflected on the synthesis and immersed myself in the options open to me, it seemed that I had two goals: the first being to adhere to the methodological framework and satisfy the academic requirements of my candidature; and the second to translate my research into practice. I decided that a synthesis, developed as an audio visual (AV) presentation, has the potential to be an educational resource and a vehicle through which conversations about DLB can be initiated. Ever mindful of the need to incorporate the essence of the care experience, whilst highlighting how and why that experience has been influenced by misconceptions and ignorance, I created the synthesis.

8.1 The Framework

The consensus from the focus group was that much knowledge and understanding of DLB, and its diversity of presentation, had been gained through participating in the research study. This information provided me with a framework for the synthesis, that is, the voice of a now informed carer reflecting on her journey of caring for her husband with DLB. However, there were a number of contextual issues that I still had to resolve as I developed the role play. Recognizing that choices had to be made, I projected scenarios that highlighted options such as, should I take the Alzheimer’s or Parkinson’s
route? Was my husband still at home or in care? Which symptoms did he have? How could I appropriately raise issues that I had not detected, but which may be central to the experience of others? In resolving these questions I chose a pathway which allowed me license to be empathically creative, from the carer perspective, whilst remaining authentic with respect to DLB and my understanding of it. Immediately, that raised another question – were these options valid?

### 8.2 Validity

Although I have discussed general aspects of validity or rigour in qualitative research in Chapter 5, validity in an AV role-play requires further discussion, particularly if one accepts the obligation on the qualitative researchers “to present the research findings in a way that enables others to apply the knowledge or insights in other situations” (Nuttall, 2006, p.438). According to a synthesis of contemporary views of validity, “attention to both process and product, art and science, contribute to validity and subsequently quality in qualitative research” (Whittemore et al., 2001 p.534). In contending that the synthesis is the art and product of the research, I adopted the authors’ stance that four techniques associated with the presentation of research attest to validity. Those techniques are:

1. providing an audit trail;
2. providing evidence that supports interpretations;
3. acknowledging the researcher perspective; and
4. providing thick descriptions.

Auditing the content of a synthesis is a problematic activity particularly as the synthesis is an original integration. My voice is a triangulation of my understandings of being a carer, the aged care system and carer support services, the carers’ collective experience, and the accumulated repository of knowledge that informs the study. Consequently, it seemed feasible to audit the synthesis from these perspectives as a test of its authenticity. The audit also provided the opportunity to verify the evidence, either from the carers or the research, to support my interpretations.
Providing thick descriptions of the experiences of caring and the frustrations that it entails, whilst canvassing a range of carer concerns and frustrations coherently, is a challenge that is virtually impossible to achieve when faced with the task of condensing so much into a 25 minute AV presentation. I constantly remind myself that this is only one part of the presentation of my findings and that poignant, thick, raw vignettes are presented elsewhere. Furthermore, even as an educational resource, the AV presentation is not intended to be a standalone product but will, in its present form, be couched within the researcher’s perspective, as an aid to comprehending information delivered in the more traditional milieu.

As a further, and perhaps even more rigorous, authenticity check, I invited the research participants to view and comment on the presentation and their reactions are also discussed. In doing so I explained how the thematic analyses of the research data provided rich evidence of the difficulties encountered by the carers.

### 8.3 Creating the Synthesis

The power of incubation should never be underestimated. Whilst I was immersed in the thematic analyses and looking and listening for nuances of meaning and experience, I was germinating the seeds of the synthesis. Moustakas speaks of being haunted by one’s passion and I have a real sense of this phenomenon. Sitting on trains, trying to meditate at the ends of yoga classes, engaging in chatter, I would find myself in self-dialogue exploring angles, scenarios and themes which I wanted to include. I then sought expert advice about producing the synthesis as a DVD from personnel in the multi media services of the University. I was assured that my project was achievable. The incubation continued. After numerous attempts to script both the introductory sentences and the body of the presentation, I gave up, ordered the camera and decided that the time for procrastination had passed.

I reflected on the interviews that I had undertaken with the research participants and decided that, if I were to role-play a carer whose husband had been diagnosed with DLB, then having someone else with whom I could engage in conversation would present a more realistic synthesis. Consequently I developed the role of my brother and created a scenario which provided him with some background information to the role-
play relationship and recent history of contact. The synopsis of that relationship (Figure 8.1) sets the scene in the presentation:

The scenario is that of a carer talking to her brother, Peter, prior to them visiting her husband, Dan, in his care facility in suburban Melbourne. Although there has been sporadic contact, the family has not spent time together since Peter’s daughter was married in Perth five years earlier.

Figure 8.1: Scenario for role-play.

With that background, I rolled the camera 24 hours later. After a review of the first cut I was concerned that the ‘what happens in the end’ conversation was too definitive and I added a further take the following day to suggest that the disease progression may take alternative courses. The editing was undertaken with assistance from the multi media unit and during that time I learnt some of the finer points of creating multi media presentations; particularly about moving backgrounds, camera angles and placement, idiosyncratic personal gestures and changing light. Aware that I was possibly over sensitive to the things that I saw as deficiencies, and being so immersed in the topic that I may have a blunted view of its impact, I coerced a couple of friends and held the initial public viewing. They provided some good technical feedback but, most importantly, spontaneously engaged in a probing and stimulating 90 minute conversation about DLB and the issues that I had hoped the presentation would raise. Consequently, I addressed their technical concerns, added the appropriate acknowledgements and then shared it with the research participants.

8.4 The Synthesis

This presentation is formatted as a DVD. It can be viewed on a computer with a DVD drive or by using a DVD player and television.
8.4.1 The Audit Trail

To create the audit trail I deconstructed the role-play and listed the topics of conversation in chronological order. This enabled me to then match each topic with the research participants’ experiences and provide evidence of the research literature that supports each contention. As all of the literature referenced in the audit trail has been cited in full in other parts of the thesis, I have provided the first author’s last name and year in the trail to indicate where each topic is supported by the literature. In most
instances the research literature concerns the diagnostic criteria for DLB as stated in the third report of the DLB Consortium (McKeith et al., 2005).

<table>
<thead>
<tr>
<th>Discussion concept or topic in synthesis</th>
<th>Research participants who mentioned topic</th>
<th>Significant research literature – cited previously by 1st author &amp; year</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ability of spouse to communicate by phone</td>
<td>Olive, Kerrie, Norman</td>
<td></td>
</tr>
<tr>
<td>Carer’s lack of understanding improved through research activity</td>
<td>Ruth, Fran, Wendy, Sara, Betty</td>
<td></td>
</tr>
<tr>
<td>Difficulty of getting a diagnosis – no knowledge of DLB – internet as a resource</td>
<td>Yvonne, Ruth, Sara, Glenda, Olive, Trudy, Betty, Lucy</td>
<td>Hansen 2008, Chodosh 2004</td>
</tr>
<tr>
<td>Work issues</td>
<td>Yvonne, Ruth, Fran, Wendy, Sara, Betty,</td>
<td></td>
</tr>
<tr>
<td>The early signs – depression / apathy / inappropriate behaviours/ driving/ RBD</td>
<td>All</td>
<td>McKeith 2005</td>
</tr>
<tr>
<td>GP dismissing carer</td>
<td>Yvonne, Ruth, Wendy, Olive, Trudy, Betty,</td>
<td></td>
</tr>
<tr>
<td>Early hospitalization</td>
<td>Yvonne, Sara, Glenda, Olive, Janet, Lucy</td>
<td></td>
</tr>
<tr>
<td>PD diagnosis &amp; medications</td>
<td>Yvonne, Ruth, Fran, Olive, Trudy, Kerrie, Janet, Lucy</td>
<td>Parkinson’s Association 2008, 2009</td>
</tr>
<tr>
<td>Obsessive behaviours</td>
<td>Yvonne, Ruth, Fran, Sara, Olive</td>
<td></td>
</tr>
<tr>
<td>Driving</td>
<td>Yvonne, Ruth, Fran, Wendy, Glenda, Olive, Trudy, Betty, Kerrie, Norman, Janet, Lucy</td>
<td>Bradshaw 2007, RTA (NSW) 2007</td>
</tr>
<tr>
<td>GP’s lack of knowledge</td>
<td>Fran, Sara, Olive, Trudy, Betty, Norman, Lucy</td>
<td>Pond 2008</td>
</tr>
<tr>
<td>Referral to psychogeriatrician for assessment</td>
<td>Fran, Wendy, Sara, Glenda, Olive, Betty, Kerrie, Janet, Lucy</td>
<td></td>
</tr>
<tr>
<td>Causes - signs &amp; symptoms</td>
<td>Yvonne, Sara, Glenda, Olive</td>
<td>McKeith 2005</td>
</tr>
<tr>
<td>Supportive features</td>
<td>Yvonne, Ruth, Wendy, Betty, Kerrie, Janet</td>
<td>McKeith 2005, Tolosa 2007</td>
</tr>
<tr>
<td>Pathology</td>
<td>Sara, Norman</td>
<td>McKeith 2005</td>
</tr>
<tr>
<td>Discussion concept or topic in synthesis</td>
<td>Research participants who mentioned topic</td>
<td>Significant research literature – cited previously by 1st author &amp; year</td>
</tr>
<tr>
<td>----------------------------------------</td>
<td>------------------------------------------</td>
<td>---------------------------------------------------------------</td>
</tr>
<tr>
<td>Suggestive features</td>
<td>Yvonne, Fran, Wendy, Glenda, Olive, Trudy, Betty, Kerrie, Norman, Janet, Lucy</td>
<td>McKeith 2005</td>
</tr>
<tr>
<td>Impact on family</td>
<td>Yvonne, Ruth, Fran, Wendy, Sara, Olive, Betty, Kerrie, Norman, Janet, Lucy</td>
<td></td>
</tr>
<tr>
<td>AD / DLB dementia</td>
<td>Ruth, Fran, Glenda, Olive, Trudy, Betty, Janet, Lucy</td>
<td>Villemagne 2009</td>
</tr>
<tr>
<td>Subcortical dementia</td>
<td>Yvonne, Ruth, Glenda, Olive</td>
<td>Collerton 2003, Montoya 2006</td>
</tr>
<tr>
<td>Knowing</td>
<td>All</td>
<td></td>
</tr>
<tr>
<td>Requiring prompting with names</td>
<td>Yvonne, Wendy, Glenda</td>
<td></td>
</tr>
<tr>
<td>Relinquishing care</td>
<td>Ruth, Fran, Glenda, Olive, Trudy, Betty, Kerrie, Lucy</td>
<td></td>
</tr>
<tr>
<td>Motor deficits</td>
<td>All</td>
<td>McKeith 2005</td>
</tr>
<tr>
<td>Nocturia</td>
<td>Yvonne, Ruth, Fran, Sara, Glenda, Trudy, Betty, Kerrie, Norman, Janet, Lucy</td>
<td>Ransmayr, 2008, Sakakibara, 2005</td>
</tr>
<tr>
<td>Exhaustion</td>
<td>Yvonne, Fran, Sara, Glenda, Olive, Betty, Kerrie, Norman, Janet, Lucy</td>
<td>Black 2004</td>
</tr>
<tr>
<td>Progressive nature of DLB</td>
<td>Yvonne, Ruth, Fran, Glenda, Olive, Trudy, Janet</td>
<td>McKeith 2005</td>
</tr>
<tr>
<td>Severe neuroleptic sensitivity</td>
<td>Ruth</td>
<td>McKeith 2005</td>
</tr>
<tr>
<td>Dread of hospital admissions</td>
<td>Yvonne, Ruth, Fran, Glenda, Janet</td>
<td>McKeith 2005</td>
</tr>
<tr>
<td>First classified 1996</td>
<td></td>
<td>McKeith 2005</td>
</tr>
<tr>
<td>Inability to let go</td>
<td>Ruth, Fran, Sara, Glenda, Trudy, Betty, Kerrie, Janet</td>
<td></td>
</tr>
<tr>
<td>Support family &amp; friends</td>
<td>All</td>
<td></td>
</tr>
<tr>
<td>PV</td>
<td>Yvonne, Olive, Trudy, Kerrie, Norman</td>
<td></td>
</tr>
<tr>
<td>AAV</td>
<td>Yvonne, Fran, Wendy, Trudy, Betty</td>
<td></td>
</tr>
<tr>
<td>Time to answer</td>
<td>Glenda</td>
<td></td>
</tr>
<tr>
<td>Insight</td>
<td>Ruth, Fran, Wendy, Glenda, Trudy, Betty</td>
<td></td>
</tr>
</tbody>
</table>
8.5 Research Participants’ Reactions

All the research participants were invited to a session to view the DVD and learn about the research outcomes. Seven participants attended together with three adult children. Two other participants who were unable to attend on the nominated day requested to view the video at a later date. During the presentation I was conscious of a few sniffles and on a couple of occasions there was a spontaneous outburst of laughter. At the end I found the absolute silence to be quite unsettling. It was broken by one participant who in a quavering voice remarked: *that was my life*. As others agreed I commented that I was very aware of particular segments of my story belonging to individual research participants and a lively discussion followed as those present claimed ownership.

Accepting that every aspect of DLB could not be covered in 25 minutes, the research participants who have seen the presentation wholeheartedly endorse it as a valuable educational resource with many commenting that they wished they had had access to it, or something similar, years ago. They encouraged me to promote it actively and increase awareness of DLB throughout the community. Several participants even offered to facilitate opportunities for me to present it within their local communities.

Recognizing the subjectivity of any creative work, it was gratifying to have the synthesis endorsed by those whose story I was encapsulating. With their endorsement I am confident that I have captured the essence of caring for a person with DLB at this time. Hopefully aspects of the experience will change with awareness and education.

8.6 Implications for Practice

A significant motivator for embarking on this doctoral study was a personal lack of knowledge about DLB. My first task was to ascertain if the knowledge was out there but not easily accessible. Almost three years after that first search, a Medline query on “DLB” raises 1,929 hits (“dementia” 63,815 hits) but when the search is refined to include “carer” it collapses to three. Through my research I now understand why this is so and I recognize that my challenge will be to ensure “wide dissemination of [my] findings to effect changes in community awareness, clinical practice and health policy” (Draper et al., 2009 p.S72). It could be argued that this is a completely unrealistic expectation for an emerging researcher in psychosocial research. I will say more on this
point in the next chapter but there is a critical need to raise the profile of DLB. The creative synthesis as an AV presentation has the potential to be a useful educational resource. Throughout the last three years I have taken every opportunity to use my skills as an adult educator and share my knowledge. To date these opportunities have utilized the traditional paper, poster and Powerpoint techniques which have been adequate for the background information but are insufficient when presenting the voices of others.

A united voice of the carers’ focus group was that government, doctors, carers (family and professional) and the general public all need to be educated about DLB. For me, who came to this study from fields that should have afforded opportunities to at least be cognizant of some of the research on DLB, I now see that I was not alone in my ignorance. The experience of caring for a person with DLB is complex and challenging. It is also confused by perceptions of the nature of Parkinson’s disease and dementia. In order to redress this situation messages about DLB, and its impact on carers, need to be disseminated in a way which is accessible, particularly to those who are not readers of research journals, the traditional method of research dissemination. This is my challenge as I look beyond this study. There is an increasing expectation, particularly in dementia research, that the researcher should be both a knowledge producer and a knowledge broker – potentially the dedicated expert (Draper et al., 2009; I. D. Graham et al., 2006). Although Draper and his colleagues demonstrate that there is considerable argument about what are the most effective knowledge transfer strategies applicable for disseminating dementia research to the divergent groups of service providers, consumers and the public, I believe this synthesis will enable me to start the process.

The creative synthesis is the culmination of the heuristic journey. The DVD provides insights and a perspective on the caring experience, however understanding an experience does not necessarily change attitudes or effect societal change. In the next chapter I discuss the implications of acknowledging DLB and its emergence as a significant health issue.
Chapter 9  
DLB: Challenges for Policy and Practice

What is the experience of caring for a person with dementia with Lewy bodies? When I started to explore this question there were four subsidiary questions that I thought would focus my attention and give me direction:

1. To what extent do carers’ perceptions of impairment provide evidence for the differential diagnosis of DLB?

2. How do carers’ perceive and experience the changes in their relationship with the person being cared for and with others from the onset of change until diagnosis?

3. To what extent does knowledge impact on perceptions of the experience of caring?

4. What are the implications for carer support services?

However, as I interacted with the research participants, and analyzed the data from their interviews, these questions merged into the central question. Now, as I reflect on the experience of caring for a person with DLB, and ponder the implications of that experience, some of these questions once again have salience. They provide a structure through which I can interpret my new understandings of the issues that surround caring for a person with DLB and examine how others handle and modify the presence of DLB as an emerging health issue. Those aspects are concerned with knowledge of DLB, diagnostic issues, matters that transcend the intimate relationships explored in previous chapters and the impact these issues may have on carer support services.

9.1 Knowledge of DLB

When I tell people about my topic, a common reaction is: “Dementia with what?” To a degree that was also my initial reaction, and the motivating force for exploring the experience of caring for a person with DLB. However in doing so I have found that, in comparison to AD and PD, very few people have any understanding of DLB and the effect that it has on the people diagnosed with it and their carers. Moore contends that:

public attitudes to disease are important, because they shape the context in which the ill person and their families and carers must live (S. Moore, 2006b p.15).
DLB has been a disease entity for 15 years yet there appears to be little recognition of it within the medical and allied health professions outside the specialist domains of geriatrics and psycho-geriatrics. One specialist’s comments about the lack of a reference for AD in his 1970s medical texts reminded me that, although my topic is novel, the situation is not unique and, even in the medical world there is resistance to adopting new perspectives. Carers in this study expressed difficulties in relation to dealing with neurologists, whom I would have thought would be well versed in the DLB/PD debate. I wondered if this was an artefact of sample size and co-incidence, in that several carers mentioned the same neurologist, so I was interested to hear the following comments in the specialist’s focus group (SFG):

- *Probably half the patients I diagnose are referred to me by neurologists who say: ‘I have this patient who has got PD and now he is seeing these funny little creatures, so can you check’. So some neurologists are switched on and are open minded (SFG:7.3).*

- *I have got an advanced trainee who is really very good but he trained in [an Australian city] and his supervisor there didn’t really believe that DLB existed. So consequently the trainee had never seen a case. I am sure he had but it just wasn’t recognized (SFG:7.2).*

The specialists felt confident in their strategies to educate medical students: *I teach [them] that there are three things about diagnosing DLB and I think that is getting through to them* (SFG:14.6), but lamented about seemingly insurmountable problems associated with up skilling in general practice: *wouldn’t recognize it [DLB] if they fell over it— the average GP*(SFG:9.2). Several specialists remarked that although there are always interested general practitioners (GPs) who attend seminars, invariably they were always the same faces. Also, there are reduced opportunities for GPs to learn about DLB because funding for some aged care/GP networks within the divisions of general practice has been cut. Traditionally these networks have instigated much of the professional development activities.
A pilot study, recently reported on by a fellow Alzheimer’s Australia Research scholarship recipient, concluded that most people acquired their knowledge of dementia from acquaintances and the media, although if they were concerned about their memory, they would visit their GP (Millard, 2009). It appears that routine screening is not actively promoted by GPs and in an effort to address this situation instruments are being developed for GPs to determine whether their patients wish to be routinely screened for dementia, specifically AD (Boustani et al., 2008). However, if the general public, because of their perceptions of dementia, memory loss and PD, and the majority of GPs do not have DLB on their radars, health screening and routine visits to the local doctor may not necessarily expose people with early DLB. In this study it was invariably the spouse who agitated for assessments and second opinions, at times in defiance of both the “patient” and the doctor, and, according to one of the specialist participants, it would seem that carers’ quests for answers are not atypical:

we get this all the time, that the patient, or carer, says
they have to argue for a long time with their health
professional before a diagnosis was made, usually by a
referral on (SFG:6.3).

Earlier, in acknowledging the homogeneity of my sample, I raised concerns about those with DLB who do not have spousal carers. These concerns intensified when one specialist remarked my bet is that this group is an unusual group in that they have all got a carer, and it hasn’t been a diagnosis that hit people, they have had to push (SFG:6.5). Nonetheless, I do not know if a non-resident family member or friend would easily identify the early signs of DLB – the indications are that they would not - but evidence from this study indicates that more community awareness of the mere existence of dementias such as DLB and fronto-temporal lobar degeneration (FTLD), that do not involve memory loss, would be beneficial.

Raising this opinion in the SFG sparked a lively debate about who should be educated and how that might be achieved. One specialist considered that educating the general public was too daunting: it is hard to educate the general public about something we can’t educate the GPs about (SFG:14.4), whilst another suggested that having the public acknowledge dementia in its broad terms was sufficient:
It is difficult to know to what extent you can educate the general public about the finer points. Just to have the general public being aware that dementia is a public health issue and that if someone has got cognitive problems they should be taken for assessment that I think is a worthy goal………..the reality is that public education tends to be painted in broad brush strokes - differentiating…I think these messages are too complex to get out (SFG:13.11).

The use of the Internet was acknowledged by the specialists as a resource for information: people who are net savvy are probably more than capable of accessing information from overseas and there are good web based resources out there (SFG:11.8). I concur with the comments about accessing the Internet, as that was a finding of the study; a finding supported by research which suggests that people who access online health information are tertiary educated women, under 65 who are experienced online users (Leaffer & Mickelberg, 2006). However, it appears that the Internet was accessed when the carers were well into their caring journeys, and when they were not satisfied with either the diagnoses or information being provided - sometimes to the embarrassment of the specialists:

I had a patient recently and I suddenly put it together. The patient was in a rehabilitation centre and I thought likely to have DLB. Nobody had thought about it, or presented it as such, but at the family meeting I said look I think this is DLB. The family said: ‘yeah we have worked that out’. [They] hadn’t told the doctor that they had worked out the diagnosis (SFG:6.1).

Would the general public be as resistant to new information as was suggested? The campaign to have dementia recognized as a significant health issue has been very successful, so much so that everyone who loses their keys, or forgets something, is either concerned for their own wellbeing or mocked by others. That campaign was, to a significant degree, an initiative of Alzheimer’s communities worldwide, supported by
consulting specialists however there are numerous health campaigns which aim to educate the public to early signs and symptoms. Admittedly, many of these have significant public health implications in that they have infectious (swine flu) or preventable (obesity) components, but all have the consistent message that accurate assessment and diagnosis is vital. It is suggested that online access is “changing the patient–doctor dynamic for good, and mostly for the better” (Leaffer & Mickelberg, 2006 p.54) but even when there is accessible information on the Internet regarding the different forms of dementia, it appears that dementia and AD are seen as the same condition, as evidenced by the remarks of one of the specialists:

I think really relatives just want to know if it is dementia and some of them will ask about the different forms of dementia because they have been on the internet and they will know a bit, but really they just want dementia – I commonly get asked about dementia and AD! (10.6)

Unfortunately, it appears from the literature and the data that DLB has yet to develop a strong professional profile and, as a consequence, no medically informed public profile, yet the carers in this study and the specialists agree that early and accurate diagnosis is important.

9.2 Diagnostic Issues

It is clearly evident that the people in this study knew something was wrong with their spouses and wanted help to diagnose, treat and manage the medical condition that was present, be it dementia or PD. There are some insights into the difficulties GPs face in dealing with dementia. Some can not see the benefit in diagnosing dementia because they do not consider that a diagnosis assists the patient or that the medications available are helpful (Hansen et al., 2008). As well, in the opinion of the SFG, GPs do not have the skills to interpret the screening tests, if they do them. Furthermore, the MMSE, the most widely used screening test, is an optional component of the recommended Older Persons Health Assessment (Pond, Magin, & NICE, 2008) and has been shown to be unreliable in culturally and linguistically diverse and poorly educated populations (Brodaty et al., 2006).
There are medical advocates who are striving to improve practice and raise the DLB profile. As an example the General Practitioner Assessment of Cognition Tool, (GPCOG) (Brodaty et al., 2002) has undergone further development and, as part of the Australian Government’s Translating Dementia Research into Practice initiative, is now available on line (www.gpcog.com.au) in eight languages. The test can be quickly administered and, if cognitive impairment is indicated, the GP is provided with a list of recommended investigations and asked to refer to the national guidelines (Bridges-Webb, Wolk, Pond, & Britt, 2003). The guidelines alert GPs to the possibility of DLB and the dangers of prescribing antipsychotic drugs. Nevertheless, changing GPs’ practices in relation to the assessment and differentiation of the dementias is seen, by the specialists in the study, to be a challenge:

Let’s be pragmatic about it. Do we need separate screening tools for DLB and fronto temporal or can we better utilize the only tools being used at the moment including the MMSE? It is not going to change in the next five years [using the] MMSE plus clock, so maybe the message we should be getting out to GPs is look at the pattern! It would be a big step, but look at the pattern and if their short term memory is relatively preserved, their attention might be down, ie remembering the words, and then they have trouble with the clock and the intersecting pentagons - it might be DLB (SFG:9.7).

The consensus was that a referral to a specialist should be considered more readily:

I think the message is think about cognition and assess it and if you are in doubt send them on (SFG:9.8).

If you really think that a person has got problems, but the MMSE is not showing it, get a second opinion (SFG:9.9).

Diagnosing PD is also problematic, even in specialist movement disorder clinics (Caslake, Moore, Gordon, Harris, & Counsell, 2008; K. S. Taylor & Counsell, 2006). In the United Kingdom, the National Institute for Clinical Excellence (NICE) guidance
notes recommend that GPs should refer people they suspect of having PD to specialists for assessment and diagnosis (A. Moore, 2006a). In contrast, or perhaps as an adjunct, the Parkinson’s Association in Australia recently launched an e-learning professional development program for GPs to improve their skills in PD diagnosis (Parkinson's Australia, 2009). As well as the six hour full course, there are extra resources, case studies and a frequently asked questions (FAQ) section. All and any information is useful, but as I worked through the program I became increasingly frustrated over what I viewed as a lost opportunity to educate GPs about DLB and raise its profile. For example, in the FAQ Advanced Management section I found the conclusion to the question: “Will all patients with idiopathic Parkinson's disease develop dementia?” quite discouraging in that it suggested that a person’s inability to construct the intersecting pentagons from the MMSE (an indicator or visuo perceptual deficits) may be a simple ‘bedside’ assessment [that] could be used as a screen for initial reassurance, or indeed as a predictor of poor prognosis (Parkinson's Australia, 2009). (See Appendix 8 for the complete answer.)

Patient confidentiality and privacy also have the potential to impede GPs utilizing input from a family member in the assessment process. My initial query was: do carers’ perceptions of impairment provide evidence for the differential diagnosis of DLB? It was my intention to recruit a large sample of carers of people with dementia and PD and use the questionnaire to isolate those who may have been caring for a person with undiagnosed DLB. However, although this approach was rejected for ethical reasons, the question lingers. In discussing the results of the questionnaire (Table 6.3 p.94) with the specialists, they were sceptical:

You will have a lot of trouble interpreting them unless you get another group who do not have DLB and see whether they actually do stand out as different or are these just symptoms of old age (SFG :4.3)

and also tantalized:

it would be interesting to compare this table to exactly the same number of AD and another group of PD because
there is all this discussion that LB is on this continuum (SFG:4.4).

If the results were reproducible in a larger study then potentially being aware of the criteria and asking the right questions may facilitate diagnosis or referral to the appropriate specialists. McKeith (2009), an acknowledged researcher of DLB, stated in a webinar hosted by Alzforum in June 2009 that DLB is a common disease, but for every person correctly diagnosed there are two or three people not diagnosed or misdiagnosed, even though there are established diagnostic criteria available and the criteria are predictive of Lewy body pathology in 90% of cases (McKeith et al., 2005). In terms of predictive criteria, one specialist commented:

*I mean if someone came along to me and said my husband is having violent dreams just about travelling out of bed, he’s seeing little creatures outside the window and he is finding it difficult to turn the tap on I’d say yeah, there could be something going on here* (SFG:4.7).

9.2.1 Medication Management of DLB

The specialists in the focus group voiced strong opinions that early and accurate diagnosis was important for medication management suggesting that people, once diagnosed, wanted to know if any drugs would help. The carers in this study frequently made mention of the medications prescribed for their spouses, whether the dosages should be changed and, particularly where PD was an initial diagnosis, conflict with specialists. I mentioned in my introductory chapters that pharmacology was not an area I intended to explore in depth, however from my review of the literature and the data there are three areas of medication management that are consistently highlighted. These are associated with neuroleptic sensitivity, the use of cholinesterase inhibitors and the efficacy of PD medication.

**Neuroleptic Sensitivity**

Understanding that severe neuroleptic sensitivity is a suggestive feature of DLB (McKeith et al., 2005) and that people suspected of having DLB should never be treated with neuroleptics is an important message for treating practitioners and carers, both
informal and formal. Although it is difficult to ascertain how many people are unwittingly exposed to potentially harmful medications, it is acknowledged that there are risks associated with many drugs. The rather alarming headline, ‘The NHS must stop killing dementia patients with drugs’, that accompanied the release of the Banerjee report into the use of antipsychotic medication in the United Kingdom (UK) (Banerjee, 2009), highlights the problem. The report estimated that there are some 1800 deaths of people with dementia per annum directly attributable to these medications – a situation that according to the government’s response is totally unacceptable.

We do not have comparable figures for Australia, but according to one of the specialists in the focus group, even people with a DLB diagnosis are vulnerable in our hospitals:

In hospitals for those who have been diagnosed, and that is the minority, you could have stickers on top of the file like allergies. You could have a DLB sticker saying ‘careful with antipsychotics’ because every year you have a couple who die because this is ignored (SFG:14.2).

The US Food and Drug Administration released several public health advisories in 2008 alerting prescribers to the potential of deaths with inappropriate antipsychotic drug treatment, both conventional and atypical, (FDA, 2008). Also there are pilot programs aimed at reducing the use of sedatives and antipsychotics in Australian care facilities (National Prescribing Service Limited, 2008a; Westbury, Shane, & Peterson, 2009) and there is information about the drugs of concern and their effects readily accessible on the internet (Alzheimer's UK & McKeith, 2008; J. E. Galvin et al., 2008).

However, the dissemination and uptake of this information relies on two things: firstly, that there is a diagnosis, or even a suspicion of DLB; and secondly, that the message is patent and consistent, particularly from authorities which are assumed to be credible. The handout notes from a 2009 interactive workshop, run by the Australian National Prescribing Service Limited (NPS) on treating symptoms of dementia, is a case in point. Handout notes are invariably the take home messages of educational activities and are designed to be a reference for future use. The notes in question list the conventional (Serenace, Haldol, Largactil and Stelazine) and atypical antipsychotic drugs. Then there
is a list of behavioural and psychological symptoms of dementia that do not respond to antipsychotics. This list contains many of the behaviours commonly seen in people with AD, including sundowning, shadowing and wandering. That list is followed by another list of behaviours that are most responsive to the drugs. The list has three lines:

- Physical aggression and violent behaviour
- Psychosis (hallucinations and delusions)
- Aggression.

There is no mention of DLB on the handout. Other NPS material contains sentences such as: “severe sensitivity reactions to conventional antipsychotics also occur in patients with Lewy body dementia” (National Prescribing Service Limited, 2008a p.7) but the messages are not loud or particularly clear.

Alerting the general public about the inappropriate prescribing of antipsychotic medication for people with DLB is a priority for the Lewy Body Dementia Association Inc. of America (LBDA). I was advised by email as part of a subscription to the LBDA that it was using a significant donation from the John W. Blankert LBD Memorial fund to develop and screen a 30 second television commercial. The screening was incorporated into a nationally viewed Pro Football parade to ensure a prime time audience of 81 million households. The advertisement, which was able to be viewed for a short time on YouTube, focused on the dangers and adverse side effects of these medications.

One of the most challenging tasks in providing appropriate information is keeping track of the latest research and translating that research into practice. An example is the information contained on web pages accessed in December 2009. Alzheimer’s Australia’s January 2007 Update sheet entitled “Risperidone (Risperdal). What is it?” describes the drug as an antipsychotic medication which is listed in Australia for the treatment of behavioural disturbances characterised by psychotic symptoms and aggression in people with dementia. Within the sheet there is a warning that extreme caution should be exercised in prescribing the drug for people with DLB. In the Current Issues paper on the LBDA website the following warning is given:
Typical neuroleptics (such as haloperidol) and atypical neuroleptics with D2 receptor antagonism (such as olanzapine and risperidone) should be avoided due to the risk of severe neuroleptic sensitivity reactions, neuroleptic malignant syndrome, parkinsonism, somnolence and orthostatic hypotension (J. E. Galvin et al., 2008 p.7).

On the Risperdal website (2009) the first safety warning reads:

*Elderly Patients with dementia-related psychosis treated with atypical antipsychotic drugs are at an increased risk of death compared to placebo. RISPERDAL ® (risperidone) is not approved for the treatment of patients with dementia-related psychosis.*

http://www.risperdal.com/risperdal/

The biggest dilemma is the at-risk population of people who have been admitted to nursing homes through the social model of referral to ACAS rather than through the medical model. If DLB is not listed as a possible diagnosis and the staff are not aware of the potential for DLB as a diagnosis, then avoiding adverse drug reactions and possible deaths is problematic.

**Cholinesterase Inhibitors**

On a more positive note, the medication of choice for people with DLB appears to be the cholinesterase inhibitors (ChEIs) (sometimes referred to as acetylcholinesterase inhibitors (AChEIs)) approved in Australia for the treatment of AD. The evidence for this is not gold standard because DLB is not a diagnostic category in the DSM-IV. This limits the ability of international pharmaceutical companies to allocate funds to conduct major randomized controlled drug trials. From the trials that have been conducted the Cochrane Review, as of 2008, is ambivalent (Wild, Pettit, & Burns, 2003), however in the opinion of Galvin (2008), there is no doubt:

*ChEI’s have been considered by LBD experts to be the gold standard in treating cognitive and psychiatric symptoms of LBD. A recent comparative analysis of independent clinical studies of ChEI’s in LBD*
demonstrated all ChEI’s significantly improved cognitive and neuropsychiatric measures and that there was no significant increase in United Parkinson’s Disease Rating Scale (UPDRS-III) scores. However, the study revealed no compelling evidence that supports any one ChEI as better than any other in treating DLB (J. E. Galvin et al., 2008 p.9).

It would seem that ChEIs are more effective in the treatment of DLB than AD and the specialists in the focus group were strongly supportive of prescribing this class of medication for everyone with DLB: the fact is there are drugs that work in some domains and they should be tried (SFG:16.7). From the information provided, only eight of the research participants’ spouses were prescribed ChEIs, with donepezil (Aricept) being the most common. All had marked positive responses, particularly in their levels of alertness.

But prescribing this class of drug for people with DLB poses added difficulties. The Australian National Prescribing Service states:

\begin{quote}
The cholinesterase inhibitors (donepezil, galantamine, and rivastigmine) and the N-methyl-D-asparate (NMDA) memantine, are approved for use in Alzheimer’s disease. These drugs are not approved for any other type of dementia (National Prescribing Service Limited, 2008b p.1).
\end{quote}

This situation leaves two options: (1) prescriptions not covered by the Pharmaceutical Benefit Scheme, an unpalatable choice for most people; or (2) adjustments to the diagnosis to meet the prescribing criteria. The first option may not be of ongoing concern as Aricept, the most widely used ChEI, is manufactured by Pfizer and its patent expires in 2010. Generic versions of donepezil may come onto the market at a competitive and affordable price.

The second option is more contentious. There are valid reasons for arguing that AD pathology is concomitant with DLB pathology (McKeith, 2009; Villemagne et al.,...
yet, for most, that argument is academic. In reality a person is given the DLB diagnosis and then told that, for prescribing purposes, they have AD. How to address this issue was a topic of hot debate at the specialists’ focus group, but all agreed that there needed to be a way of ensuring that people with DLB were given the opportunity to have the medication. At this point in the discussion in the focus group I related the situation experienced by one dyad where their specialist had not discussed ChEIs as a treatment option. For an unrelated reason the family sought a second opinion and were subsequently prescribed Aricept (with positive results). On returning to their specialist he commented that he was pleased they had found someone who would prescribe the medication as he was unable to do so (7:27.6). In response the specialists reacted quite vehemently and the conversation ran thus:

*I would be distraught if there were people who are not getting cholinesterase inhibitors because they could not find a prescriber who would give them a cholinesterase inhibitor. That would upset me.*

*Let’s be honest there are a huge number of people who aren’t getting it any way because they don’t present.*

*I would hope that we can set up a resource line where they learn that it is possible to get these drugs*

When I interjected: ‘but you see the patient has no idea that it may help’, a specialist replied:

*That’s the issue isn’t it (SFG:15.13-16.5)*

Sadly that is the issue and until the rates of correct diagnosis improve and people are aware that these drugs are beneficial they will only be prescribed to a fraction of those who could benefit.

**Parkinson’s Medication**

The popular PD literature is littered with references to medication management. A positive reaction, improvement in motor function, to levodopa (Ldopa, Sinemet, Madopar) is considered the “gold standard” treatment for the early stages of the disease and the “gold standard” diagnostic test. Pamphlets on available medications,
progressions in the use of those medications, strategies to deal with the on-off phases of
dropping blood concentrations of the medications and common side effects are readily
available (Parkinson's Victoria, 2008b) and the public, particularly those affected by PD
are encouraged to access them. Despite the apparent reluctance of the PD community to
acknowledge, let alone embrace, DLB, I cannot help but wonder if, in some people,
some of the listed side effects of PD medications, such as confusion and hallucinations,
are indeed side effects or rather missed diagnostic criteria for DLB - a thought also
voiced by one of the specialists: *a lot of people on Ldopa will get visual disturbances,
so is that just unmasking DLB or is it a side effect of the medication?* (SFG:7.4)

The DLB literature is clear – people with DLB respond sub-optimally to
antiparkinsonian drugs (Burn, 2006; J. E. Galvin et al., 2008; McKeith & Gauthier,
2006). This was borne out by the experiences of the research participants, some of
whom had heated debates with their PD specialists about medication compliance.
According to one of the specialists, there appears to be a place for minimal doses of
levodopa, a dopamine replacement therapy, both for the amelioration of physical
symptoms and, potentially, as a diagnostic indicator:

*Most clinicians would try levodopa and a failure to respond would not surprise. I would suggest that before a diagnosis has been confirmed a failure to respond should alert you to the diagnosis but some do respond and it is really dependent on where the pathology is*  (SFG:8.1).

The PD community promotes further classes of medications for people with PD once
the effects of levodopa wane. The actions of these other drugs are more complex. Like
the ChEIs, research into the efficacy or otherwise of antiparkinsonism drugs is
hampered by the lack of large controlled trials in DLB, but the message promoted on
the LBDA web site seems unambiguous for both lay people and professionals:

*There are no clinical trials on the best treatment of motor features in LBD[sic]. However, levodopa is generally the first-line treatment of PD and some improvement is seen in motor function with levodopa therapy in most cases of LBD(sic). There is a risk, however of provoking*
behavioural or psychotic symptoms ….. Other PD medications such as amantadine, COMT inhibitors, MAO inhibitors and anticholinergics have the risk of exacerbating cognitive impairment and should be avoided if possible (J. E. Galvin et al., 2008 p.9).

Medication management is a topic of discussion included in education forums presented by both AAV and PA. In future educative activities I contend that there are three messages that can and should be stated very succinctly to help raise awareness of DLB within the health professions and the general public. These messages are:

1. Antipsychotic medications should not be prescribed.

2. Dementia drugs (cholinesterase inhibitors) may help and should be trialled.

3. Antiparkinsonian medication may not be all that effective.

However what is critical is getting a diagnosis, if indeed someone is proactive enough to push for one. If the medical model is pursued then there is a tension between diagnosing dementia or PD, a situation influenced by the presenting symptoms and, consequently, the referral patterns of ill-informed GPs. It is worth noting that the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-V) is due for release in 2013. Early reports indicate that there will be a significant reclassification of the neuro-cognitive disorders by aetiology and that DLB will be classified under the Lewy body disease group. One positive suggestion is that memory impairment would not be necessary for diagnosing either a minor or major neuro-cognitive disorder (APA, 2008). This release may afford a significant professional development activity for the medical profession.

In the specialist focus group when I asked whether getting a differential diagnosis within the dementia milieu was all that important, the specialists agreed that it was. However, the reasoning of one specialist indicated that, perhaps, some specialists’ remain focused on the assessment and diagnostic phase of the disease and unaware of some of the subtleties of the impact of DLB on families:
Well, at end stage in a nursing home it doesn’t matter if they came through Alzheimer’s, DLB or fronto-temporal lobar degeneration. It doesn’t matter, but in the early stages its got huge implications with respect to treatment, what areas you are going to be managing: prognosis, planning, driving (SFG: (9.2).

Certainly those early implications are critical, but as this study has shown they are only a small part of the caring experience.

9.3 Beyond Relationships

In Chapter 7 I explored three issues raised consistently by the carers as creating additional concern and burden within their caring roles. These are driving, continence management and alternative care options. Although these issues are not unique to carers and people with DLB, this disease challenges us to consider them in the broader context of policy and practice.

9.3.1 Driving

Driving is a complex skill and, like any skill, is a tripartite construct of learning in the cognitive, affective and psychomotor domains (Nicholson, 2007). DLB compromises each of these domains. In the introduction to a discussion paper on older drivers, the NSW Road Traffic Authority states that:

 Older drivers are over-represented in pedestrian fatalities and have a greater chance of being killed when they are involved in a motor vehicle crash. Dementia and vision problems are likely to be the most significant health issues affecting the future generation of older drivers (Road Traffic Authority NSW, 2007).

In contrast to most European countries and a number of Australian states and territories, Victoria does not require its older drivers to have either a medical test or a driving test in order to renew their licences (Road Traffic Authority NSW, 2007). Instead, Victorian drivers are issued with three year licences once they are 75 years old and are provided with a comprehensive booklet that contains a checklist that focuses heavily on
intersection, roundabout and lane changing issues. The checklist accommodates both the driver and the passenger’s assessment (Vic Roads, 2008).

The Victorian handbook continues with a discussion about the responsibility of ensuring capability and suggests older drivers should discuss any concerns they may have with their local doctor. From a medical perspective, there appears to be no requirement for mandatory reporting tagged specifically to a diagnosis of dementia in Australia or elsewhere. In a couple of American states reporting is mandatory, although reporting does not automatically exclude a person from driving (Rapoport et al., 2007). The universal stance suggests that receiving a diagnosis of dementia does not mean that a person should cease driving (Berndt, Clark, & May, 2008; Lukas & Nikolaus, 2009; Rapoport et al., 2007). This view is supported by Alzheimer’s Australia (Alzheimer's Australia, 2004) and is also the rationale used within the PD communities (Parkinson's Australia, 1999; Parkinson's Disease Foundation, 2005) although there is some evidence to suggest that Australian GPs would argue against such a stance with forty-four percent of respondents (N=485) in one study believing that “a diagnosis of dementia is sufficient justification to recommend driving cessation” (Snellgrove & Hecker, 2002 p.210).

Whilst the research communities contemplate the relative merits of neuropsychological tests, on road versus off road assessments and the contribution of each domain to ‘safe driving’, the reality is different. A recent retrospective medical review of the adherence of Canadian GPs to that country’s recommendations for dementia assessment is a case in point. The study found that over a four year period 160 people were diagnosed with dementia. Of those only 57 had a notation of driving safety in their records and of those, 25 were referred for formal driving assessment (Pimlott et al., 2009). The overall situation is expressed well by the authors of a systematic review of dementia, driving and risk:

Drivers with dementia are poorer drivers than cognitively normal drivers, but studies have not consistently demonstrated higher crash rates. Clinicians and policy makers must take these findings into account when addressing issues pertinent to drivers with a diagnosis of
This study has shown that the carers of people with DLB are conscious that their spouses are having difficulty driving very early in the course of their disease. How they negotiated the cessation of driving varied as did people’s reactions to that loss. Research indicates that the deficits experienced by people with DLB are those that impact on driving ability. A major finding of a study which assessed driving in a sample that contained people with AD, PD and healthy controls, found that “unsafe driving was related to performance on measures that involve visuospatial and executive components” of cognition (Grace et al., 2005 p.774). Another study reported that:

- increasing the demand on attentional selectivity resulted in a worsening level of performance in DLB, relative to patients with DAT [AD] and controls, and this effect was most pronounced when tasks were framed within an executive or spatial context (Bradshaw, 2007 p.1134).

In my professional practice, as a physiotherapist and a dementia advisor, I have dealt with the issue of safety and driving in a very practical manner. I ask the question: “Are you comfortable with having your children/grandchildren as passengers?” It always seems to clarify people’s thought processes and allows them to take the necessary steps to assist the person of concern cease driving. The Victorian process promotes honest communication about driving ability and then, if that approach fails, there is a process for reporting concerns about an unsafe driver to VicRoads (2008). From the data obtained from participants in this study it seems that honest communication appears to work with people with DLB.

Further studies to evaluate driving competence in people with DLB are warranted but, like other aspects of managing this disease, awareness of DLB and the impact that it can have on a person has to be understood first. A comment from the specialist’s focus group was that people wanted to know about the three ‘Ds’ – diagnosis, drugs and driving. If driving is a burning issue when specialists assess people, and it takes five years, on average, for those specialist assessments and the diagnosis of DLB to be made, then potentially there are a number of unsafe drivers on the road. If the issue
were to be approached from an occupational health and safety perspective, it would be possible to apply a risk management approach and invoke the ‘reasonably practicable’ paradigm of the OHS Act ("Occupational Health & Safety Act," 2004), that is, what is known, or ought reasonably to be known, about the risk and ways of eliminating or reducing it. Highlighting the nature of the dementia experienced by people with DLB and the impact that it will have on driving in educational activities would not negate the Alzheimer’s Association’s policy statement on driving (Alzheimer's Australia, 2004) or the various Parkinson’s help sheets. However, it may aid decision making and enable carers and people with DLB to manage the risk appropriately and in a timely manner.

9.3.2 Continence

I have come to understand that there is a significant difference in the way in which I understood continence in the presence of AD and the challenges of managing the problem in DLB. The carers in this study provided a number of examples of its presentation and management strategies, yet few people spoke of incontinence (the loss of control of bladder and/or bowel function (Alzheimer's Australia, 2005b)). One dyad was troubled by faecal incontinence, secondary to medication. A number of carers mentioned that their spouses had become incontinent of urine with time, but that appeared to be a relief and easier to manage than the stress of assisting their spouse to maintain continence. The stress of assisting spouses to maintain their continence was significant, resulting in physical injury to the carer, sleep deprivation and depression. It was repeatedly cited as a significant factor in relinquishing care; a view reinforced by the specialists: if you look at the literature on what wears out general dementia carers sleep disturbance comes way up the pile (SFG: 17.3). It is important to emphasize that in this study the stress was associated with maintaining continence not managing incontinence.

As urinary dysfunction, a severe autonomic dysfunction, appeared to be a significant issue in this study, I revisited the literature to ascertain if there were any studies that had investigated this aspect of DLB. Although it is a recognized non motor issue of Parkinson’s disease (Blackett, Walker, & Wood, 2009) there is little research about either the mechanism of urinary dysfunction in DLB or the psyco-social aspects of this symptom. One study (Allan et al., 2006) reports that autonomic dysfunction,
specifically urinary dysfunction, constipation and postural hypotension, is more prevalent in PDD, DLB and vascular dementia patients than either healthy controls or AD patients (all p < 0.05), and that this is associated with poorer outcomes in all measures of physical activity, activities of daily living, depression and quality of life.

Other recent literature reports (Blackett et al., 2009; Sakakibara et al., 2005) suggest that urinary dysfunction is a common feature of DLB. It is not only a result of cognitive deficits and impaired mobility, including over-activity of the detrusor musculature (Ransmayr et al., 2008), but is also a deeper neurological dysfunction of the somato-autonomic pathways (Ransmayr et al., 2008; Sakakibara et al., 2005). When there is urinary dysfunction it manifests as frequency, urgency and particularly nocturia. However, because it can present as an early sign of DLB it is often investigated as a urological problem. One disadvantage of the urological approach is that people are often prescribed anticholinergic medication which can result in increased confusion (J. E. Galvin et al., 2008).

This aspect of DLB warrants further research. Identifying people with DLB and intervening to assist in the management of this issue before entrenched patterns of behaviour, from both the carers and people with DLB, are established demands early diagnosis. It also requires some creative thinking from a multidisciplinary team of carers, continence advisors, physiotherapists, psychologists and dementia specialists to inform the development of innovative programs so that carers can be better educated, prepared and supported. Although much of the information contained in the National Continence Management Strategy (2005) and available from AAV (2005b) is pertinent, it failed to meet the needs of the carers interviewed. I cannot help viewing this problem through my occupational health and safety lens. As well as sleep deprivation, carers are also exposed to a number of manual handling risks. These risks could be mitigated through early interventions such as revamped bathrooms, no pyjama pants and teaching the person with DLB to get into bed like a child (by climbing in rather than sitting on the edge of the bed and then trying to swing their legs up).

From a care perspective, the literature suggests that the functional disabilities of DLB are much greater than those found in other dementias (A. Burns, 2005), care costs are
higher (F Boström et al., 2007a) and carer burden significant (J. D. Davis & Tremont, 2007). The impact of autonomic dysfunction, particularly urinary dysfunction appears to be a major contributor to all areas, not only for informal carers but potentially in care facilities as well.

9.3.3 Alternative Care Options

My personal experience of alternative care is that it is fraught with difficulty. Within the day respite sphere the intrusion by care workers into a person’s personal domain is extremely confronting, particularly when this is compounded by the workers assisting with personal hygiene. To live through being dropped off for day respite, at an unfamiliar location with strangers, can be terrifying. In my father’s case, his abject despondency at relinquishing care of my mother was so great that, against advice, he took her home rather than accept a transition from enforced respite to full time care. Within a week he acknowledged the reality of their situation and recognized that it was time for him to let go. Yet as a carer, my father felt that my mother’s needs were met adequately to extremely well through engaging with the services offered and used. But he had the benefit of additional support; most of his early experience with day and overnight respite was provided by family and friends.

However, the carers in this study reported dissatisfaction with services offered to them. Are there different challenges in the presence of DLB and if so, how, and for whom, do those differences manifest? It is difficult to reach any valid conclusion; particularly as the dissatisfaction expressed by the carers were compounded by their own confusion regarding their spouses’ illness. Intuitively, they knew that services designed for people with either AD or PD were not appropriate, but it seems that they lacked the ability to articulate their concerns and argue for change because of that confusion. When people who appear normal one day are fluctuating, hallucinating or falling the next day, it must also be challenging for service providers to design appropriate programs and assign staff. Regardless of how well the person centred care philosophy (Brooker, 2004; Kitwood, 1997) is promoted, cost and time constraints inevitably encourage the one size fits all, task orientated, approach to service provision. Until there is differentiation in the development of dementia policy, and recognition of the idiosyncrasies of each
presentation so that there is adequate funding for those planning, assessing, and delivering care, changes will be slow.

Nevertheless, an empowered carer can make informed choices and influence others as was demonstrated by Yvonne. At the end of November 2009 I telephoned the carers to ascertain who would be attending the viewing of the DVD. When I called Yvonne she told me that Tony had died in August. He was living at home with minimal services at our last contact in April and I asked what had happened. Their experiences highlight the positive and negative aspects of care options and, with her permission I am able to use them to illustrate the complexities of the issues.

Yvonne is the youngest of the cohort, she has an allied health background, is computer literate and self educated with respect to DLB. In May Tony was admitted to high care respite because of his deterioration and Yvonne’s inability to cope without a break. In respite the situation deteriorated rapidly. The service was not able to meet his care needs and when they were not met to his satisfaction he reacted. For example, when left in a wet, soiled bed for longer than he felt appropriate Tony got up, found some clean linen and another bed and made himself comfortable. Although that incident had a humorous element to it, other incidents did not. In reaction to his behaviour the care facility had Tony sectioned under the Mental Health Act and transferred to a psychiatric unit. After an assessment, a medication review, a family conference and home visits by the psychiatrist and members of the team to discuss the situation with Yvonne they, in Yvonne’s words, came to the conclusion that (other than DLB) there is nothing wrong, he will arg up when his needs are not met, he just wants to go home.

Yvonne managed well for about a month, but only with the constant help and support of a friend, whose husband had died with fronto-temporal lobar degeneration. Her youngest son also returned home on the weekends to provide some respite. Tony was on an extended aged care at home - dementia EACH-D package but his fluctuations precluded appropriate use of services because it was impossible to book a time for personal care or even medical appointments. According to Yvonne, the fluctuations were such that Tony went from being unconscious to walking independently, declaring
that the walking frame was a nuisance and throwing it aside. Consequently, his personal care, hydration and nutrition needs were met on demand.

Towards the end of June Yvonne recognized that Tony’s deterioration was life threatening and she contacted a palliative care service, organized the necessary equipment to facilitate his care at home, and worked with the local doctor to implement an appropriate end of life plan. By the time that service commenced mid July, Tony was immobile and dysphagic but alert and aware when he was awake. He was able to indicate when he was hungry and thirsty, although at that stage he was being sustained on jelly and baby food. For the last week Tony had a morphine syringe in situ and he died at home surrounded by his family. There was never a suggestion that he did not know who they were and where he was and, for Yvonne and her family, that was important.

Her experiences illustrate how the system fails people with DLB if they are not supported by a capable, strong and knowledgeable carer. She expressed concerns about the adequacy of funding and how that was utilized. She explained to me that she became the educator in that she took time to educate everyone involved in Tony’s care about DLB, or more precisely, Tony’s presentation of DLB. This included the palliative care staff, for whom she has a lot of respect and gratitude. Meanwhile, service providers will struggle to offer pertinent services without an understanding of the nature of subcortical dementia, the impact of fluctuations, and the implications of autonomic dysfunction. If, in turn, the providers’ work force is not educated at a minimum to understand that dementia does not equal memory loss, then the services provided will continue to fall short of the expectations of the carers.

Parkinson’s Victoria and Carers Australia’s recent report into the difficulties carers experienced when accessing respite for people living with PD (Spillare & Rebeiro, 2008) makes a number of recommendations aimed at enhancing the experience for all concerned. Medication management was a significant focus of the report however the recommendations concerning the tripartite nature of respite, and the need for good communication exchanges that address care needs, interests and stimulation, are as pertinent to DLB as they are to PD. However, it would appear that an ACAS
assessment may not pick up the subtleties of caring for a person with DLB. This was implied by the carers in the study, as many spouses were initially referred to low care facilities for respite and, whilst in respite, reassessed as requiring high care when the facilities could not meet their needs. Such situations further disadvantage people with DLB and their carers as there is limited funding for high care respite beds in the system.

Funding in the aged care system is complex. In community care it is dependent on the service provided, the EACH-D package being the most generous ($131 per day) and highly sought after. In facility based care, funding has two components: (1) a basic daily fee of $32 for hotel services; and (2) a care component. The care component is a needs matrix of three domains - activities of daily living, behaviour and complex health care. A facility can claim the highest category in the behaviour domain if the person being assessed has a diagnosis of dementia (Australian Government Department of Health & Ageing, 2009). My unsupported assumption is that funding for dementia care is based on an AD view of dementia. The notion that parkinsonian and neuropsychiatric symptoms are cost determinants in AD is relatively new (Murman, Kuo, Powell, & Colenda, 2003) and the first study to investigate comparisons of the cost of care between AD and DLB was undertaken in Sweden in 2007 (F. Boström, Jönsson, Minthon, & Londos, 2007b). The latter study found that overall DLB costs of care (45,800 USD) were twice the costs of AD care (22,200 USD). Using these figures one could argue that an EACH-D package for a person with DLB should be about $260 per day. To achieve that increase there needs to be strong advocacy and a receptive funder. In the current economic climate I doubt funders would listen, particularly if one added that the “costs of care in DLB patients with apathy was almost three times as high as in AD patients with apathy” (F. Boström et al., 2007b p.718). My fear is that even without the figures, care providers will quickly recognize that providing services for people with DLB is not economically feasible or sustainable and the carers will be left to shoulder the burden. This is another area that warrants further studies.

A final component of care to be considered is the palliative care experience. Yvonne directed me to some of the resources that she had found helpful, particularly the Planning for Palliative Dementia Care Resource Guide (de la Perrelle, Obst, & Heard, 2009). This led me to reflect upon my own experience and the experiences of the other
two bereaved research participants, Glenda and Sara. The resource guide espouses a philosophy of care that I found challenging:

> Broadly, the palliative approach is appropriate from the time of diagnosis of a life-limiting condition and throughout the journey until death. It is used to improve the quality of life of people with a life-threatening condition, and families. Philosophically, it is aligned with relationship-centred care and quality dementia care and is best activated when an individual is identified as living with dementia. The palliative approach promotes advance care planning while the individual still has mental capacity to be involved in making decisions for the future (de la Perrelle et al., 2009 p.17).

Whilst the advance care approach is promoted by AAV and was an approach that my own family adopted, I immediately recalled Glenda’s inability to engage with that service because she found the initial intervention with AAV too confronting and without hope. Within the guide the authors present a diagrammatic view of the progression of chronic illness (Figure 9.1). I related immediately to the “prolonged dwindling” representation of dementia however I surmised that the middle diagram would have more resonance with Yvonne, Glenda and Sara. Yvonne’s email confirmed my thoughts:

> Middle one is best match if taken over last 10 year period i.e. episodic "downs". Several hospital admissions, several casualty trips, a couple of "call the ambos" for help, catastrophic reaction / episodes with residential respite care and then very rapid decline at the end.

Accepting that there is evidence to suggest that the death of a person with DLB may follow the chronic illness pathway with intermittent crises rather than one of dwindling does not negate the need for advance care planning. It does illustrate that a different approach in providing support for carers of people with DLB may be required.
Figure 9.1. Chronic illness in the elderly typically follows one of the three trajectories. (Lynn & Adamson, 2003 p.8)

The need for improved education about DLB is a continuing theme of my discussion and of others, as evidenced by the report of the summit which followed the release of the Banerjee report (2009) in the UK. A conclusion from one of the discussions was that “with regard to the causes of dementia it was imperative the public debate moved beyond assuming dementia is only caused by Alzheimer’s disease” (International Longevity Centre UK, 2009 p.24). In order to move that public debate and have DLB recognized socially as well as medically, the role of the support services must be considered.
### 9.4 Support Services

Alzheimer’s Australia and the Parkinson’s Association are the two support services that should have a vested interest in DLB. Each has a different perspective on DLB’s relevance as a disease and this impacts how they promote awareness of DLB within their own spheres, and to wider audiences. They have a similar structure in that they have both national federations and state associations. Although much of the policy direction and advocacy is co-ordinated nationally and the resources shared, each of the state organizations is autonomous. As shown in Table 9.1 the Associations present comparable public profiles (Alzheimer's Australia Vic, 2009; Parkinson's Victoria, 2008a) and offer national services such as Help lines and educational packages.

<table>
<thead>
<tr>
<th>Vision</th>
<th>Alzheimer’s Association</th>
<th>Parkinson’s Association</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>A society committed to the prevention of dementia, while valuing and supporting people living with dementia.</td>
<td>A world without Parkinson’s</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Mission statement</th>
<th>Alzheimer’s Association</th>
<th>Parkinson’s Association</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Our mission, as the National peak body for people living with dementia is to provide leadership and efficacy (sic) policy, services and research.</td>
<td>That all people living with Parkinson’s have access to comprehensive and relevant services, encouraging independence and improved quality of life. We achieve this by providing information, education, advocacy and support services to all those living with this chronic, progressive, neurological condition, their families, carers and allied health professionals.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Brand</th>
<th>Alzheimer’s Association</th>
<th>Parkinson’s Association</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Dementia Expertise with Compassion</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Values</th>
<th>Alzheimer’s Association</th>
<th>Parkinson’s Association</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Respect for all individuals and community</td>
<td>Sensitive to the needs of people living with Parkinson’s.</td>
</tr>
<tr>
<td></td>
<td>Cooperative working relationships</td>
<td>Accountable to our stakeholders and transparent in the way we do business.</td>
</tr>
<tr>
<td></td>
<td>Interpreting</td>
<td>Innovative through valuing new ideas, knowledge, experience and research.</td>
</tr>
<tr>
<td></td>
<td>Innovation, creativity and flexibility</td>
<td>National in our outlook. We are committed to a vibrant, national organization.</td>
</tr>
<tr>
<td></td>
<td>Valuing the contribution of all people involved in our work</td>
<td>Caring for people in the delivery of our services.</td>
</tr>
<tr>
<td></td>
<td>Strength and unity with respect for diversity</td>
<td>We value integrity through acting with honesty and according to our values.</td>
</tr>
</tbody>
</table>
Table 9.1: Public profiles of Alzheimer’s Australia & Parkinson’s Association. Source: 2008 Annual Reports.

Both Alzheimer’s Australia Victoria (AAV) and Parkinson’s Victoria (PV) were established in the early 1980s; AAV by a group of carers, and PV by four women with PD. Since that time both Associations have grown, however AAV has outstripped PV in terms of attracting government funding, other income from bequests and memberships, staffing, volunteers and, as a consequence, the services that it offers. One reason for this is that, currently, eight people are diagnosed with dementia to every one diagnosed with PD in Victoria every day (Access Economics, 2009; Parkinson's Victoria, 2008a). Both PV and AAV staff have been aware of this study from its conception and I met with senior staff of both associations in the latter part of 2009 to inform them of my preliminary results. In those meetings I ascertained whether DLB was a focus in their future planning.

PV’s focus is PD, younger onset PD (YOPD) and PD-Plus (multiple system atrophy (MSA) and supranuclear palsy (PSP)) and this is a significant load for a support service with an income stream of about $750,000 per annum, of which only $200,000 is government grant money (Parkinson's Victoria, 2008a). The current staff consider that PV’s commitment to the DLB community has been met through the development and production of the Parkinson’s and Lewy Body Dementia DVD (Parkinson's Australia & Alzheimer's Australia, 2007). The stance espoused in my meeting was that people with PD, who appear to have early dementia, are referred to CDAMS clinics and PDD is just part of the progressive nature of PD. The interests of the staff also appear to determine the direction of new initiatives with fellowships focusing on YOPD and PD-Plus being taken up by two of the PV staff during 2009.

PV expressed a desire to work collaboratively if AAV developed services for people with DLB. This seeming reluctance to accept DLB into the PD domain by PV, and the Parkinson’s Associations globally, is reinforced, perhaps subliminally, by a wider, more authoritative group coalescing under the banner of “movement disorders”. The provisional program of the 2010 2nd World Congress on Parkinson’s is a testament to this in that the conference topics relating to alpha-synuclein, PD and autonomic dysfunction, PD and cognition, PD and sleep disorders are all listed in the three day
program, whilst DLB is not mentioned once. In an attempt to ignite the debate between the (aged) psychiatric and movement disorder communities, McKeith’s article in Practical Neurology drew some correspondence to which he replied:

Perhaps my plan has been (like Gulliver) to get into the governing bodies of two cultures [psychiatry and movement disorder] in order to help negotiate a settlement between them. I won’t be drawn further on the point but it is a possibility! (McKeith, 2007 p.381)

Fortunately other organizations and conference committees within the PD domain, such as the 7th International Congress on Mental Dysfunctions and Other Non Motor Features in Parkinson’s Disease and Related Disorders, appear to be more inclusive and offer a few avenues to advance research into and awareness of DLB. It could be argued that this lack of promotion of DLB is just a semantic issue, but comments on dementia funding in USA suggest otherwise:

Between 2000 and mid-2007, the National Institutes of Health (NIH) funded 2895 projects directly related to AD including 29 Alzheimer Disease Centers through a number of earmarked funding programs (Source: http://crisp.cit.nih.gov). In contrast, during this same time period, NIH funded only 29 grants directly related to clinical, basic science and educational projects related to LBD[sic]. This disparity impedes progress in LBD research and leaves patients with LBD with a host of unmet needs (J. E. Galvin et al., 2008 p.12).

Even within the dementia communities the profile of this common illness is low. DLB featured in the title of only one paper delivered (by this author) at the 2009 Alzheimer’s Australia Conference (FTLD was the focus of a plenary presentation and PDD was not mentioned) (Alzheimer's Australia, 2009).

AAV is the peak body for dementia advocacy and services and this is reflected in its government funding allocation of $6M (Alzheimer's Australia Vic, 2009). If there was parity between funding for AAV and PV, based on diagnosed cases per day in Australia
(190:25) and using the AAV allocation, PV would gain about $600,000. Even with its current funding, and other income, AAV is exposed to considerable fiscal demands, yet it recognizes the need to ensure that its services are relevant to people living with dementia and their carers. It acknowledges that an entrenched dementia / memory loss / AD mindset within the Association may be counterproductive to service provision for DLB and FTLD clients and is cognizant that, as evidenced in this study, the Association’s name inappropriately reinforces the public mindset to the point of deterring carers from accessing its services. This is a pity because a significant proportion of the information available and the education that AAV provides is as pertinent to informal and formal carers of people with DLB as it is to carers of people with the other dementias.

Whilst it is not my intention to presume to tell AAV how to restructure its offerings, this study illustrates that living with a person with DLB is not the same as living with a person with AD. Communication strategies are different; the physicality of caring is different. The timing of and type of leisure activity that is appropriate, the management of behaviours of concern and continence, indeed most aspects of living with a person with DLB, are different. Yet there is commonality. Carers across the board face peripheral issues that are constant and there are similar legal and financial considerations. A common critical area of need is support in understanding and dealing with the aged care system - what services are available, how does one access them, at what cost and where?

The consensus of the specialists in the focus group was that AAV’s role as the lead support service is secure. As one mused:

\[
I \text{ think if the various dementias got carved off and PA } \\
\text{ looked after DLB, another group looked after FTLD and } \\
\text{ Stroke looked after vascular ……no I don’t think that } \\
\text{ would be good. It should all stay with AAV (SFG:12.6).}
\]

Nonetheless, there was considerable debate around the formation of sub-interest groups for both DLB and FTLD, with endorsement of the work undertaken by AAV in its service delivery for people living with younger onset dementia (YOD):
Use the YOD model. They already do that quite well, they recognize it. It is a state wide service and they do focus on younger people with dementia really really well. So you might say that is a model for the sub types (SFG:12.5).

On a slightly more scathing note, one specialist remarked:

_I think AAV needs to beef up their information, both in terms of the net, the knowledge of the counsellors and the written information they can send out. They are not ignorant about this condition, as you well know, but they probably ought to do better than they are currently doing_ (SFG:11.7).

There is support in the literature for the development of dementia carer support networks that provide relevant information, at the right time. Acknowledging the generic dementia bent of the research, it could be argued that the propositions have even greater currency when targeted specifically at any one of the dementias:

_It was very evident that carers’ priorities change over time. It was those in the early stages of caring at home who were most concerned about cognition, early diagnosis and better pre-and post-diagnostic GP support for families, whereas it was mainly former carers who were most concerned about alleviating pain and discomfort in non-verbal patients and, specifically, about research looking at palliative care and end of life issues (Nurock & Wojciechowska, 2007)._

_This study shows that psychosocial intervention with a clearly defined aim that combines giving information and conversation groups can have significant positive effects during a 1-year follow-up of caregivers of people with dementia, and some variables are more sensitive to_
change than others. Intervention is most effective early in the progression of dementia (Andrén & Sölve, 2008).

Caregivers stressed the importance of information as a means to empowerment, and expressed concern that without knowledge 'sometimes out of the goodness of your own heart you may be doing the wrong thing.' Caregiver knowledge emerged as an important research outcome (Brodaty, 2007 p.366).

Caregiver knowledge is also associated positively with adherence to dementia care guidelines (Chodosh et al., 2007) and the ability to cope (C. Graham, Ballard, & Sham, 1997).

Carers in other countries have been proactive in mobilizing resources to meet their needs either through established support services or through their own networks. From my perspective the most succinct and factual source of information at present is a factsheet on the Alzheimer’s UK website (Alzheimer’s UK & McKeith, 2008). However, it is medically orientated, offers little in the way of carer support, and directs the reader to Alzheimer’s UK for advice and information. It is interesting to note however, that in June 2006 the Lewy Body Society was registered as a charity in the UK. The Society’s patron states that it is the only organization of its type in Europe (J. Brown, 2009) and its mission is to support research into DLB and to raise awareness and educate the public, the medical profession and those in health-care decision-making positions about the disease (Lewy Body Society, 2006-7). How the establishment of this charity was viewed by Alzheimer’s UK is open to conjecture although both organizations benefit from the scientific advice of the leaders in DLB research.

The Lewy Body Dementia Association (LBDA) is the North American equivalent of, or forerunner to, the Lewy Body Society. Amalgamating two Yahoo-based DLB caregiver groups, it was formed in July 2003 and is a not-for-profit incorporated organization dedicated to raising awareness of, and supporting people impacted by, DLB (2004). It is a comprehensive Internet site providing specific information on diagnosis, symptoms
and treatment options, as well as moderated forums for both caregivers and people with DLB, LinkedIn and Facebook communities. It also hosts numerous carer support groups which appear to be run in much the same way as the Parkinson’s support groups that operate in Australia. The LBDA has some links with the American Alzheimer’s Research Forum with that organization hosting much of the medically orientated discussion. Judging by the carers’ questions that were tabled as part of the Alzforum webinair referred to previously (page 180) and addressed by the LBDA, American carers raise similar issues to those in this study including questions about length of time to diagnosis, knowledge of doctors and appropriate drug regimes. The Alzheimer’s Association provides some information about DLB under the heading of other dementias and provides a link to the LBDA website.

It is my understanding that a carer of a person with DLB has approached AAV to discuss the establishment of a dedicated DLB support service. It could be argued that that would be counterproductive to the DLB cause. However, if AAV is to be the support service for carers of, and people with DLB, it must improve its understanding of the condition and the impact that it has on those confronted with it. It is therefore imperative that AAV finds an acceptable way to move beyond the dementia, memory loss, AD paradigm under which it currently operates. This has massive implications for the education of its staff, the resources it provides and the services it offers. AAV staff have indicated that this issue is on the national agenda of Alzheimer’s Australia. FTLD is also recognized by the service as a dementia that demands a wider perspective.

9.5 Summary

In this chapter I have addressed a number of issues that arose from my analysis of the data and went beyond those where meaning is made through intimate relationships. I wanted to consider where and how societal meanings may need to be shifted so that within the various interpretations of community – lay, medical, service providers – the needs of carers of people with DLB can be met. Regardless of the issue, it is impossible to escape the fundamental truism – dementia with what? I started at that point myself three years ago and what I find most disconcerting is that, over that time, very few, in any of the communities, have joined me in the DLB wilderness.
Every aspect of DLB requires further research. The biomedical and clinical research literature on AD, dementia and PD overwhelms that on DLB as it does the psychosocial field. This study has identified numerous psychosocial aspects of DLB that warrant further studies so that there is evidence to support policy development, appropriate resource allocation and care for those affected. This study has identified a lack of knowledge about DLB in every community which then affects every aspect of living in the community, care and service provision.

In my final chapter I will reflect on the experience of caring for a person with DLB.
Chapter 10 Conclusion

The neuropsychiatric, autonomic, cognitive and motor deficits that people with DLB experience present considerable challenges that carers have to face regardless of their understanding of DLB or the infrastructure provided by their families and communities in which they live. How these challenges are understood, accepted and managed is negotiated individually, as was demonstrated by the carers in this study. The ability to cope and understand the demands of caring for a person with DLB are certainly influenced by familial factors, including personal strengths and weaknesses, family knowledge and dynamics, education and computer literacy. The effects that the dynamics of the pre-morbid relationships have are difficult to ascertain other than to state that in stable, loving, long term marriages, the burden of caring for a person with DLB is onerous, as was evident in the interview data.

There are also a number of extraneous factors that add burden. They are worth reiterating as they may well be the factors that have the potential to be ameliorated by changing societal knowledge and attitudes:

- ignorance of DLB as a disease within the community in general and within the medical and service provider communities;
- difficulties of getting a timely, accurate diagnosis;
- health professional / carer relationships which are impacted by ignorance and privacy considerations; and
- lack of appropriate information and support.

That we, as a society, place these additional stressors on such a vulnerable group of people highlights the need for education, training and further research in every aspect of this disease.

10.1 Implications

This study has afforded me a greater understanding of the experience of caring for a person with DLB. In doing so it has given voice to a small but representative sample of people dealing with a progressive neurodegenerative illness. It is representative in that some have progressed through a dementia pathway, others through a PD pathway. It
has also reflected issues associated with caring at home, accessing respite, relinquishing full time care and accepting palliative care and loss.

This study has provided evidence to empower a small but growing demand to challenge the dementia / memory loss / AD outlook so prevalent in our society. There are indications that Alzheimer’s Australia is prepared to lead in this area and that can only be of benefit to the community as a whole and those impacted by DLB (and other less well recognized dementias such as FTLD).

Currently the global PD community seems to be resistant to embracing DLB. It appears that this stance and financial limitations impedes the local Parkinson’s Association’s ability to develop further resources to respond to the specific needs of people with DLB and their carers. Parkinson’s Victoria recognizes the unmet need and is supportive of and interested in being involved with other initiatives.

This study has identified innumerable avenues for further research in the assessment and psychosocial realms of DLB and dementia care. There is some progress within the medical arena, associated with PET scanning and the introduction of more sensitive rating instruments, but the study has exposed deficiencies in the carers’ perceptions of:

1. the medical services, particularly those associated with general practice and hospital admission;
2. service provision, as in home respite, day placement, facility based care and palliative care; and
3. support, education and information targeted at their particular needs.

By association this raises questions as to the deficiencies in the provision of care for those with the illness. Although not canvassed directly in this study, it would seem that there is sufficient evidence to suggest that people with DLB may well be able to eloquently express their own opinions and concerns. Consumer reference groups and targeted research would provide avenues for their voices to be heard, voices which may illuminate the plight of those who do not have the benefit of a spousal carer. The experiences of professional carers, particularly in the nursing home environment, also need to be heard.


10.2 Reflections

My quest in this study has been to understand DLB and the challenges that caring for a person with this illness presents. At the outset I raised two predicaments that I considered could be contentious - my own insider-outsider position within the heuristic research paradigm, and the evaluative component of the study. Rather than being contentious, both have enhanced my ability to make meaning of DLB, the caring relationship and the personal and societal challenges it presents.

From an heuristic perspective the criteria for success or achievement is personal. As I reflect on my journey I have a sense of personal satisfaction in that I have achieved my aim. I found it difficult to divorce the research participants from their caring roles in the interviews because DLB is all consuming. This may be a factor of the spousal relationship, but from the initial concern that something was wrong, through caring at home, to relinquishing care, the focus of the carers was one of holding on to a connectedness. Even if it became sporadic or fleeting it was captured, held and cherished and that impelled the carers to fight for understanding, dignity and appropriate services for their spouses. This fight did not abate for those in the study whose spouses died, indeed they became more vocal about the need to make others aware of DLB and the effects that it has on people with this illness and those who care for them.

As is the expectation of academia, throughout my candidature I have taken opportunities to present my research and share my new-found understanding with others. Even prior to engaging with the research participants I learnt that one of the most important contributions I can make is to start the discussion and raise the idiosyncrasies of DLB, particularly those associated with sub cortical dementia. The heuristic process of developing a creative synthesis became a natural extension of my desire to continue educating people about DLB. Even without that resource I have learnt that sharing new understandings can be personally challenging. To date, at every presentation I have made, I have been approached by someone seeking further information or advice because they are concerned about a relative. Mindful of my limitations and the inappropriateness of assuming the role of a diagnostician I have developed a further resource (Appendix 9), drawn from this study, to give to people
who approach me. It also is designed to complement the DVD in my personal educational activities.

My conceptual framework of meaning making has also been illuminating. Symbolic interactionism is concerned with self-action or dialogue and group action, where attitudes are aligned to those of the group with which one is interacting. Group attitudes, confuse and confound our ability to embrace DLB. I could argue that the entrenched belief that James Parkinson was right in his opinion that the disease he was describing was purely a motor disease, has blinkered generations of neurologists, particularly in light of their apparent rejection of the French scientists’ cautious considerations of cognitive impairment in the early descriptions of PD. I also contend that the memory loss connotation of dementia has been articulated too strongly to the detriment of the caring professions’ and the public’s ability to contemplate alternative scenarios.

Counter to those arguments is, of course, the stance that interactionism is centred on our ability to interpret new meanings and change attitudes. The difficulties faced by the carers in this study were that they found themselves in situations where they were attempting to interpret and create new meanings through self dialogue because they could not find compatible groups. I found it disconcerting that the one group within the study, the specialist’s focus group, that theoretically could lead the way on attitudinal change, at times espoused attitudes that the carers would have found confronting. Hopefully this study may provide impetus for changing societal attitudes to DLB, and create an environment in which other sub cortical dementias also gain currency. From my perspective the “dementia with what?” statement is not a difficult one to address.

I have been privileged to have met, talked with and represented my research participants – the carers. Whilst their generosity and openness was humbling, I was also acutely aware of their unmet needs. I sincerely hope that within the limits of the researcher/participant boundaries I was able to answer their questions honestly and guide them to the appropriate resources.

The experience of having, or caring for a person with, DLB is so far removed from that of AD that I find myself re-evaluating my own experience. Is it reasonable to be glad
that my mother had AD rather than DLB? I recall her occasional delusional episodes and short periods of rigidity and how they both created additional strain on my father. Her last years exemplified the palliative dwindling experience. Cocooned within her own world her death was inevitable and peaceful – she just stopped breathing. Do I resent that AD meant that she did not know who I was for the last four years of her life? Yes, I resolved that years ago, but I am acutely aware of the impact that knowing, or being able to maintain a presence and connection with others, has, and has had, on the carers in this study.

I embarked on this study viewing the world through a lens of personal enquiry and private evaluation. In doing so I acknowledged that I would come to a point where I have to address the ‘what next’. That time has come and my understanding of the experience of caring for a person with DLB creates an opportunity for me to make a difference. Whether that opportunity is realized in association with AAV or through some other agency is irrelevant, the critical outcome is that the profile of DLB is raised and service provision associated with DLB is improved. To use the words of the carers - *DLB it is a foul disease and a bugger of a way to go.*
References


Alzheimer's Australia. (2005a). 1000 People a Week will be Diagnosed with Dementia in 2005. Canberra: AA.


Collerton, D., Burn, D. J., McKeith, I. G., & O’Brien, J. (2003). Systematic Review and Meta-Analysis Show that Dementia with Lewy Bodies is a Visual-Perceptual


Parkinson's Australia. (1999). Parkinson’s Australia Fact Sheet 26: Driving PA.


Parkinson's Disease Foundation. (2005). Driving and Parkinson's Disease - When is it time to give up the keys? (pp. 2). New York: PDF.


Stiasny-Kolster, K., Doerr, Y., Moller, J. C., Hoffken, H., Behr, T. M., Oertel, W. H., et al. (2005). Combination of 'idiopathic' REM sleep behaviour disorder and olfactory dysfunction as possible indicator for {alpha}-synucleinopathy demonstrated by dopamine transporter FP-CIT-SPECT. *Brain, 128*(1), 126-137.


Appendices
## Appendix 1 - Questionnaire Carers Stage 1

<table>
<thead>
<tr>
<th>Code</th>
<th>Data entered</th>
<th>2\textsuperscript{nd} Stage</th>
</tr>
</thead>
</table>

Can I please first ask you some general questions about yourself and your spouse/partner?

1. Carer demographics

<table>
<thead>
<tr>
<th>First Name</th>
<th>Gender</th>
<th>Age</th>
</tr>
</thead>
<tbody>
<tr>
<td>Relationship</td>
<td>Length</td>
<td>Children</td>
</tr>
<tr>
<td>Phone no</td>
<td>Postcode</td>
<td></td>
</tr>
</tbody>
</table>

2. Cared for demographics

<table>
<thead>
<tr>
<th>First name</th>
<th>Gender</th>
<th>Age</th>
</tr>
</thead>
<tbody>
<tr>
<td>Occupation</td>
<td>Retirement (year or age)</td>
<td></td>
</tr>
</tbody>
</table>

Current residence – home, respite, hostel, psycho-geriatric NH, NH, Deceased

1\textsuperscript{st} Diagnosis –
dementia, Alzheimer’s, FTLD, DLB, other, PD, PDD, other, not sure

Diagnosed by –
GP, Neurologist, Geriatrician, Psycho geriatrician, CDAMS, other, not sure, don’t know

Date

Was ......................... still working when you realized something was wrong? Y/N

Did ................have any other diagnosed health problems at that time
Heart, lungs, arthritis, joint replacements, prostate/gynaecological problems, other

If 1\textsuperscript{st} Diagnosis not DLB

When was DLB diagnosed?

By whom?
GP, Neurologist, Geriatrician, Psycho geriatrician, CDAMS, other, not sure, don’t know
Now I would like you to think back to the early stages of your partner’s illness. I will ask you a number of questions most of which you can answer with Yes (always) or No (never). You can also say I don’t know or sometimes (rarely / frequently) if it makes it easier………..

3. First I am going to ask some questions about …………… physical ability.

Did you notice a difference in …………….’s ability to:

(Physically) get out of bed
Do up buttons, tie ties, put on jewellery, tie shoe laces
Hold a glass, cup or mug steady
Have trouble starting to move (reaching for a cup, starting to walk)
Walk quickly
Walk in crowds
Walk over rough or different surfaces
Get out of a low chair
Pick up something dropped on the floor
Get up and down onto the floor/ in the garden?

When getting up from the bed/chair/floor did ……..complain or comment that she/he felt
Light headed
Dizzy
Faint
or did she/ he stumble or fall?

4. Now I would like to move on to the autonomic system and some of the other senses

4.1 Did ………..comment that his/her sense of smell had
Changed
Gone
Altered in that he/she could smell things that you couldn’t?

4.2 Did …………….. comment that he/she could h ear noises or voices that you could not hear?

4.3 Did ……………. tell you that he/she saw people who were not there?
Parents / Children / Other family / Friends
Others / Animals / Insects

Did this upset ……………………………?

4.4. Did you notice a change in …………….’s ability to choose the right clothes for the weather?
Did………………start taking all the doona
Throwing off the doona
Perspire more than previously
Perspire less than previously
Complain of being hot or cold inappropriately?

4.5. Did ………………… have bad dreams in the early stages or at any time?
Toss in his/her sleep
Had restless jumpy legs
Ever accidentally hurt you or broken bedside lights in his/her dreams
Been that restless that you had to sleep in separate beds
If Y how long?

4.6. Did ………………… mention a change in his/her bowel habits?
More constipation
More diarrhoea
Was constipation an ongoing issue for …………………

4.7. Were you aware of any urinary incontinence?
Wet underpants
Urgency
Accidents

4.8. Was there a change in your sexual relationship? Y/N

5. Let me ask you some questions about ………………… memory and behaviour – in the early stages

5.1. Was it obvious to you that ………………… was having trouble doing things that he/she had previously done well like:
Paying the bills
Cooking the meals
Doing the shopping
Driving in unfamiliar places
Driving around roundabouts and crossing busy intersections
“Reading” the traffic
Reading street directories/recipes/instruction
Solving crosswords/sudoku/puzzles
Fixing broken furniture/cars/sewing/hobby activities
Playing bowls/tennis/bridge/golf
Socializing at bowls/tennis/bridge/golf
Making decisions about holidays
Making decisions about superannuation
Making decisions about buying/selling big $ items/houses/cars/boats/furniture
Knowing when to stop drinking/gambling/teasing/arguing?

5.2. Was ………………… able to “rise to the occasion” - was he/she
Better at some times than others:
Were there good days
  good hours
Better when family came
Better in social situations than when at home with you
Did he/she lack motivation / initiative /enthusiasm?

5.3 Did …………………
Repeat the same story over and over again
Ask the same question repeatedly
Get angry with you if you tried to reason with him/her
Have trouble following a conversation
Have trouble following a film or book
Accuse you of trying to do the wrong thing by him/her (affairs/
leaving/poisoning/stealing being unreasonable)
Tell you stories about his/her life that you believed were not true
Mistake you for someone else or someone else for you
Talk to his/her reflection in the mirror
Believe others were trying to harm or hurt him/her or you
Argue or get cross with you because he/she had mis interpreted your action of tone
Become withdrawn
Lose interest in your live together
Lose interest in your family’s life and doings?

6. Finally there are a few questions about …………… medical management
Are you able to tell me which medications……………..was prescribed?
Aricept
Ldopa

Did ……………….have any bad reactions to prescription medication?

If Yes Do you know the name of the medication?

. Were you present when …………. was formally assessed and diagnosed?
1st time
2nd time

Were you interviewed separately?

Did you have to complete any forms?

Thank you - this gives me some background information. Now can we arrange a time
for the interview?

Place Date Time

If you would like to discuss today or if you have any questions please give me a call on
54270153 or call the Alzheimer’s Helpline on 1800100500 and ask for the duty
counsellor.
Appendix 2 - Focus Group Plan: Carers

“Dementia with Lewy Bodies: The caring experience.”

Introductory round:

Scene setting: My “discovery” of DLB and the questions it raised…

“What stands out for you from the presentation today?”

“Before being told by the doctors that your husband had DLB had you heard of the disease?”

Transition questions

“Does knowing about DLB alter anything for you?”

“Do you think many people know about DLB?”

“Have you talked about some of the criteria and been ignored?”

“Would it have helped to hear more specific information about DLB at your information session at either PA or AAV?”

Key Questions

“Do we need to educate professionals about this disease?”

“Why is that important?”

“What difference would it have made to you?”

“Is there value in specific support groups / information sessions for people with DLB?”
Appendix 3 - Ethics Approvals

5 June 2008

Dr P.K. St Leger
Melbourne Graduate School of Education
The University of Melbourne

Dear Dr St Leger

I am pleased to advise that the Health Sciences Human Ethics Sub-Committee approved the following Project:

Project title: Dementia with Lewy Bodies: Evaluating Carers' Experiences
Researchers: Dr P.K. St Leger, Professor D.J. Ames, Kathryn Ann Nicholson
Ethics ID: 072148B

The Project has been approved for the period: 02-Jun-2008 to 31-Dec-2008.

It is your responsibility to ensure that all people associated with the Project are made aware of what has actually been approved.

Research projects are normally approved to 31 December of the year of approval. Projects may be renewed yearly for up to a total of five years upon receipt of a satisfactory annual report. If a project is to continue beyond five years a new application will normally need to be submitted.

Please note that the following conditions apply to your approval. Failure to abide by these conditions may result in suspension or discontinuation of approval and/or disciplinary action.

(a) Limit of Approval: Approval is limited strictly to the research as submitted in your Project application.

(b) Variation to Project: Any subsequent variations or modifications you might wish to make to the Project must be notified formally to the Human Ethics Sub-Committee for further consideration and approval. If the Sub-Committee considers that the proposed changes are significant, you may be required to submit a new application for approval of the revised Project.

(c) Incidents or adverse affects: Researchers must report immediately to the Sub-Committee anything which might affect the ethical acceptability of the protocol including adverse effects on participants or unforeseen events that might affect continued ethical acceptability of the Project. Failure to do so may result in suspension or cancellation of approval.

(d) Monitoring: All projects are subject to monitoring at any time by the Human Research Ethics Committee.

(e) Annual Report: Please be aware that the Human Research Ethics Committee requires that researchers submit an annual report on each of their projects at the end of the year, or at the conclusion of a project if it continues for less than this time. Failure to submit an annual report will mean that ethics approval will lapse.

(f) Auditing: All projects may be subject to audit by members of the Sub-Committee.

If you have any queries on these matters, or require additional information, please contact me using the details below.

Please quote the ethics registration number and the title of the Project in any future correspondence.

On behalf of the Sub-Committee I wish you well in your research.

Yours sincerely,

[Signature]

Mc Kate Murphy - Secretary
Health Sciences HESC
Phone: 83402073, Email: k.murphy@unimelb.edu.au

cc: HEAG Chair - Psychiatry
Kathryn Ann Nicholson

Melbourne Research Office
The University of Melbourne Victoria 3010 Australia
12 February 2009

Dr P.K. St Leger
Melbourne Graduate School of Education
The University of Melbourne

Dear Dr St Leger

Project title: Dementia with Lewy Bodies: Evaluating Carers' Experiences
Researchers: Dr P. K. St Leger, Professor D. J. Ames, Kathryn Ann Nicholson
Ethics ID: 0721488

I am pleased to advise that the amendment to the project dated 10 December 2008 was approved by the Health Sciences Human Ethics Sub-Committee on 9 February 2009.

Please note it is your responsibility to ensure that all people associated with the Project are made aware of the amendment.

Yours sincerely

Ms Kate Murphy
Executive Officer, Human Research Ethics
Phone: 8342873, Email: k.murphy@unimelb.edu.au

cc: HEAG Chair – Psychiatry
Kathryn Nicholson
Appendix 4 - Plain Language Statement and Consent Form

This letter is to fully explain the research that you have indicated an interest in as a participant.

I am doing research for my PhD at the University of Melbourne in the Centre for Program Evaluation. My supervisors are Dr Pam St Leger (pksl@unimelb.edu.au) and Professor David Ames (dames@unimelb.edu.au). The title of the project is “Dementia with Lewy Bodies: Evaluating Carers’ Experiences”.

There are 3 stages where carers will be involved and a 4th stage which will involve health professionals.

In Stage 1 we want to investigate carers’ perceptions of their partners’ early difficulties and problems. This will involve a telephone survey that will take approximately 30 minutes to complete. If you agree to participate, I will start by asking you to provide some information about yourself and an overview of your partner – their age, date of diagnosis, diagnosis. Then I will ask you to think back to the early stages of your partner’s illness when you started to realize that something had changed. I will ask you a number of questions. There are no right or wrong answers – in some instances you will think – yes that absolutely happened and probably for many questions you will think – no I didn’t notice that. The final questions will relate to your experiences getting help from family, doctors and other services in the early stages and the pathway that you took to get a diagnosis of dementia with Lewy bodies (DLB).

Stage 2 will be a face to face interview. The interview can be conducted in your home or anywhere that you would feel comfortable to talk. I expect that it will last somewhere between 60 – 90 minutes and I would like to tape record our conversation. I will then transcribe the tape and analyze it in conjunction with the tapes of other interviews. Staff from Alzheimer’s Australia may be involved in the analysis.

The aim of this stage of the project is to evaluate the experience of caring for people with DLB to see if carers face common problems or have similar thoughts about their changing relationships and the impact of the illness on their lives. I anticipate that I will be interviewing about 10 carers. Consequently, the interview will involve you talking about your experiences and perceptions of the changes to your partner and how that affected you in the early stages of his/her illness. I would also like you to talk about how you involved others (family, friends, health professionals), how supported they were and what use you made of the information they provided.
Stage 3 will bring you together with the other carers whom I interview to provide you with information about DLB and the findings from the surveys and interviews. Then I will give you some time to reflect on this and how it makes you feel. After a general question and answer discussion and lunch (which will be provided) I will facilitate a group discussion or focus group which I will audio-tape on how you believe the community in general, health professionals and support services staff can learn about this disease to better assist other carers.

It will be a challenging day which will be held on a day mutually convenient to everyone from 10am to 3.30pm at Alzheimer’s Australia Victoria at 98-104 Riversdale Road Hawthorn.

In the 4th stage with the health professionals I will provide them with information about DLB and the findings from the surveys and interviews then facilitate focus groups like the one in Stage 3.

If you would like to participate in this research there are some things that you should understand.

Your involvement in the project is voluntary and you are free to withdraw at any time, and to withdraw any unprocessed data previously supplied. This means that it you find it too difficult recalling this time in your life you can leave the project after you have completed Stage 1 or Stage 2 or even in the middle of the interview.

I am a Helpline Advisor and sessional educator for Alzheimer’s Australia Victoria (AAV) and my role as the researcher in this project is independent of AAV, however AAV counsellors who are familiar with the project will be available for you to talk to at any time during and after the project. You can also ask me and Dr St Leger and Professor Ames questions but as we will not know your partner /spouse we will not be able to answer specific questions relating to them or their treatment.

In accordance with my ethics approval I intend to protect the anonymity and confidentiality of all participants to the fullest extent possible. Obviously you will meet the others whom I have interviewed and you may share experiences. I will ask everyone to respect each others’ confidentiality. At the time of the surveys I will give people pseudonyms or false names. I will retain the pseudonyms assigned to all participants and people about who they speak when I transcribe the tapes of the interviews and focus group, analyze them with staff AAV or talk to the health professionals in Stage 4. I will ensure that no written material in my thesis (or in subsequent presentations or journal articles) will identify you by your name (unless you specifically ask that your names be used).

The audio tapes of the interviews and group discussions and any written material will be kept in a locked office and the transcribed data will be kept on a password protected computer. The tape, any written material and transcript will be securely kept for five years after the completion of the project and then destroyed in accordance with the Faculty of Education’s procedures.
At the end of your participation (after Stage 3) you may have information that you would like to share with family, friends and people involved in your partner's care. To assist you in doing that a week or two after our day together there will be an information session about the project and dementia with Lewy bodies specifically for you and people whom you invite. At this session Professor Ames and I will discuss the research into DLB and the project.

Once the project has been completed, I will send you a report and there will be other opportunities for you to attend information sessions to learn more about the project and the findings from all stages of it. I will notify you when they have been scheduled. It is also likely that the results will be presented at academic conferences and in journals.

Should you require any further information, or have any concerns, please do not hesitate to contact Dr Pamela St Leger on 8344 6086 or email pksl@unimelb.edu.au or me Kathryn Nicholson on 54270153 or email kathryn.nicholson@ihsipl.com.au. Should you have any concerns about the conduct of the project you are welcome to contact the Executive Officer, Human Research Ethics, The University of Melbourne on ph: 8344 2073 or fax: 9347 6739. The ethics ID is 0721488.

If you would like to participate in this research please sign the attached consent form and post it in the envelope provided.

Yours sincerely

Kathryn Nicholson
“Dementia with Lewy Bodies: Evaluating carers’ experiences”

I …………………………………………..…have read and understood the information given to me and consent to be a participant in Kathryn Nicholson’s PhD research project at the University of Melbourne under the supervision of Dr Pam St Leger (pksl@unimelb.edu.au) from the Centre for Program Evaluation (CPE) in the Faculty of Education and Prof David Ames (dames@unimelb.edu.au) from the Department of Psychiatry of Old Age.

My involvement in the project is voluntary and I understand that I am free to withdraw at any time, and to withdraw any unprocessed data previously supplied.

I understand that the aim of this project is to evaluate the experience of caring for a person with dementia with Lewy bodies through a 3 stage process of a telephone survey, an interview and participation with others, who have been surveyed and interviewed, in a discussion and focus group.

The survey will take about 30 minutes on the telephone, the interview about 60 to 90 minutes either at my home or somewhere where I feel comfortable and the group activity will run for most of the day in Hawthorn.

Both the interview and focus group will be audio tape recorded.

In accordance with the ethics approval (ID 0721488) associated with this project I understand that my anonymity and confidentiality will be respected to the fullest extent possible. I understand that pseudonyms will be assigned to all participants and people about who they speak when the tapes are transcribed. This will ensure that I will not be identified by name in Stage 4 of the project (the focus groups with health professionals). No written material, either during the analysis that may involve staff from AAV, or in the thesis (or in subsequent presentations or journal articles) will identify me or my spouse/partner, or others by name unless I give express permission for our names to be used.

I will respect the privacy and confidentiality of fellow participants.

Signature        Date

Researcher’s signature        Date

Please call me on _____________________ to arrange a time for the survey.
Appendix 5 – Thematic Analyses

Grid 1:  Relationships – Carers and the Medical Profession
Grid 2a:  Relationships – Carers and Spouses
Grid 2b:  Relationships – Carers and the Medical Profession
Grid 3:  Carers’ Understandings of Illness
Grid 4:  Carers’ Sources of Knowledge
Grid 5:  Relationships – Family and Friends
Grid 6:  Relationships – Support Services
Grid 7:  Carers’ Issues

Sample of Transcript
### Grid 1: Relationships – Carers and the Medical Profession

<table>
<thead>
<tr>
<th>1. GEM PRACTITIONER</th>
<th>2. HOSPITAL</th>
<th>3. SPECIALIST</th>
<th>4. DRUGS</th>
<th>5. EXPRESSED LACK OF SUPPORT</th>
</tr>
</thead>
<tbody>
<tr>
<td>5.2, 5.3</td>
<td>5.2, 6.1, 6.2</td>
<td>3.4, 6.3</td>
<td>10.2, 14.2</td>
<td>4.4, 6.4</td>
</tr>
<tr>
<td>5.3, 18.2</td>
<td>14.2, 16.2, 17.3</td>
<td>34.6, 10.2, 14.2, 19.5</td>
<td>25.4</td>
<td>10.1, 29.4, 39.6</td>
</tr>
<tr>
<td>5.4, 5.1, 17.1</td>
<td>29.6, 31.2</td>
<td>11.2, 31.5, 11.2</td>
<td>28.3</td>
<td>9.5, 17.1</td>
</tr>
<tr>
<td>6.1</td>
<td>12.1, 11.3</td>
<td>7.1, 9.3</td>
<td>14.1, 15.4</td>
<td>7.2</td>
</tr>
<tr>
<td>2</td>
<td>2.4, 2.3, 3.2, 21.2</td>
<td>2.4, 3.2, 23.4</td>
<td>2.4, 3.2, 25.4</td>
<td>2.4, 3.2, 27.4</td>
</tr>
<tr>
<td>6</td>
<td>26.1, 29.4</td>
<td>21.2, 22.2, 26.2</td>
<td>12.1, 13.2</td>
<td>12.1, 13.2</td>
</tr>
<tr>
<td>13</td>
<td>12.2, 9.1</td>
<td>22.1</td>
<td>2.6</td>
<td>2.6</td>
</tr>
<tr>
<td>12</td>
<td>12.1, 13.2, 14.4</td>
<td>2.6, 10.4</td>
<td>2.6, 12.5, 13.5</td>
<td>2.6, 12.5, 13.5</td>
</tr>
</tbody>
</table>

247
<table>
<thead>
<tr>
<th>CARER</th>
<th>1. LOVE</th>
<th>2. LOSS</th>
<th>3. ANGER</th>
<th>4. COMMITMENT</th>
<th>5. COMMUNICATE</th>
<th>6. LETTING GO</th>
<th>7. GUILT</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>4.5, 7.5, 8.4, 10.2, 10.3, 10.4, 11.1, 18.2, 10.2</td>
<td>4.5, 7.5, 8.5, 9.1, 10.2</td>
<td>1.3, 8.4, 10.2, 11.3, 15.2, 16.1, 16.5, 18.2</td>
<td>4.5, 9.1, 16.1, 16.5, 18.2</td>
<td>11.2,</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>7.6, 8.4, 10.6, 21.2</td>
<td>3.1, 11.2</td>
<td>3.4</td>
<td>2.4, 4.3, 8.1, 12.4</td>
<td>11.2,</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>1.4, 2.2, 4.3, 4.4, 5.1, 8.2, 14.3</td>
<td>4.5, 8.1, 15.4</td>
<td>12.6</td>
<td>8.2, 15.2, 15.3, 18.2, 3.1, 11.5, 12.6, 14.3, 15.8,</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11</td>
<td>4.3, 7.7, 14.5, 15.1</td>
<td>1.5, 2.1, 15.1</td>
<td>4.7,</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### Grid 2b: Relationships - Carers' Perceptions of Spousal Situation

<table>
<thead>
<tr>
<th>CARER</th>
<th>1. LOVE</th>
<th>2. LOSS</th>
<th>3. APATHY</th>
<th>4. KNOWING</th>
<th>5. COMMUNICATION WITH SPOUSE</th>
<th>6. COMMUNICATION WITH OTHERS</th>
<th>7. INSIGHT</th>
<th>8. REASONING</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>4.5, 16.1</td>
<td></td>
<td></td>
<td>9.5, 18.3</td>
<td>14.1, 19.1, 4.5,</td>
<td>8.5, 16.1, 19.1,</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>2.1, 5.3, 31.2, 36.1</td>
<td>5.2, 22.3, 18.3, 27.4, 17.2,</td>
<td>22.3, 23.1, 22.5,</td>
<td></td>
<td>5.3, 31.2, 36.1,</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>14.3, 21.1, 33.3, 38.1</td>
<td>27.2, 14.3, 6.1,</td>
<td></td>
<td></td>
<td>22.5,</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>15.3, 3.5, 4.3, 8.3, 12.3, 16.2, 9.4, 12.4, 2.4, 16.2, 8.3,</td>
<td>2.3, 11.2, 15.3, 12.4, 16.2,</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>15.3, 1.5</td>
<td>16.4, 8.1, 16.3, 16.4, 9.2,</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>25.7, 41.4, 44.2, 11.2, 41.1, 4.4, 20.5, 34.3, 4.3, 19.3, 33.1, 2.2, 15.5, 25.4, 25.7, 36.5, 43.1, 5.1, 34.4,</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>8.2, 8.4, 8.6, 9.3, 9.4, 12.4, 27.1, 32.1, 13.3, 27.1, 28.3, 8.3, 11.4, 16.2, 7.1, 8.2, 22.2, 25.4, 4.4, 6.3, 8.6, 21.5, 17.4, 32.1, 18.1, 32.5,</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>38.4, 5.1, 12.3, 31.5, 32.3, 5.1, 6.3, 7.3, 12.3, 32.6, 34.4, 36.5, 23.6, 24.3, 38.4, 31.4, 38.4, 7.5, 14.1, 17.1, 31.1, 36.5, 31.4, 31.5,</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CARER</td>
<td>ACCURATE</td>
<td>CONFUSED</td>
<td>RESEARCH</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>-------</td>
<td>----------</td>
<td>----------</td>
<td>----------</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>3, 4</td>
<td>14, 3</td>
<td>1.3, 2.2, 7.5, 19, 2</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>2, 2, 3, 4, 7</td>
<td>21.4, 0.1</td>
<td>3, 3, 18.1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>6, 2</td>
<td>7, 2, 14, 17.7</td>
<td>2, 6.3, 0.3</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>5</td>
<td>10, 3, 12.6</td>
<td>19, 1, 2.4, 27.3</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>6</td>
<td>10, 2, 19.1</td>
<td>33.1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>8</td>
<td>4, 1, 45.3</td>
<td>22.2, 0.3</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>9</td>
<td>20, 3</td>
<td>28, 3</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>10</td>
<td>31, 15.3</td>
<td>21, 2.4, 27.3</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>11</td>
<td>14, 2</td>
<td>2, 7, 4, 11.4</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>12</td>
<td>14, 6, 10.6</td>
<td>96, 9.7</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11</td>
<td>13</td>
<td>27, 4.2</td>
<td>2, 2, 3, 4, 7</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CARER</td>
<td>1. DOCTORS</td>
<td>2. SUPPORT SERVICES</td>
<td>3. FAMILY &amp; FRIENDS</td>
<td>4. WWW/LIBRARIES</td>
<td>5. RESEARCH</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>-------</td>
<td>------------</td>
<td>---------------------</td>
<td>--------------------</td>
<td>-----------------</td>
<td>-------------</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>HELPFUL</td>
<td>CONFUSING</td>
<td>HELPFUL</td>
<td>CONFUSING</td>
<td>HELPFUL</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>7.1</td>
<td>6.1, 6.2,</td>
<td>13.3,</td>
<td></td>
<td>6.3, 7.1, 7.2</td>
<td>7.3,</td>
<td>20.5</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>22.1</td>
<td>11.2,</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>22, 9.5</td>
<td>10.1, 11.3,</td>
<td>14.1, 6.3,</td>
<td>14.1,</td>
<td>17.6, 19.2,</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>10.1</td>
<td></td>
<td>23.2</td>
<td>21.2</td>
<td>21.2, 22.1, 12.3, 30.2</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>26.4</td>
<td></td>
<td>10.2,</td>
<td>19.7</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>6.3</td>
<td>24.7</td>
<td>10.2,</td>
<td>19.3, 46.3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>1.1, 26.1, 29.4</td>
<td>1.1, 2.3, 4.4, 18.1, 26.2,</td>
<td>19.8</td>
<td>16.1</td>
<td>4.4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>19.1, 29.2</td>
<td>29.5</td>
<td>25.4</td>
<td>3.4, 29.4</td>
<td>29.7</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>10.2</td>
<td>3.5</td>
<td>3.3</td>
<td>2.1 (PD), 22.2,</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11</td>
<td>10.2</td>
<td>3.5</td>
<td>3.3</td>
<td>13.1</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12</td>
<td></td>
<td></td>
<td>14.2</td>
<td>12.4, 14.3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13</td>
<td>11.1,</td>
<td></td>
<td></td>
<td>21.3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CARER</td>
<td>1. CHILDREN</td>
<td>2. DISTANCED</td>
<td>3. KNOWN</td>
<td>4. GRAND CHILDREN</td>
<td>1. SUPPORTIVE</td>
<td>2. IN NEED</td>
<td>1. STEADFAST</td>
<td>2. PWD INVOLVED</td>
</tr>
<tr>
<td>-------</td>
<td>-------------</td>
<td>--------------</td>
<td>----------</td>
<td>-----------------</td>
<td>--------------</td>
<td>-----------</td>
<td>------------</td>
<td>----------------</td>
</tr>
<tr>
<td>1</td>
<td>12.3, 21.1</td>
<td>13.2, 31.4</td>
<td>18.3</td>
<td>18.3, 27.4</td>
<td>9.5, 13.3</td>
<td>8.5</td>
<td></td>
<td>9.2, 27.1</td>
</tr>
<tr>
<td>2</td>
<td>9.2, 11.1, 13.2, 27.1</td>
<td>20.1, 20.1</td>
<td>37.1, 38.2</td>
<td>37.1, 38.2</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>13.1, 6.3, 36.5, 37.1,</td>
<td></td>
<td></td>
<td></td>
<td>5.4, 8.2, 13.4</td>
<td>6.2, 8.2, 13.4</td>
<td>4.5</td>
<td>4.5</td>
</tr>
<tr>
<td>4</td>
<td>5.2, 16.4</td>
<td>5.2,</td>
<td>14.4</td>
<td>2.3, 6.1, 9.2, 16.4</td>
<td>5.1, 8.2, 17.2</td>
<td>16.4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>7.4, 10.3, 16.3,</td>
<td>32.3, 16.2,</td>
<td></td>
<td>15.3</td>
<td>15.3, 12.1, 22.4,</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>6.3, 7.1, 14.2, 24.3, 35.3,</td>
<td>9.5, 24.3, 23.6</td>
<td>36.3</td>
<td>7.5, 4.1, 9.3, 32.5</td>
<td>4.1, 8.2, 9.5, 4.1, 8.2, 4.1, 26.4, 26.7,</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>12.5</td>
<td>28.3</td>
<td>28.3</td>
<td></td>
<td>4.3, 5.1, 5.2, 27.4, 28.1</td>
<td>28.1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>4.2, 11.6</td>
<td>3.3</td>
<td></td>
<td>8.1, 7.5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11</td>
<td>3.2, 6.4, 8.4, 9.3,</td>
<td>8.3,</td>
<td></td>
<td>2.5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12</td>
<td>4.3, 6.4, 16.4,</td>
<td>8.1, 6.4, 18.3,</td>
<td>8.1, 18.3, 8.1, 18.3, 20.2, 4.3,</td>
<td>28.1,</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
## Grid 6: Relationships – Support Services

<table>
<thead>
<tr>
<th>1. COUNCIL</th>
<th>2. ACAS</th>
<th>3. HACC</th>
<th>4. AAV</th>
<th>5. PARKINSON'S ASSOC.</th>
<th>6. OTHERS</th>
</tr>
</thead>
<tbody>
<tr>
<td>( +VE )</td>
<td>( +VE )</td>
<td>( +VE )</td>
<td>( +VE )</td>
<td>( +VE )</td>
<td>( +VE )</td>
</tr>
<tr>
<td>( -VE )</td>
<td>( -VE )</td>
<td>( -VE )</td>
<td>( -VE )</td>
<td>( -VE )</td>
<td>( -VE )</td>
</tr>
<tr>
<td>( 1 )</td>
<td>( y )</td>
<td>( y )</td>
<td>( y )</td>
<td>( y )</td>
<td>( y )</td>
</tr>
<tr>
<td>( 2 )</td>
<td>( y )</td>
<td>( y )</td>
<td>( y )</td>
<td>( y )</td>
<td>( y )</td>
</tr>
<tr>
<td>( 3 )</td>
<td>( y )</td>
<td>( y )</td>
<td>( y )</td>
<td>( y )</td>
<td>( y )</td>
</tr>
<tr>
<td>( 4 )</td>
<td>( y )</td>
<td>( y )</td>
<td>( y )</td>
<td>( y )</td>
<td>( y )</td>
</tr>
<tr>
<td>( 5 )</td>
<td>( y )</td>
<td>( y )</td>
<td>( y )</td>
<td>( y )</td>
<td>( y )</td>
</tr>
<tr>
<td>( 6 )</td>
<td>( y )</td>
<td>( y )</td>
<td>( y )</td>
<td>( y )</td>
<td>( y )</td>
</tr>
<tr>
<td>( 7 )</td>
<td>( y )</td>
<td>( y )</td>
<td>( y )</td>
<td>( y )</td>
<td>( y )</td>
</tr>
<tr>
<td>( 8 )</td>
<td>( y )</td>
<td>( y )</td>
<td>( y )</td>
<td>( y )</td>
<td>( y )</td>
</tr>
<tr>
<td>( 9 )</td>
<td>( y )</td>
<td>( y )</td>
<td>( y )</td>
<td>( y )</td>
<td>( y )</td>
</tr>
<tr>
<td>( 10 )</td>
<td>( y )</td>
<td>( y )</td>
<td>( y )</td>
<td>( y )</td>
<td>( y )</td>
</tr>
<tr>
<td>( 11 )</td>
<td>( y )</td>
<td>( y )</td>
<td>( y )</td>
<td>( y )</td>
<td>( y )</td>
</tr>
<tr>
<td>( 12 )</td>
<td>( y )</td>
<td>( y )</td>
<td>( y )</td>
<td>( y )</td>
<td>( y )</td>
</tr>
<tr>
<td>( 13 )</td>
<td>( y )</td>
<td>( y )</td>
<td>( y )</td>
<td>( y )</td>
<td>( y )</td>
</tr>
</tbody>
</table>
Grid 7: Carers' Issues

<table>
<thead>
<tr>
<th>CARER</th>
<th>1. CONTINUENCE</th>
<th>2. DRIVING</th>
<th>3. RUTO</th>
<th>4. ALTERNATIVE CARE</th>
<th>5. PALLATIVE CARE</th>
<th>EVENT</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>PERCEPTION</td>
<td>PROBLEMS</td>
<td>ANGER</td>
<td>ISSUES</td>
<td>PROCESS</td>
<td>QUESTION</td>
</tr>
<tr>
<td>1</td>
<td>11.4, 11.2</td>
<td>14.1</td>
<td>3.92</td>
<td>11.4, 11.2</td>
<td>10.1</td>
<td>20.3, 21.1</td>
</tr>
<tr>
<td>2</td>
<td>11.4, 11.2</td>
<td>14.1</td>
<td>3.92</td>
<td>11.4, 11.2</td>
<td>10.1</td>
<td>19.4, 19.5</td>
</tr>
<tr>
<td>3</td>
<td>9.2</td>
<td>21.4, 14.2</td>
<td>day</td>
<td>27.3, 28.2</td>
<td>day</td>
<td>21.2, 22.1</td>
</tr>
<tr>
<td>4</td>
<td></td>
<td></td>
<td></td>
<td>12.4</td>
<td>12.4</td>
<td>21.2, 21.3</td>
</tr>
<tr>
<td>5</td>
<td></td>
<td></td>
<td></td>
<td>17.3</td>
<td>17.3</td>
<td>35.5</td>
</tr>
<tr>
<td>6</td>
<td></td>
<td></td>
<td></td>
<td>9.2, 28.2</td>
<td>9.2, 28.2</td>
<td>37.6</td>
</tr>
<tr>
<td>7</td>
<td></td>
<td></td>
<td></td>
<td>11.1</td>
<td>11.1</td>
<td></td>
</tr>
<tr>
<td>8</td>
<td></td>
<td></td>
<td></td>
<td>104.1, 11, 12.3</td>
<td>104.1, 11, 12.3</td>
<td></td>
</tr>
<tr>
<td>9</td>
<td></td>
<td></td>
<td></td>
<td>20.5, 20.5, 31.2</td>
<td>20.5, 20.5, 31.2</td>
<td></td>
</tr>
<tr>
<td>10</td>
<td></td>
<td></td>
<td></td>
<td>15.5, 15.1, 34.5</td>
<td>15.5, 15.1, 34.5</td>
<td></td>
</tr>
<tr>
<td>11</td>
<td></td>
<td></td>
<td></td>
<td>10, 10.4, 11.6</td>
<td>10, 10.4, 11.6</td>
<td></td>
</tr>
<tr>
<td>12</td>
<td></td>
<td></td>
<td></td>
<td>1.5, 10.2, 13.5, 16</td>
<td>1.5, 10.2, 13.5, 16</td>
<td></td>
</tr>
<tr>
<td>13</td>
<td></td>
<td></td>
<td></td>
<td>13, 13.5, 21.1, 18.1</td>
<td>13, 13.5, 21.1, 18.1</td>
<td></td>
</tr>
<tr>
<td>Kathryn</td>
<td>Betty</td>
<td>Coding:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>---------</td>
<td>-------</td>
<td>---------</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>It is recording and it should be fine .......The purpose of this is to get an idea of how you have coped and looking over the information that you gave me you have the diagnosis of DLB in 2006 but prior to that there were a lot of things happening</td>
<td>It is him and his concern and anything that might upset him I don’t talk about</td>
<td>2a/1</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>That weren’t making sense or you were not getting answers for and that is what I would like to hear about</td>
<td>Right er yeah it was the doctors appointments and the tests that they put him through that I don’t feel were adequate drawing numbers and squares and it was all too complex to diagnose so we went to one of the top neurologists in Melbourne and then they shovelled us off to another one and he gave the same answer and I I just didn’t feel that that was good enough</td>
<td>1/3-</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No because what they were saying didn’t satisfy what you saw?</td>
<td>No That’s right They were not here to see it and it was only what I was telling them Jeff appeared well to anybody he is quite OK. Yeah well when I did say to our doctor that I wasn’t happy with the reports that we got she suggested that we go to ...... Hospital which I wish she had done in the first place we got answers there what I didn’t what but at least we got them and when you think back prior to being diagnosed there were little</td>
<td>1/1+ 1/3 + 1/5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Or you didn’t realise they were important perhaps?</td>
<td>things that I didn’t pick up on because I didn’t want to</td>
<td>7/2</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>------------------------------------------------</td>
<td>--------------------------------------------------------</td>
<td>-----</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Well I didn’t realise they were important he was doing things differently what did scare me we travelled we travelled a lot and um on one of the trips our last trip actually he got half way there and wanted to come home because he just felt he was a danger to himself he said and everybody else. We overcame that because I didn’t feel that he was and I was there to support him and help him</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>And that was with his driving?</td>
<td>That was his driving so he couldn’t uncouple the caravan and just little things when I think back now I just put them aside and said oh I will do it don’t worry about it do something else but it was happening perhaps 2 years before the diagnosis</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I think you said it was too complicated. How long before were you going to the neurologists?</td>
<td>12 months oh we have been going to one neurologist for about 5 or 6 years for another problem</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Can I ask what the other problem was?</td>
<td>Well he has restless legs that was a neurological complaint and on our last visit he said I don’t want to see you for 6 years well that’s not what you want If I hadn’t pursued it I don’t think or complained that we have got as far as we have got And I feel for people who don’t pursue or their doctors are not diligent enough to send them somewhere else that things get undiagnosed and you just cope with oh he has gone crazy or he doesn’t know what he is doing</td>
<td>1/3-1/5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Was he ever diagnosed with Parkinson’s?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Question</td>
<td>Response</td>
<td>Time</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>-------------------------------------------------------------------------</td>
<td>---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td>------</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No they did test him for that they did test him because apparently they go hand in hand so he was tested for that I must say that …… was absolutely wonderful the tests they ran every test bar pregnancy (laughter) yeah it was good it was good but then again they don’t want to see us any more they don’t you are diagnosed and that is what you do and that’s it Not enough follow up to my way of thinking</td>
<td>1/3 – 1/3 + 6/1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>So what sort of follow up do you think you would like?</td>
<td>Well I think you should after a certain time should he still be on the same medication he has been put on</td>
<td>1/5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>um</td>
<td>Should they test him to say well perhaps he could go on a stronger dosage or a weaker dosage but to be diagnosed I mean well we did have a couple of visits but after that well just your own doctor he has even given our doctor the right to prescribe the medication for him now he doesn’t even do that for us so I just feel tat even thought the diagnosis was good and the help we got there was very good and there is help there if we need it there is not enough follow up I don’t feel no</td>
<td>1/4  1/5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you think you understand the disease now?</td>
<td>I think so I have read a little bit about it and I well as far as I know I understand it and I can cope with it I couldn’t at first no I couldn’t because your life changes</td>
<td>4/4+</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How did it change?</td>
<td>Well ummmm</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Obviously travelling.</td>
<td>Yes that’s right we stopped doing that we have sold the caravan he is not allowed to drive of course and he has been very good about that but your lifestyle doe change.</td>
<td>7.2</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Question</td>
<td>Response</td>
<td>Page</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>-------------------------------------------------------------------------</td>
<td>---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td>------</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>So it has isolated you?</td>
<td>Yes well to a certain extent I have one day a week to myself now which is Friday I mean I can do anything I like but I won’t go and leave him for any great length of time I mean I might go to the library for an hour. I know that if I leave him in bed I know that he is safe but he doesn’t stay in bed every day. I said to him this morning we were out Sunday, Monday, Tuesday if you would like to stay in bed today you can just sit around he doesn’t always want to get dressed um everything is an effort to go so it does change not that we were very socially active but there were different things and now you think I well I won’t even think about that now we won’t go because I know he is not going to enjoy himself so he would just sooner stay home and he likes me to be here so that’s um er I just think oh well</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you feel that is a burden?</td>
<td>No no I don’t. No he is my responsibility and I am going to look after him as long as I can um (teary) I am getting upset over things I am sorry</td>
<td>2a/4</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No that is perfectly alright. What are the things that upset you?</td>
<td>Oh just him not being well Knowing what he was and what he can and can’t do now he can’t do anything he</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>And what about your communication. Has that changed?</td>
<td>was an electrician and he can barely plug the power in (waving at the power point) but the changes in him he is not interested in anything around you know little jobs he just can’t do them he has just lost all those skills and it is SAD</td>
<td>2a/1 2a/2 2b/1 2b/3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td>---</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Or no we ohh yeah it must It is very hard to make him see reason at times but we don’t have the long conversations we used to have we used to drive and talk about every mortal thing</td>
<td></td>
<td>2a/2</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>um</td>
<td>And those conversations have gone I just read a few things out of the paper to him because he has trouble with his eyes no when I think about it it is me I am talking about not him I don’t want people to think I am the one who is suffering I am not</td>
<td>2a/4 2a/5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No but to a degree you probably are. But it is him and I just I just I don’t feel that he is a real burden</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Some of the other people I have been talking to comment on the person’s inability to say thank you and please.</td>
<td>Oh yes yes but he appreciates what I do for him he told me my job was quite safe last night I am not going to loose it cos I said to him is my job safe and he yes very safe so but just little contact things (touched one arm with the other hand) that don’t happen now that’s lost the …………..interest</td>
<td>2a/1 2a/2</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lost the intimacy</td>
<td>Yeah I think so but he ..I feel it</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>But he knows you? He knows who I am and he loves me but things change</td>
<td>2b/1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix 6 – Attestation

Letter of Attestation

This letter of attestation is in relation to the audit of Kathryn Nicholson’s PhD thesis entitled: *Dementia with Lewy Bodies: The Caring Experience*.

The purpose of the audit was explained to me and I was provided with the text relevant to validity and auditing (pp 91-94) which contained the components of the audit. I understood that my role as auditor was to inspect and verify for the reader those components of the thesis that would not be publicly available because of the requirements of anonymity and the volume of the transcripts.

The audit has a number of components and in order to undertake it Kathryn provided access to the original tapes, copies of the transcriptions and the text. My findings are as follows:

1. **Adherence to process.**

   In relation to anonymity I found that Kathryn used the coding consistently and accurately.

2. **Adherence to product.**

   a. Audio tape to transcript.

   I chose 4 transcripts and selected 2 segments from each.

   Transcript for Sara, pages 4.4 and 6.1

   Transcript for Betty, pages 21.3 and 22.4

   Transcript for Ruth, pages 16.2 and 19.1

   Transcript for Norman, pages 1.1 and 3.6

   I then listened to the corresponding audio tapes which had been downloaded onto a computer. I found that in Betty’s transcript (page 21.3) there was minimal editing in that repetitions of “I get” and “um um because” were omitted, however their omission did not affect the context and in all other instances they were true transcriptions.

   b. Transcript to reference in any chapter.

   From chapters 6 and 7 of the text I randomly selected 11 instances where quotes had been taken from the transcripts. In every instance these quotes were found to be accurate.

   c. Verification of the DVD audit

   I selected 3 participants; Yvonne, Fran and Lucy and requested to be shown the transcripts that indicated that they had mentioned the topics referred to in the audit:

   Yvonne - work issues, obsessive behaviours, driving and exhaustion;

   Fran - Parkinson’s diagnosis and medications, GP’s lack of knowledge and her inability to ‘let go’; and
Lucy - early hospitalization, difficulty in gaining a diagnosis, lack of knowledge and nocturia.

All references were accurate.

d. Contextual inference from the focussed discussion with specialists.

In Chapter 9 Kathryn supports her discussion with quotes from medical specialists. I selected 5 (SFG 4.7, 6.1, 7.3, 9.9 and 14.2) quotes to verify. From my reading of the transcript and the discussion in the text I found that all of these quotes have been used with integrity.

I am therefore pleased to attest that the transcripts and citations which I examined on the 24th March 2010 in relation to Kathryn’s thesis are true and accurate.

Judith Buck

12 Zig Zag Road,
Mount Macedon
Victoria 3441
# Appendix 7 - Specialists’ Focus Group Presentation

<table>
<thead>
<tr>
<th>Outline of presentation</th>
<th>Consensus from specialists</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Introduction</strong></td>
<td></td>
</tr>
<tr>
<td>Research question</td>
<td></td>
</tr>
<tr>
<td>Methodological Approach</td>
<td></td>
</tr>
<tr>
<td>Representation of the DLB criteria (McKeith et al. 2005)</td>
<td>General discussion about how patients present and to whom. Researchers often hear a different story and some early signs are common symptoms of ageing in general. Suggestion for further study using AD and PD groups as well.</td>
</tr>
<tr>
<td>Research Participants (Carers) Demographics Questionnaire used in study Diagnostic pathway of spouse Early signs noticed by carer</td>
<td>Support for the DLB diagnostic criteria being specific. Agreement that driving difficulties are not mentioned because of fear of loss. Discussion re medial versus social model of presentation. Discussion about referral patterns and lack of acceptance of DLB by some neurologists and geriatricians. Consensus that GPs are not well informed. Discussion about assessment tools and the value of PET scans.</td>
</tr>
<tr>
<td><strong>Diagnostic issues</strong></td>
<td></td>
</tr>
<tr>
<td>Value of correct diagnosis</td>
<td>Imperative in early stage for management although some felt that relatives only wanted to have their fears confirmed and “dementia” was an adequate term. Agreement that DLB (and FTLD) will present increased pressure on support services and they need to lift their game. Discussion on models of service provision Acknowledgement that DSM-V may drop “dementia”.</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
</tr>
<tr>
<td>PBS issues with cholinesterase inhibitors and other medications</td>
<td>Agreement that it is a big problem but the bigger problem is that many are not being prescribed drugs that works or are being prescribed the wrong drugs.</td>
</tr>
<tr>
<td>Carer issues</td>
<td></td>
</tr>
<tr>
<td>Loss and knowing</td>
<td>Acknowledgement that it is a “horrible” illness. General discussion about death because of autonomic failure.</td>
</tr>
<tr>
<td>Death</td>
<td></td>
</tr>
<tr>
<td>Acknowledgement &amp; thanks</td>
<td></td>
</tr>
</tbody>
</table>
Q. Will all patients with idiopathic Parkinson's disease develop dementia?

A. Answering this question at an early stage of a patient’s disease raises a number of difficult issues. Patients are often far more concerned about losing their autonomy and becoming a burden to others because of increasing cognitive impairment rather than the physical constraints of advancing disease.

Cognitive impairment, rather than dementia, is very common and affects over 50% of patients with long standing idiopathic Parkinson’s disease. The pattern of deficits most commonly seen impact the domain of executive function, with patients struggling at tasks like planning and working memory. The frequency of dementia has been variously reported as being between 10-80%, but is usually quoted at around 15-20% of patients. However, recent work has just been published from a longitudinal twenty year study conducted in Australia. Over 100 newly diagnosed patients were followed and researchers found that those who survived 15 years about 50% were demented and after 20 years about 80% had dementia.

The likelihood of dementia will be greatly influenced by a number of factors including:

* Population studies would suggest the prevalence of dementia is 10-30% in the ‘healthy’ elderly. Therefore, not surprisingly, those patients with a later age of disease
onset are more likely to proceed to dementia with their idiopathic Parkinson’s disease.

* Similarly, longer disease duration with accumulating idiopathic Parkinson’s disease pathology is also associated with an increased risk of dementia.

* It would also appear that sub-groups of disease exist, presumably representing the underlying neuropathology. Patients with more marked signs of rigidity and akinesia, as opposed to tremor have a higher risk of dementia as do those patients who develop depression.

It would appear that those patients with an aggressive cognitive decline differ in their pattern of deficits from those patients with relative cognitive sparing. It has been postulated that this relates to an increased level of cortical Lewy body pathology in such individuals. Patients who show early deficits in tasks targeted to more posterior cortical functions, such as construction of intersecting pentagons or generating a list of animals in ninety seconds appear to be more likely to go on to develop dementia. Thus, the utilisation of such simple ‘bedside’ assessments could be used as a screen for initial reassurance, or indeed as a predictor of poor prognosis (Parkinson's Australia, 2009).
Appendix 9 - Educational Handout

Dementia with Lewy Bodies (DLB) Information Sheet

**DLB is a common neurodegenerative disease of ageing.** The criteria for diagnosing DLB were first published in 1995. DLB is one of a spectrum of diseases, known as Lewy body disorders that share a common pathology - the formation of Lewy bodies in the brain. Other conditions in the spectrum are Parkinson’s disease (PD) and Parkinson’s disease dementia (PDD).

Medical researchers are trying to discover how, why and when Lewy bodies form. It is known that the protein alpha synuclein is the major constituent of Lewy bodies and that they are found in a number of areas of the brain including the cortex (particularly the occipital cortex), the mid brain and the brain stem.

What are the early signs of DLB?
The dementia in DLB is different from Alzheimer’s disease (AD) dementia because the hippocampus, the memory encoding part of the brain, is not affected in the early stages of DLB.

**DLB dementia** affects a person’s ability to multi-task and to plan and carry out sequences of activities. They can be apathetic and find it hard to cope in noisy or crowded places. Other early signs may include **fluctuations**, where a person has ‘good’ days and ‘bad’ days, some signs of **parkinsonism** and **vivid hallucinations** of people or animals. A loss of smell and active dreams are also very early symptoms which may indicate DLB.

Diagnosing DLB.
It is thought that many people with DLB are not diagnosed or else they are told they have AD or PD. DLB should be considered if a person:
scores well on the MMSE (a test most GPs use when screening for dementia) but has difficulty reproducing the intersecting pentagons;
has difficulty with the clock drawing test; or
presents with a number of the ‘non-motor’ symptoms of PD.

Is getting the right diagnosis important? **YES.** Although there is no cure, people with DLB and their carers benefit from good management, particularly medication management because:
Cholinesterase inhibitors, the drugs prescribed for AD, benefit people with DLB.
PD medications may not have as much benefit as expected.
People with DLB can have severe adverse reactions to antipsychotic medications.

What next?
This gives you some basic information about DLB, a common yet poorly recognized disease of ageing. Review the questions on the back of this sheet and if you are concerned about a relative or friend contact your GP or the Cognitive Dementia and Memory Service (CDAMS) in your area. It may help if you complete the questionnaire and take this sheet with you to the appointment.
Questions for review.
The following questions are taken from a questionnaire given to carers of people with DLB in a research project. The carers responded positively to these questions, however their relatives had already undergone full medical assessments and been formally diagnosed.

A positive response to these questions does not mean your relative or friend has DLB. A person must have a thorough medical assessment before any definitive diagnosis can be made.

Questions.
Is it obvious to you that your relative or friend is having trouble doing things that he/she has previously done well like:
Driving in unfamiliar places?
Driving around roundabouts?
Driving through busy intersections?
Completing hobby activities successfully? Examples include fixing broken furniture, tinkering with cars or sewing.

Has your relative or friend:
Started to argue or become annoyed with you because he/she has misinterpreted your actions or tone of voice?
Become withdrawn?
Does he/she now lack motivation and initiative?

Does your relative or friend seem to be better at some times than at others?
Would you describe it as he/she having ‘good days’ and ‘bad days’?
Is it easier for your relative or friend to interact with you one on one, rather than in a crowd?
Does your relative or friend tell you that he/she saw people who were not there?
Are they upset by these hallucinations?

If your relative or friend is a sleeping partner:
Do they act out their dreams?
Have they ever accidentally hurt you or broken bedside lights in their dreams?
Are they so restless that you sleep in separate beds?

For further information and support contact:
Alzheimer’s Australia Helpline 1800 100 500 or
Parkinson’s Helpline 1800 644 189.

© This information sheet has been written by Kathryn Nicholson, a PhD candidate at the University of Melbourne. Email: k.nicholson3@pgrad.unimelb.edu.au
Author/s:
Nicholson, Kathryn Ann

Title:
Dementia with Lewy bodies: the caring experience

Date:
2010

Citation:

Persistent Link:
http://hdl.handle.net/11343/35479

File Description:
Dementia with Lewy bodies: the caring experience