Opportunities and Challenges:
Managing transitions in late-stage Parkinson’s disease
The centrality of ‘Bridging’ and ‘Scaffolding’ in developing community-based care and support

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# Contents

**Executive Summary** ................................................................. 1  
  Background ............................................................................ 1  
  Methods ................................................................................ 1  

**Findings** ................................................................................ 2  
  Bridging ................................................................................ 2  
  Support for Bridging .............................................................. 2  
  Scaffolding ............................................................................ 2  
  Recommendations .................................................................. 2  

1. **Introduction** ........................................................................ 3  
  Background ............................................................................ 3  
  Parkinson’s disease ............................................................... 3  
  Defining early and late-stage in Parkinson’s disease ............... 4  
  Adjustment and coping in Parkinson’s disease ...................... 5  
  Aims and objectives .............................................................. 5  

2. **Study design and Methodology** ........................................ 6  
  Sample and recruitment ....................................................... 6  
  People with Parkinson disease and their family carers .......... 6  
  Practitioners from the Movement Disorder Clinic ................ 7  
  Data Collection ..................................................................... 8  
  People with Parkinson’s disease and family carers ................ 8  
  Grounded theory approach to interviewing ......................... 9  
  Data Analysis ....................................................................... 9  
  Ethics .................................................................................... 9  
  Reference Group ................................................................... 10  
  Study design: implementation and modification .................. 10  
  Data collection and analysis ............................................... 11  
  Theory development ............................................................ 13  

3. **Findings** ............................................................................. 16  
  Enduring structures: .............................................................. 16  
  Adjustment stages: .............................................................. 16  
  ‘Bridging’ as an emergent theory ......................................... 16  
  Fleshing out the ‘Bridging’ .................................................... 17  
  Enduring Structures ............................................................ 19  
  Coming to terms .................................................................... 21  
  Bridging: The Adjustment Stages ........................................ 22  
  Bridging the Present ............................................................ 23  
  Broaching Collapse ............................................................. 27  
  Coping fatigue ....................................................................... 29  
  Fractured Bridging .............................................................. 33  
  Relational Bridging: partnerships and networks of support .... 37  
  Being me-Being us -Being together ..................................... 38  
  Professional roles and ‘Bridging apart’ ................................. 39  
  ‘Bridging apart’ and the PDS ............................................... 41
<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parkinson’s Disease Nurse Specialist</td>
<td>42</td>
</tr>
<tr>
<td>Scaffolding</td>
<td>44</td>
</tr>
<tr>
<td>Social scaffolding</td>
<td>45</td>
</tr>
<tr>
<td>4. Recommendations</td>
<td>50</td>
</tr>
<tr>
<td>Moving Forward Assessment and intervention: ‘Bridging’ and ‘Scaffolding’ in practice</td>
<td>50</td>
</tr>
<tr>
<td>Scaffolding</td>
<td>50</td>
</tr>
<tr>
<td>Palliative care: Integrating Social and Physical ‘Scaffolding’</td>
<td>50</td>
</tr>
<tr>
<td>Conclusion</td>
<td>51</td>
</tr>
<tr>
<td>5. Discussion</td>
<td>52</td>
</tr>
<tr>
<td>Psychological Adjustment</td>
<td>52</td>
</tr>
<tr>
<td>Family based care</td>
<td>52</td>
</tr>
<tr>
<td>Relational Practice</td>
<td>53</td>
</tr>
<tr>
<td>Palliative Care</td>
<td>53</td>
</tr>
<tr>
<td>Policy and practice</td>
<td>53</td>
</tr>
<tr>
<td>Memory and Cognition</td>
<td>54</td>
</tr>
<tr>
<td>Participatory methods</td>
<td>54</td>
</tr>
<tr>
<td>Conclusion</td>
<td>55</td>
</tr>
<tr>
<td>6. Fellowship Programme</td>
<td>56</td>
</tr>
<tr>
<td>Outputs</td>
<td>63</td>
</tr>
<tr>
<td>Publications (Accepted)</td>
<td>64</td>
</tr>
<tr>
<td>Conference Papers (Presented)</td>
<td>64</td>
</tr>
<tr>
<td>Invited Presentations</td>
<td>64</td>
</tr>
<tr>
<td>Future Projects</td>
<td>65</td>
</tr>
<tr>
<td>Appendix 1: Semi-structured Interview Guide: People with PD and their carers</td>
<td>73</td>
</tr>
<tr>
<td>Appendix 2: Semi-structured Interview Guide: Movement Disorder Clinic Practitioners</td>
<td>77</td>
</tr>
<tr>
<td>Appendix 3: Gantt Chart: Preparatory Stage</td>
<td>80</td>
</tr>
<tr>
<td>Appendix 4: Sampling frame</td>
<td>84</td>
</tr>
<tr>
<td>Appendix 5: Understanding Parkinson’s Disease: Lay Insight Diagrams</td>
<td>88</td>
</tr>
<tr>
<td>Appendix 6: Journal Publication</td>
<td>92</td>
</tr>
<tr>
<td>Appendix 7: RAPID Checklist</td>
<td>110</td>
</tr>
<tr>
<td>Acknowledgements</td>
<td>112</td>
</tr>
</tbody>
</table>
Executive Summary

Background
This research examined the experiences of people with late-stage Parkinson’s disease (PD) and their families and identified the coping and decision-making strategies that were developed as part of people’s adjustment to a long term condition and how these change over time. The research has implications for how therapeutic strategies used by multidisciplinary professionals may support people with late-stage PD and their families. In summary, this is a critically under researched area with a limited range of studies available to construct an evidence base to develop practice. Living with late-stage PD results in a number of challenges for patients, ranging across motor disability, mental change, psychosocial difficulties and a number of nonspecific symptoms. Hobson et al (2001) emphasised how the experience of care giving and coping in PD is poorly understood and highlighted the need for further research in this area. This longitudinal qualitative study sought to explore issues around coping, adaptation and adjustment for people living with later stage PD and their carers.

Data collection was completed from 2007 to 2009 and consisted of 101 longitudinal interviews with 13 people with PD and their carers and 15 interviews with multidisciplinary team members.

Methods
The study utilised a modified grounded theory approach (Glaser, 1978; Charmaz, 2000) based on a combination of constructivist grounded theory and centre-stage storyline generation. It involved the use of diagrams and other visual artefacts to identify ‘centre-stage’ events that highlight the most important ‘storylines’ for those living a life with late-stage PD. In order to place this within an appropriate temporal analysis, the whole approach was underpinned by a biographical perspective. The longitudinal study involved a 28 month period of data collection.

They were seen initially at monthly visits then at negotiated intervals as part of building a picture of adjustment using theoretical sampling. The inclusion criteria for the study focused on patients with an accepted diagnosis of PD (Brain Bank Clinical Criteria) presenting with either tremor dominated or rigid movement and gait problems that produce disabilities and influence their potential to be independent. The sample was drawn from patients living at home with an informal family carer and under the care of Movement Disorder Clinic (MDC). The severity of the illness was determined using the Hoehn and Yahr scale. For the purpose of the study patients were described as being in ‘later adjustment’ when assessed at being between stage 3 and stage 4. At stage 3 people with PD have mild to moderate physical disabilities progressing to more severe disabilities at stage 4, associated with increasing incapacity. In addition a total of 8 multi-disciplinary practitioners from the Movement Disorder Clinic were also recruited into the study to supplement the accounts of patients and family carers. Practitioners included two Parkinson’s Disease Nurse Specialists (PDNS), two nurses based in the MDC, an occupational therapist, a physiotherapist, consultant physician and a research psychologist. Some practitioners were interviewed more than once.
Findings

Bridging

In the research people with PD and their carers described how their adjustment was built on personal and biographical ‘Bridging’ strategies. Adjustment in late stage PD involve three ‘Bridging’ stages that are built around maintaining stability in their lives and two biographical ‘Enduring’ structures that underpin lived experience.

Support for Bridging

• The PDNS role was crucial in managing symptoms and modifying medication.
• The relationship established at early stage PD with the PDNS and Consultant at the MDC was fundamental in maintaining good symptom management as people experienced increasing difficulties and decline.
• The individualised approach employed by the PDNS and the Consultant were highly valued by people with late-stage PD and allowed them to adopt a flexible strategy to symptom control.
• People with late-stage PD had areas of support that were not addressed as currently health and social support was segmented and involved a limited range of interventions and was underutilised.
• The involvement of the multidisciplinary team with people with late-stage PD and their carers in the community was very limited, ‘ad hoc’ and mainly enacted in response to crisis. There was a lack of preventative or anticipatory interventions by community staff with limited involvement by GP’s, community nurses, physiotherapy, speech and language therapy and occupational therapy.

Scaffolding

• People with PD learnt to develop their own strategies for adjustment based on lived-experience expertise with stability grounded in the ‘Enduring’ structures that relied on building on the past.
• In late-stage people with PD and their carers did not have access to readily available information that would be beneficial in maintaining ‘Bridging’ strategies.
• There was little effort to use biographical knowledge to support ‘Bridging’ processes and stages in order to maintain stability.

Recommendations

• Supporting people’s efforts to bridge requires ‘Scaffolding’ that is centred on managing transitions based on learning and supporting relational networks.
• As part of ‘Scaffolding’ there should be access to a structured programme of education following diagnosis that involves multidisciplinary professionals providing education about self management, practical skills and sources of reliable information.
• The purposeful development of late-stage support should extend beyond the PDNS role and involve enhancing the role of the PD Support Worker and local support groups.
• Admission to hospital and the management of medication requires a patient-held medication chart to be utilised.
• The management of problems with memory related difficulties requires greater structure and better established links and shared developments with memory-clinics. Shared learning between memory clinic and PD multidisciplinary teams would be beneficial in identifying problems earlier and broadening the range of interventions.
• A defined and integrated approach to palliative care and end of life care in late-stage PD is required that is focused on understanding ‘Bridging’ stages, supporting ‘Scaffolding’ using biographical knowledge.
1. Introduction

The research was conducted as part of a postdoctoral fellowship programme funded by RCBC Wales/The Health Foundation. The research study examined the experiences of older people (over 60 years) with Parkinson’s disease (PD) and attempted to understand the transitions experienced by patients and their families as they encounter greater disability. Ongoing work in North Wales has focused on the ‘biographical work’ of people with PD and their families during early adjustment to the diagnosis. It has highlighted the importance of strategies developed by people themselves in managing their condition and coping with a degenerative disease. The RCBC Fellowship programme provided an opportunity to develop a study that focused on people with late-stage PD and their families living at home and supported by a Movement Disorder Clinic (MDC) in North Wales.

This report will outline the significant issues that confront living with late-stage PD and how people develop strategies as part of a number of stages of adjustment. The report will also discuss the methodology and innovative methods used to construct a grounded account of adjustment with people as active participants and suggest some possible next steps in developing practice and services.

Background

The three-year study mainly addressed the management of chronic conditions, focused on a period of 28 months data collection. It aimed to further understand the complex process of later adjustment in older people and their families living with PD. The research question explored how people with PD, their families and the multidisciplinary team (MDT) address the difficult issues that emerge as part of managing their life with a progressive illness. The study examined adjustment by placing patient participation in health (and social) care at the centre of chronic illness management by using the experiences narrated by patients and their families in conjunction with those of practitioners. Furthermore, the study was directed towards defining what PD patients require in terms of service delivery in order to support their wellbeing and the adoption of a range of adjustment approaches to living with their condition. Arguably, the study findings have implications on a wider level as part of policy development in understanding how best to support older people and their families living with PD and other neurodegenerative conditions, examining the role of multidisciplinary teams and specialised services such as MDCs.

The purpose of the study was to develop an understanding of how older people (over 60 years) living with PD and their families engage in later adjustment. The complexities of later adjustment are poorly understood from the perspective of people with PD and their families. The study sought to develop an understanding of lay knowledge and map the processes of transition in PD and explore how the stages and the associated increasing levels of disability are managed by people with PD and their families, and how this relates to the strategies employed by the multidisciplinary team in the MDC.

Parkinson’s disease

PD is recognised as a neurodegenerative and incurable chronic illness that has a major impact on health and requires substantial personal and social adjustments (Playfer, 2002). Furthermore, the facts relating to the incidence of PD underscore the significance of this particular chronic illness with over 120,000 people in the UK diagnosed with PD and one person in a 100 over the age of 65 affected, increasing to one in fifty for those aged over 80 years (Bell, 2003). Older people present with a complex picture of functional decline in PD due to a range of factors, including biochemical and degenerative
mechanisms (Jankovic & Kapadia, 2001).

The symptoms become increasingly difficult to control as the disease advances, especially motor complications, fluctuations in the effectiveness of therapeutic treatment and dyskinesias (Stocchi, 2003; Verhagen, 2002).

Whilst PD occurs in people of all ages, it is most common in older people, i.e. those aged over 65 years (Bell, 2003). Bell (2003) suggests that such individuals present with a complex range of symptoms that become increasingly more difficult to ‘control’ as the disease advances, especially motor complications, fluctuations in the effectiveness of therapeutic treatment and dyskinesias (see also: Verhagen, 2002; Stocchi, 2003). Moreover, cognitive changes experienced late on in the condition may lead to a diagnosis of Parkinson’s disease Dementia (PD-D) (Emre et al., 2007) with the concomitant challenges that this diagnosis brings (Emre, 2003). The incidence of dementia is common affecting about 40% of people with PD (Emre, 2003). Within the United Kingdom (UK) there are estimated to be 120,000 people living with PD (Holloway 2007) and worldwide the Working Group on Parkinson’s Disease (PDS) (PDS, 2008) highlights the service inequalities that exist for this group and the need for services to reach out to family carers. One potential solution recommended by the report (PDS, 2008) was the commissioning of more Parkinson’s Disease Nurse Specialists (PDNS) in primary and secondary care who use a family-centred approach in order to better manage the distressing range of psychomotor and physical signs and symptoms that are a hallmark of the condition. However, to develop such services there is a need for a more complete understanding of the experience of living with late stage PD for those affected and their families.

The NICE (2006) guidelines note that PD results in extensive disability and costs to health and social care, and has a substantial impact on family carers. However, despite growing awareness of such difficulties, there has been limited attention paid to the experiences of older people with PD and their families during late-stage disease, particularly from a longitudinal perspective (Hobson et al., 2001). Addressing this deficit was the main aim of the study reported here.

**Defining early and late-stage in Parkinson’s disease**

Hoehn and Yahr (1967) classified PD along five stages, with stage 5 indicating severe
disabilities and the loss of independence. In the present study ‘later adjustment’ describes the worsening condition of a patient as the course of the illness progresses and in relation to Hoehn and Yahr’s (1967) scale, later adjustment is located between stage 3 and stage 4. At stage 3 people with PD have mild to moderate physical disabilities progressing to more severe disabilities at stage 4.

**Adjustment and coping in Parkinson’s disease**

Research studies have increasingly attempted to understand the impact of PD on quality of life and identify the range of coping strategies employed by people and their families (MacCarthy & Brown, 1989, Hermann et al 1997, Brod et al 1998, Carter et al, 1998,). Hobson et al (2001) emphasised how the experience of care giving and coping in PD is poorly understood and highlighted the need for further research in this area. The efforts of researchers have been largely dominated by a ‘stress coping’ model (Aldwin &Park, 2004; Nolan et al, 2003). Coping methods have been described as involving cognitive, behavioural and avoidance strategies (Hobson et al, 2001), yet such concepts may not sufficiently reflect the ‘insider’ experiences of people with Parkinson’s disease and their families. In addition, in PD, the wellbeing of carer and cared-for are very closely related (Hobson & Meara, 1999).

Research studies have focused predominantly on medical treatment and drug therapy (Abudi et al, 1997) but also increasing interest has focused on issues surrounding subjective accounts of quality of life. Living with PD results in a number of challenges for patients, ranging across motor disability, mental change, psychosocial difficulties and a number of non-specific symptoms (Abudi et al, 1997).

In summary, this is a critically under researched area with a limited range of studies available to construct an evidence base to develop practice. Nonetheless, researchers (Hobson et al, 1999) acknowledge the need for more qualitative research to explore the issues around coping and adjustment, particularly within this group of people living with PD. The need for the research is supported by people with PD and the organisations that represent them. The study has a potential to make a contribution to the evidence base and give a voice to people with PD and their families.

**Aims and objectives**

The study aims were to develop a grounded theory that mapped the experiences of people with PD and their families as they attempted to manage and adjust to the transitions involved in the later stages of their life with PD. The study objectives were:

1. To seek to understand how people with late-stage PD and their families adjust to increasing disabilities and reduced independence;
2. To explore the experiences of the family and the person with PD during this period of transition;
3. To identify the strategies used by people with PD and their families to manage their transition to a different stage of life with PD, based on their own accounts;
4. To examine the therapeutic strategies used by multidisciplinary professionals to support people with PD and their families during this period of transition;
5. To explore the professional relationships between the MDT in the MDC and people with PD and their families as part of managing later adjustment but also including appropriate supplementary health and/or social care practitioners.
6. To make recommendations regarding how practitioners can incorporate the outcomes of the study into individual management plans.
2. Study design and Methodology

The study aimed to understand adjustment in later PD from an emic perspective and used grounded theory methods to generate ‘theory from data’ so that “such theory fits empirical situations, and is understandable to sociologists and laymen alike” (Glaser and Strauss, 1967, page 1). Grounded theory methodology is well suited to understanding the experiences of those living with chronic illness (Corbin and Strauss, 1987) and provides an account of the processes underpinning the phenomenon, such as adjustment. Accounting for process is crucial in understanding chronic illness (Rolland, 1988) and grounded theory provides a description of ‘movement’ in complex situations by extending beyond themes and thematic analysis and developing categories which require properties and dimensions to say ‘how’ and ‘why’ categories are important in a process, such as adjustment. It is ‘a running theoretical discussion using conceptual categories and their properties’ (Glaser and Strauss, 1967, page 31).

The touchstone of grounded theory is theoretical sensitivity (Glaser and Strauss, 1967). Glaser (1978) develops an approach to grounded theory that pivots on ensuring a focus is maintained on generating theory that explores the meanings attached to the phenomenon from the participant’s point of view. It utilises a staged approach to data analysis that is directed by theoretical sampling as a way of refining what shapes the phenomenon and how it ‘works’ in a social situation. The aim is to represent the phenomenon as a theory and keep grounding this in the data that emerges from the participants (Glaser, 1978). It is a dynamic and creative process that develops categories to concepts to theories through a process of sorting out what is ‘core’ to the theoretical story being developed and importantly identifies the processes that underpin the phenomenon.

The work of Charmaz (2000; 2006) has provided a catalyst for developing a closer attention to giving the voice to participants in grounded theory. Glaser’s (2002) response to Charmaz signals the centrality of this concept in a Glaserian approach. Charmaz (2000; 2006) argues that contemporary approaches to grounded theory need to extend beyond Glaser and Strauss’ (1967) objective of being ‘understandable’ to both researcher and participant, rather ‘meaning’ has to be ‘understood’ through negotiation in order to reach a ‘shared understanding’. In the present study, issues of ‘insight’ (Glaser and Strauss, 1967; Glaser, 1978) were addressed within the initial phase of the work to inform the researcher’s theoretical sensitivity by the establishment of a Lay and Academic Advisory Group. This ‘opened up’, rather than the ‘closed down’ the research question prior to fieldwork and contributed to the fit, work and relevance of the final findings of the study.

Sample and recruitment

The study focused on the recruitment of people with PD, their families, members of the multidisciplinary team in the MDC and community-based health/social practitioners involved in providing care in people’s own homes. Access to the patient sample was agreed through the MDC in a North Wales NHS Trust. Furthermore, as part of an existing and longstanding relationship with the NHS Trust the researcher has an Honorary Research Contract in place. The sample aimed to consist of:

People with Parkinson disease and their family carers

A sample of 15 Parkinson’s disease patients and their family carer(s) was sought for recruitment from the Movement Disorder
Clinic. The inclusion criteria for the study focused on patients with an accepted diagnosis of Parkinson’s disease (Brain Bank Clinical Criteria see Gibb and Lees, 1988). They were present with either tremor dominated or rigid movement and gait problems that produce disabilities and influence their potential to be independent. The sample was to be drawn from patients living at home with an informal family carer and attending the MDC. The severity of the illness was to be determined using the Hoehn and Yahr scale (1967). For the purpose of the study patients were to be described as being in ‘late-stage’ when assessed at being between stage 3 and stage 4. At stage 3 people with Parkinson’s disease have mild to moderate physical disabilities progressing to more severe disabilities at stage 4, associated with increasing incapacity.

The screening process for recruitment to the study was to be completed by the Consultant as the RMO and the PDNS using a number of existing assessment tools used in the MDC. Patients and their families that met the study’s criteria were to be approached through the PDNS at the MDC or during clinical home visits. They were to be provided with a detailed information leaflet outlining the aims, structure and duration of the study by the PDNS. The information leaflet was to be made available as a paper version or on audiocassette to facilitate ease of access to the information for some possible participants, with visual impairments. Subsequent involvement in the study required the completion of an Expression of Interest form returned to Bangor University. On receipt of the Expression of Interest form a meeting at the person’s home was to be organised to provide an opportunity for an informal discussion with the researcher about the study, prior to consent forms being signed. Patients and their families’ interested in participating in the study will also be able to contact the researcher directly by telephone or through the PDNS.

People with PD and their carers were to be asked for their informed consent to participate in a number of interviews over time, the choice of maintaining a memo book to record significant events, and permission for the researcher to interview members of the multi-disciplinary team regarding their clinical management and consult their medical case notes. The framework developed by Dewing (2002) underpinned the approach to the process of obtaining and maintaining consent during the course of the study. This was to include face-to-face encounters to seek and maintain consent and establishing how the person usually consents to activities and procedures through liaison with the family and members of the MDC. Capacity and competence is established by engaging a number of sources and the key is ‘around accessing the meaning of what is being communicated and interpretation’ (Dewing, 2002, p.166). The series of steps advocated by Dewing (2002) was to be augmented by the principles of Whitlatch, Feinberg and Tucke (2005) in managing the consent process with persons with cognitive impairment. At the heart of the consent will be a number of stages to ensure the veracity of informed consent, assessing the person’s:

1. Awareness of the procedure they had been through;
2. Level of competence and ability to give informed consent to a procedure; and
3. Retained a degree of verbal fluency and level of concentration.

It was considered essential that each of these criteria underpinned the consent process in the study. Furthermore, consent was to be reaffirmed at each encounter and advice from the consultant and the PDNS was to be sought if the condition of the patient deteriorates during the course of the study to ensure the appropriateness and veracity of consent.

**Practitioners from the Movement Disorder Clinic**

A sample of eight multi-disciplinary
practitioners from the MDC was also recruited into the study to supplement the accounts of patients and family carers. Practitioners included nurses, occupational therapists, physiotherapists and a Consultant physician. Information regarding the study, its aims, methods and duration was to be provided for the MDC team. This included written information and an informal discussion with the researcher to address any concerns.

Participants were approached by the researcher at the MDC and all the practitioners provided with a detailed information leaflet outlining the aims, structure and duration of the study. Subsequent involvement in the study requiring the completion of an Expression of Interest form and an informal discussion prior to consent forms being signed.

**Data Collection**

A constructivist grounded theory does not use standardised measures as a foundation of the research relationship (Charmaz, 2000), rather the theory is allowed to emerge from the data through the theoretical sensitivity of the researcher (Glaser, 1978) but also importantly in the present study by enabling the participant to become a ‘co-researcher’ of their experience and develop theoretical sensitivity through guided reflexivity. The research process is built upon the method of Constant Comparative Analysis (Glaser and Strauss, 1967).

**People with Parkinson’s disease and family carers**

The primary method of data collection was by interview and the digital audio-recording (with consent) of the encounter. Interviews initially aimed to explore the research aims and objectives. Subsequent interviews were more patient-focused and developed as part of the data gathering process, theoretical sensitivity and theoretical sampling (Glaser, 1999) informing the process. Also, as part of the data collection process, people with PD and their families were provided with ‘memo books’ (Glaser, 1978) if they wished to record significant events, experiences and/or feelings outside the conduct of interviews. Advice and support was provided for both the person with PD and their families in order to facilitate their active participation. People were given the choice of selecting their preferred form, with ‘memo books’ being provided in written or audio format. People with PD and their carers were invited to either be interviewed together or separately. The data collection process was to be underpinned by a longitudinal design, with a cycle of interviews completed every 2 months initially and then repeated for 24-28 months at negotiated intervals. Consent from patients and carers was sought at each interview and recorded on audio equipment.

Interviews were conducted in the home of people with PD. The ‘patient’ interviews completed with both the person with PD and their family member/s on each occasion, where possible. Through sustained contact it was envisaged that a mutually trusting relationship would evolve with participants and this would enhance theoretical sensitivity (Glaser, 1978). In the first instance, a semi structured interview schedule was to guide the form of the interview (Appendix 1). The first interview was to seek to gain a biographical account from the person with PD and their family, prior to exploring other issues about adjustment and coping. Based on previous experience, each of these initial areas would be explored over a number of interviews and encounters. As interviews proceed the content would be shaped by the data generated during the interviews based upon Constant Comparative Analysis and guided by theoretical sampling procedures (Glaser and Strauss, 1967; Glaser, 1978). The interview process was also to utilise diagramming techniques focused on the principles of establishing ‘what’s centre stage’ (Keady and Williams, 2007).
Practitioners from the Movement Disorder Clinic

Grounded theory interviews with the multidisciplinary team (n=8) from the MDC were to be completed at the same intervals as patients and family carers in order to examine their perspective on the condition of the person with PD, the current management of their symptoms and the support strategies being deployed. The professional interviews were to be completed in the MDC on an individual basis. In the first instance, a semi-structured interview schedule was to guide the form of the interview (Appendix 2), however as interviews progressed the content of the encounters were shaped by the data collected from people with PD and their families, based upon constant comparative analysis (Glaser and Strauss, 1967).

Grounded theory approach to interviewing

As part of the grounded theory process data collection and analysis are in many respects interwoven (Glaser and Strauss, 1967; Glaser, 1987). The researcher kept a theoretical memo book to note down observations and links to theory development (Glaser and Strauss, 1967). Furthermore, interviews with all participants were completed with the data collection process constantly informed by the process of data analysis. This included constantly comparing findings from interviews within the patient/family and also between patient/family and the practitioner. Comparing data enabled the researcher to explore the complexities of later adjustment longitudinally and examine changes in understanding, responses by practitioners, people with PD at each series of interviews and account for basic social processes over time. As part of the study design people with PD and/or their families or practitioners could withdraw as participants at any time. Once the data collection was complete the researcher completed a visit to all participants in order to discuss the findings and present a summary report.

Data Analysis

The textual data was subject to Constant Comparative Analysis, a well-known methodological approach in the development of grounded theory (Glaser and Strauss, 1967). In this way the theory is allowed to emerge from the data through Constant Comparative Analysis and the theoretical sensitivity of the researcher (Glaser, 1978). The interview data was fully transcribed and subject to grounded theory coding and analytical procedures (Glaser and Strauss, 1967; Glaser, 1978). The data was subject to analysis underpinned by the principles of theoretical sensitivity, guiding the development of categories, supported by properties and dimensions (Glaser, 1978). As the longitudinal data collection proceeded, theoretical sampling shaped and tested the emergent theory in partnership with theoretical sensitivity. At the heart of the enterprise is the identification of basic social processes (Glaser, 1978). Participants were to also involved in the ‘theoretical journey’ and through the use of diagramming they would comment upon the emerging theory. Such an active role is encouraged by Charmaz (2000; 2006). In this way the emergent categories that build concepts and theories were to be tested–out as part of the interviews, subsequently transcribed and subject to further analysis. The researcher’s memo books and the ‘memo books’ provided for people with PD and their families were to be part of this analytical process providing ‘analects’ as part of the emerging data.

Ethics

The study involved vulnerable older adults and the researcher was sensitive to the responsibilities noted under the Research Governance Framework for Health and Social Care (2001). In particular, people with PD in the study were to have cognitive impairment and consent would be a constant process, rehearsed at every encounter based on the
principles developed by Dewing (2002). An explicit strategy for disengagement from the research process was in place as part of the consent process (see Woods, 2001). The researcher also established a procedure in place to manage the reporting of abuse (Action on Elder Abuse, 2004). Issues discussed during interviews were sensitive and these required careful management (see Lee, 1993; Brannen, 1988). Guidance was based on collaboration with INVOLVE and the Parkinson’s Disease Society guidelines. The study was attentive to good practice guidelines for involving participants (see Hanley et al, 2000). The NHS Research and Development Strategy (DoH 2000) endorses the principle of active partnerships involving older people and their families in the research process and the dissemination of the research findings. From the outset the study engaged people with PD through the involvement of lay members as part of the Lay Advisory Group and the Parkinson’s Disease Society.

Approval was obtained from the North Wales Central Research Ethics Committee and the North Wales NHS Trust Research and Development (R&D) Committee. As part of the current R&D arrangements the principal researcher has an approved Honorary Research Contract which includes approval for interviewing patients and their families. As part of good research practice, the General Practitioner responsible for the person with PD were to be informed of their involvement in the study once the consent procedure was complete. As a single researcher the conduct of interviews in the community adhered to the good practice guidelines adopted by the Centre for Health Related Research (CfHRR) based on the ‘Code of Practice for the Safety of Social Researchers guides the research practice’.

**Reference Group**

The study was supported initially by a Lay Advisory Group, consisting of five people with PD (and in four cases their families) and the following academic staff: Professor Jane Noyes (Bangor University) Professor John Keady (University of Manchester) and Professor Bob Woods (Bangor University). This was established with advice from the INVOLVE Support Unit. Lay members were actively engaged with the principal researcher and received information and extensive discussion regarding the project and its methodology. The lay members were involved in reviewing and modifying the research plan, developing the researcher’s understanding of life with PD, described as part of the grounded theory methodology as ‘theoretical sensitivity’ (Glaser and Strauss, 1967). Once the research study commenced one of the lay group, Alison Underwood remained as an advisor and provided advice, guidance and an external lay perspective on the development of the grounded theory.

The Reference Group was supported by an External Clinical Reference Group based in Newcastle (co-ordinated by Dr Anna Jones). In addition, the Parkinson’s Disease Society in Wales and the UK were been consulted as part of the preparatory phase of the study design.

**Study design: implementation and modification**

The study recruited 13 people with PD and their family carer to participate with the majority of carers being spousal and two filial. The sample varied in age from 61 –89 and included 10 men and 3 women. On being recruited to the study they had a variety of symptoms and defined by the clinical team as being in ‘late-stage’. As part of the longitudinal design the main data collection occurred over 24 months but extended in some cases to 28 months as part of theoretical sampling (Glaser, 1989). Two participants were withdrawn from the study during the second year and one died. Two carers were consented but did not actively participate in the interviews and two additional family members engaged in the care-giving role for a
short period of time consented to be interviewed respectively on one occasion to discuss particular issues.

**Data collection and analysis**

The engagement of participants was facilitated by the development of the centre-stage technique (Keady and Williams, 2007). The centre stage diagrams explored four inter-related processes: i) what [is centre stage storyline in the lived representation of meaning]; ii) when [does the centre stage storyline occur]; iii) who [is centre stage]; and iv) how [is the centre stage storyline supported/accomplished). Through this diagramming process, the centre stage was also a literal and metaphorical process in that the participant places people/issues/concerns as close to, or as far away from, the centre stage as they chose. This diagramming provided an immediate visual narrative, one that could be compared as the centre stage storyline(s) change as the relationship and encounters developed over time. The interactive data collection and analysis processes of diagramming resulted in a sequence of two main theoretical diagrams focused on ‘what’s centre stage’ and ‘who’s centre stage’. These storylines were ‘fleshed out’ by additional descriptions, additional diagrams or commentaries as part of the interviews. The additional storylines based on the centre stage diagrams identified iii) how [is the centre stage storyline supported/accomplished) and iv) when [does the centre stage storyline occur]. This process of developing centre stage storylines is illustrated by the case examples of Jack and Joan and how they identified who and what was ‘centre stage’.

The diagrams developed by Jack (Figure 1 and Figure 2) utilised arrows to indicate movement ‘on’ and ‘off’ centre stage with the GP and district nurse (DN) being permanently ‘off stage’ during the interview date in Figure 1 and the problems with bowel, continence and eating and drinking also ‘offstage’ in Figure 2. The diagrams were re-visited on subsequent visits as part of the interview. The modifications in the diagrams during a series of interviews highlighted changes in the symptoms experienced by people with PD and who was involved in managing care.

The case example of Joan (Figure 3 and 4) illustrates the complexity of life with PD involving a range of symptoms ‘centre stage’, their interrelationship as overlapping circles and the development of new symptoms or conditions, such as a stroke in Figure 4. Again the arrows demonstrate movement with speech and swallow problems becoming more or less ‘centre stage’ and the interconnection between the stroke, PD and the colostomy in being ‘centre stage’ for Joan. The diagrams indicating who was centre stage (Figure 5 and 6) highlight the shifting pattern of involvement by different people over time as Joan’s condition changed. The earlier diagram describes a close network which undergoes modification in Figure 6 with a number of people closely linked, such as the PDNS and GP but being ‘off stage’ ready to become more centre stage as required. Joan’s mother is ‘off stage’ as both a source of emotional support and someone to be cared for as she lived with dementia.

The implementation of the centre stage techniques and the identification of storylines proved highly effective as a form of data collection involving diagramming but also importantly it engaged people in analysis and reflexivity.

‘Diagrams useful for thinking about things, after interviews [we] carry on talking about issues, can relate to that... Something concrete like a building blocks’ (Joan 21.04.09).
Figure 1: *Who’s centre stage: Jack as a case example.*

Figure 2: *What’s centre stage: Jack as a case example*
Theory development

The research adhered to its milestones and timetable although data collection and theoretical sampling continued for a period of 28 months as indicated in the Gantt chart (Appendix 3). The development of a grounded theory focused on ‘Bridging’ and its stages were discussed with participants and modified during interviews.

As the work progressed the main stages and supporting properties and processes were described in a journal paper and subjected for peer review (Williams and Keady, 2008; see Appendix 6) with a critical commentary. This was followed up by a number of presentations at Northumbria University and the University of Manchester to obtain critical feedback on the emergent theory by clinical and academic staff.

As Glaser (1978) notes theoretical writing is important:

“Both feedback on and use of publications will be the best evaluation of the analyst’s grounded theory. It will be his main source of criticism, constructive critique.” (Page 128).

However, as Glaser (1978) identifies the “write-up of sorts is a theory of a core variable which freezes the on-going for the moment” (page 129) and the grounded theory was subject to further theoretical sampling, modification, reflexivity and verification by additional interviews and analysis of the data until August 2009. A final account is presented in the report having now been tested for fit, work and relevance (Glaser, 1978).

Figure 3: Who’s Centre Stage – Joan (August 2007)
Figure 4: Who’s Centre Stage – Joan (April 2009)

Figure 5: Who’s centre stage  28.06.07
Figure 6: *Who is Centre Stage – Joan (April 2009)*

As part of diagramming the language of participants was used and this used a number of abbreviations/terms as indicated below:

**Key:**
- Physio: Physiotherapist.
- PDNS: Parkinson’s Disease Nurse Specialist.
- OT: Occupational Therapist.
- GP: General Practitioner.
- SLT: Speech and Language Therapist.
- Consultant: Consultant Physician.

Elderly mother supported

Friends

Neighbours

Daughter (2)

Daughter (1)

PD

Me

You

OT, Stoma Nurse, Post Discharge Team

PDNS

Consultant

GP

Physio

‘Gets battered really’ but trained up

Tension
3. Findings

‘Bridging’ emerged as being central to the process of adjustment and coping in late-stage PD. As a concept bridging is not new, and has been used as a metaphor in a variety of settings to describe a process of ‘consolidation’ or ‘reaching out’ from one place to another; for example, ‘bridging the gap’ in social care and education (Small, 2005; Higginbottom et al. 2000). It was the image of a bridge as a means of spanning, linking and moving across or over an obstacle or difficulty that resonated with participants in this study, with bridging here being an active, on-going process by which they attempted to manage the effects of late-stage PD. Bridging is therefore a dynamic, transcending process in late-stage PD and has multiple meanings and qualities, as Joan explains:

“And then the bridging you see, you can’t bridge if you haven’t built a structure of some kind you can’t get over it, it’s just like the Eiffel tower if you like.” (Interview 6, 2008)

The participants agreed that ‘Bridging’ was centre-stage and necessary to adjustment and decision-making in their day-by-day lives. The initial development of ‘Bridging’ as an emergent theory involved three stages, namely Building on the past, Bridging the present and Broaching the future (Figure 7). This formative account identified foundations that were biographical, situational and crumbling as well as a number of supporting processes. However at the end of the data collection the theory developed and co-constructed with participants was modified and ‘fleshed out’ to include a total of two supporting biographical ‘Enduring’ structures and three temporal stages of adjustment and life with late stage PD. In the final agreed theory these were named and separated into:

**Enduring structures:**
1. ‘Building on the Past’;
2. ‘Coming to terms’

**Adjustment stages:**
3. Bridging the Present’,
4. ‘Broaching Collapse’
5. ‘Fractured Bridging’.

The nature of peoples’ contact with professionals also proved important in supporting the processes that helped them to successfully negotiate their lives with late-stage PD and the nature of developing learning and support is described later as ‘Scaffolding’.

During the course of the interviews the properties or ‘foundations’ underpinning bridging at each stage and the enduring structures emerged, namely ‘Adapting’, ‘Reinforcing’, ‘Reacting’, ‘Reflecting’ and ‘Rebuilding’.

As part of the report the development, modification and final grounded theory will now be outlined.

**‘Bridging’ as an emergent theory**

The initial emergent theory of adjustment was based on interviews from May 2007 to November 2007. The starting point for uncovering bridging was the biographical narrative in the initial set of interviews with people with PD and their families based on using Gubrium’s (1993) framework. It was evident that their past life story was important in shaping their present construction of adjusting to PD. As part of narrative work this link between past and present storylines is recognised as important (Bruner, 2004; Williams and Keady, 2007). A particular feature was that people utilised past experiences in a number of ways as part of coping. Participants characterised how they were able to build on their past lives in order to manage their present difficulties.

This part of living with late-stage PD was initially labelled a stage, Building on the past (Figure 7) highlighted the importance of prior events and the nature of prior relationships in
determining the current context of care and initially labelled as a stage. This building on past experiences was already recognised by Keady and Nolan (1999) in a grounded theory study of people living with Alzheimer’s disease. Early in the analysis this was tested–out with participants as part of the narrative-based interviews prior to the examination of centre stage storylines. It was validated as important in the adjustment story and identified as an initial stage of adjustment. However in contrast to Keady and Nolan (1999) Building on the past was developed as having a range of supporting properties which identified the complex usage of past experiences to support, make sense of events and transfer ‘learning to-cope’ knowledge from relevant past experiences. The properties that comprised the Building on the past stage were embedded in the categories of constructing relationships and managing meaning. These properties interrelated and formed surface and deep levels of ‘building’. In that sense the ‘surface’ categories were apparent and evident in conversation whilst ‘deep’ categories were based on reflection, emerging from the interview process and reflection-with the researcher.

The emphasis on the present context of life with PD resulted in an emerging picture of how people constructed their day to day life with PD around the central aspect of ‘symptoms’. The production of centre stage diagrams as part of interviews to ‘flesh out’ (Glaser, 1978) how people managed adjustment and when actions or people engaged in adjustment. This uncovered the processes involved in Bridging the present as focused on the categories of ‘Managing’ and ‘Working together’. This became a substantive development and comprised the majority of activity where adjustment, adaptation and coping. It was centred in people’s daily construction of their lives and focused on the core category of ‘Maintaining stability’. This stage and its properties were tested and modified to develop a key stage (Figure 7). The categories and properties of ‘Managing medication’, protecting routine, managing meaning and ‘Maintaining stability’ interrelated as with Building on the past and formed surface and deep levels of Bridging the present.

The longitudinal series of interviews during May 2007 and November 2007 highlighted the importance of Bridging the present and Building on the past in the experiences of people with PD and their families. These two initial stages seemed to represent the main adjustment processes of participants. The ‘foundations’ or actions underpinning these stages were initially labelled as ‘biographical’ and ‘situational’, reflecting a focus on engaging in life review in the first stage of Building on the past and the immediate concerns of daily life in Bridging the present.

The third initial stage that was identified as part of the initial data collection process was the difficulties of Broaching the future. The categories and properties of ‘Crumbling managing strategies and routine’, ‘Collapsing stability’, ‘Coping fatigue’ and ‘Cracks in relationships’ formed surface and deep levels of Broaching the future. These were based on the foundations or actions labelled as ‘crumbling’ (Figure 7). Central to this stage was the inability to maintain Bridging the present due to symptom change (either in terms of severity, their overall effect and/or new symptoms) and a process of gradual or rapid decline.

Fleshing out the ‘Bridging’

As part of further interviews with participants during September 2008 to August 2009 the findings from the study embedded in the process of ‘Bridging’ (Williams and Keady, 2008) was further modified. The theory was refined and modified to take account of the complexity of decline uncovered in the later interviews, prompting a reflexive re-analysis of the dataset as a whole and theoretical sampling with a number of participants.
Figure 7: Bridging as an emergent theory

Bridging stages

Building on the Past

Bridging the Present

Broaching the Future

Foundations

Biographical

Situational

Crumbling

Processes

- Life History
- Significant events
- Relationships
- Identity

- Managing meaning
- Managing medication
- Managing stability
- Protecting routine

- Coping fatigue
- Cracks in relationship
- Crumbling managing strategies and routine
- Collapsing stability

Time
In brief, the modified bridging model involved developing and separating out the initial sets of stages, constructing a more sensitive and complex account centred on what were termed ‘Enduring structures’ and ‘Adjustment stages’ rather than the linear presentation of the data initially developed (Williams and Keady, 2008).

It focused on two ‘Enduring structures’ which identified life-based and biographically mediated supports that underpinned ‘Bridging’ and the general pattern of adjustment. The experiential patterns of Building on the past and Coming to terms were utilised in responding to PD. The ‘Adjustment stages’ were temporal stages and consisted of Bridging the present, Broaching collapse and the development of a new stage Fractured Bridging. These described how people experienced late-stage adjustment in PD over a period of time.

Together these two parts of ‘Bridging’, respectively the structures and stages, sought to explain the basic social processes of adjustment, adaptation and coping to life with PD. Of particular importance in developing the final grounded theory was theoretical sampling with a number of participants experiencing the transition into decline (n=8) that resulted in the re-orientation of Broaching the future (Williams and Keady, 2008) to Broaching collapse and the emergence of a new stage described as Fractured bridging prior to reaching saturation (Glaser, 1978). Both these stages of adjustment recognised the process of how people responded to decline and PD based on ‘fighting it’ and ‘accepting it’. These were part of the continual effort to ‘bridge’ and manage the difficulties of living with PD when symptoms were changing and decline became evident as part of daily life.

**Enduring Structures**

Enduring structures described what sustained people in their daily lives and enabled them to respond to the challenges of maintaining what they defined as stability in their lives and the achievement of quality of life, often defined as ‘contentment’. These were core biographical bridging supports that pre-dated the onset of PD and were built on experiential and reflective learning. They were closely related and underpin the main ‘Adjustment stages’ to PD which represented the stages or journey that people experienced in a life with PD. The ‘Enduring structures’ identified processes that were central to people’s overall pattern of adjustment and explain how people engage in Building on the past and Coming to terms during their lifespan. The sense of what was ‘enduring’ emerged from people’s descriptions of how they responded to the onset of PD as a disease and life with its symptoms. Importantly, ‘Enduring structures’ were a feature of an individual and shared life, experienced by the person with PD and their carer. ‘Enduring structures’ were embedded in the many challenges experienced by people during their lifespan, such as bringing up a family for Julie or Charlotte surviving the second World War and emigration.

“I’ve always said during my life when things didn’t happen to be so good that nothing would be so bad again and it wasn’t if you compare things to what you have been through, um, and what you go through at the time you see ... it’s a sort of comfort isn’t it”

(Charlotte, Interview 10, 2008)

In this way the description of ‘Enduring structures’ uncovered the hidden biographical aspects of ‘Bridging’ which informed the participants efforts to adjust and respond to PD through the ‘Adjustment stages’. The continuous building of ‘Enduring structures’ was evident in the case of Herbert and his wife Mary. Following his difficult and distressing death Mary continued to engage in the processes of ‘Reflecting’ and ‘Rebuilding’ with her family. It was clear from the data that there was a reciprocal relationship between
the ‘Enduring structures’ based on the processes of ‘Reflecting’ and ‘Rebuilding’ and that these foundations were interrelated. These ‘Enduring structures’ will now be outlined:

Building on the past

The structure of Building on the past provided the ‘biographical’ foundations on which current bridging activities in the ‘Adjustment stages’ were built (Figure 8). In the context of PD most participants had received their diagnosis some time ago and thereby all were well-versed in the impact that PD had upon their lives. However, in order to make sense of their present they needed to ‘build’ upon the past by engaging in continual life review involving the processes of ‘Life history’, ‘Significant events’, ‘Identity and relationships’. Everyday events were shaped by the past and continually recast and reconstructed in the light of challenges presented by the current symptoms of PD. The categories and properties established earlier in the research work were elaborated and tested and key processes mapped. These were:

Life History: Participants with late-stage PD ‘worked’ with their life history and engaged in ‘storying’ past experiences with their carer and created a sense of ‘lived time’ with a sense of meaning. The meanings of the storied life emphasised connections and continuity and represented an accepted and shared storyline. For both individuals this process of revisiting, reviewing and re-building life history in order to construct a coherent storyline for life with PD was a situational (day-to-day) and cyclical process that was repeated regularly as the disease progressed in order to build a new storyline.

Significant events: This continuing review of life history helped to identify personal and shared significant events. Such key events influenced the relationship of the person with PD and their carer and were central in mapping a storyline based on prior lives, such as the shared experience of raising a family. Within this context the diagnosis of PD represented a highly significant ‘past’ event, which, as Joan noted, had been ‘a stony road ...a 19 year journey’ (Interview 3). Past events acted as individual or shared resources that were used in difficult times, such as Jack and Daniel who recounted with their spouses earlier times when they had travelled and achieved ambitions. Such past events could also be used as a ‘refuge’ when people experienced distress or depression.

Relationships: Maintaining a sense of closeness and relationship between the person with PD and their carer required both parties to construct and re-construct their life history together to take account of significant events and identify a sense of purpose and connection. This occurred both when relationships had been longstanding, such as with Daniel or Joan, but also where relationships had been more recent, such as in Ben’s case. All of the above factors influenced the current identity of the person with PD and their carer. It emphasised a ‘sense of being together’ now with PD built on the strengths of the past relationship.

Identity: Biography and prior life experiences helped individuals to shape their identity in the face of PD. For example, Charlotte had a strong sense of being a ‘survivor of hardship’ following key events in her life, such as the loss of her husband and surviving the war years in Germany: “bombed out we had only the things we had on ...we lived in the cellar for three years”(Interview 3). Equally, Jack and Daniel had lived through a series of extraordinary events during the war in Europe and Asia. However, identity was not only based on ‘extraordinary’ events, but was linked to personality. John and Julie and their carers had a sense of ‘being determined’ and always worked hard to ‘make a life’ and bring up their families. This sense of a shared and
collective identity was built on the foundations of the past and was crucial in shaping a new life, understanding what was happening and what to do with this ‘new body’ in the light of PD. As the disease progressed identity was not only (re)negotiated between the person with PD, their partner/carer, and their family but also with practitioners, such as the PDNS and their GP. Consequently, continually framing and re-framing the meaning of past events helped to support existing relationships by providing a shared sense of identity and continuity both between partners and, to a more limited extent, those professionals involved. This ‘building on the past’ provided the ‘foundations’ upon which ‘Bridging’ was built.

Coming to terms

This ‘Enduring structure’ was linked to the ‘reflecting’ processes of Building on the past as an individual or shared life-review through Building on the past. People with PD and their carers developed a sense of ‘acceptance’ that in some way ‘coming to terms’ was a pattern of the life course. However, this process was not easily accommodated or rapid but involved learning from past events and locating its relevance in their present lives. The Coming to terms structure was not only constructed from building on past events but also involved learning from present life-events and then integrating these into a previous or past storyline.

The Coming to terms structure involved difficult processes and was subject to constant review and evaluation (Figure 9). As part of their life with PD this stage focused on major events for the person with PD and their carer. For instance, Joan suffered from a stroke, Herbert’s wife Mary experienced bereavement, and for Julie and Tudor the key event was selling their home and re-locating some miles away to a different village to a bungalow because of recurrent falls due to PD. Coming to terms involved accommodating change and integrating a pattern of adjusting to transitions as part of their philosophy or approach to life. Peter and Joan described their storyline of coming to terms as an ‘acceptance road’ from the onset of the PD and Charlotte identified how ‘you can’t give in’:

“Yes, you have to, you can’t give in, yes. What else can one do?, one day I wrote a letter absolutely perfect and the next day I couldn’t write it so, he said ‘It's definitely Parkinson’s’. I was sixty, I think I was sixty two by then, and he said that’s the age most people get it actually, around about the sixty age mark. So I thought well I’ve had it now, I’m dying (laughs). But I was in the bungalow and I could, sort of, arrange my day to what I knew I could do and that’s how I’ve carried on. For instance, I still go on the bus to the supermarket, it stops right outside the house here and uh, it takes me into town, I only have to do, walk a few yards and I always go on a day when I know my daughter can pick me up. So I do a little bit of shopping, go to Boots, go to the supermarket, do odds and ends like that, because it’s the only time I really feel I’m independent you know, just for about an hour or two’” (Charlotte, Interview 9, 2008).

The properties and processes consist of the following:

Taking actions: This was based on initial and later actions that required an assessment of what was ‘going wrong’ and seeking to control by understanding and making sense of events. At times this required obtaining help or guidance from a variety of sources but mainly focused on experiential learning.

Evaluating events: As part of ‘taking actions’ an evaluation of events included not only seeking to understand the event or what was ‘going wrong’ but also seeking continuity. In this way people reflected on their past life and attempted to identify past experiences as a resource and integrated
previous storylines. This was illustrated by Charlotte who had a sense of being a survivor yet faced increasing difficulties and was required to ‘come to terms’ with her changing PD by noticing change, seeking control and redefining herself as a survivor of much worst situations focused on the war in Germany. “Well I’m getting worse there’s no doubt about it and I’m falling more, I fell this morning and it was bleeding... I’m losing my balance more” (Interview 13, 2008). For Charlotte there was a sense of continuity constructed between the past and present in order to ‘come to terms’ with her changing circumstances.

**Defining responsibility:** The evaluative process generated a sense of events having a personal meaning that required people to define responsibility for why ‘things happened’ or ‘went wrong’. Asking ‘why me’ was then followed by reviewing a past life and reflecting on the sequence or series of events, such as what led to a diagnosis of PD, a deterioration in walking leading to being chair-bound and housebound or experiencing a bereavement.

**Locating meaning:** The processes of *Coming to terms* was underpinned by an attempt to locate meaning in events or a situation and where possible develop a shared sense of meaning and a storyline. This process of locating and affirming the purpose of change was a recurrent process triggered by change and was centred on maintaining continuity measured against a life storyline.

Together the ‘Enduring structures’ of *Building on the past* and *Coming to terms* represented established patterns of adjustment that were utilised and modified in response to PD. As PD became a feature of people’s lives it also became integrated into a life storyline and over time often became the dominant storyline. The actions of ‘Reflecting’ and ‘Re-building’ that underpinned these two stages resulted in people feeling a variety of responses.

**Bridging : The Adjustment Stages**

The ‘Adjustment stages’ mapped the social processes of adaptation and coping in late-stage PD. They were linked to the onset and progress of PD and the continuing significance of biographical ‘Enduring structures’. The stages of adjustment consist of *Bridging the present, Broaching collapse* and *Fractured bridging*. These represent a sequence or journey of adaptation and people’s purposeful attempts to respond to the day to day difficulties encountered in a life with PD which was also compounded by other chronicity. The stages were dynamic and there was a sense of movement as people reached a point of crisis then based on intervention or a remission of symptoms they returned to a previous stage. However, the underpinning ‘trend’ once people moved to a particular stage was progression towards the following stage. In this sense the stages were complex, interrelated and subject to a range of conditions. The ‘Adjustment stages’ were underpinned by the foundations of ‘Adapting’, ‘Reinforcing’ and ‘Reacting’ actions. These actions described the focus of people’s life and were linked to a series of processes that described the detail of people’s adjustment work (Figure 10).

As part of these stages the movement ‘back and forth’ and the conditions which precipitated change or consolidation presented opportunities for intervention that were often not realised by MDT services to maintain ‘stability’. In this sense the span of people’s bridging activities were often weakened over time and without further MDT intervention to strengthen or manage the process of decline resulted in a shift to the final stage of *Fractured bridging* as identified in the study. This final stage was characterised by isolation, crisis and an erosion of relationships.

The ‘Adjustment stages’ described and explained how people with PD and their families responded to the experiences of transition. The stages identified how shifts in
the hidden processes that underpinned the stages caused a shift to another stage, such as Bridging the present to Broaching collapse. However, these stages were not linear although they identified how people experienced progression and transition over a period of time. The critical stage would seem to be Broaching collapse. In many respects it represents a fulcrum which enabled a situation to be stabilised and returned to successful Bridging the present and the collapse and/or fracturing stages to be delayed or managed so as to minimise any crisis. A number of ‘critical junctures’ or turning points were influential in ‘pushing’ people from one stage to another or ‘pulling’ them back towards a previous stage. These critical junctures identified what precipitated a shift to another stage (Figure 11). It is important to note that these were often a combination of events that were linked to PD, other chronicity, family/relational issues or key events and varied in terms of complexity, duration and impact. However the movement from Bridging the present to Broaching collapse pivoted on the stress on daily life of added complexities which occurred for a period of time (duration) and had an impact on the person with PD and/or their carer. For instance Charlotte experienced an increasing number of falls, memory loss and excessive fatigue and moved from Bridging the present to the more unstable Broaching collapse.

The shift towards Fractured bridging from Broaching collapse seem to pivot on a single key event but one that required an accumulation of events to weaken people’s substantial ability to cope with symptoms and change. Movement through these stages or back and forth along the stages was either gradual or rapid. For instance, Joan and her husband experienced a major family crisis which resulted in Broaching collapse, followed by a sudden stroke. Joan and her carer experienced the instability of the Broaching collapse stage but did not progress to Fractured bridging as their coping thresholds and resources were not exceeded. In a period of some months they returned to Bridging the present by having additional support and a relational response that was grounded in Building on the past and Coming to terms (Enduring structures).

Each of the stages will now be detailed including a description of the complex processes that underpinned the movement from Bridging the present to Fractured bridging.

Bridging the Present

The stage of Bridging the Present captures the need for individuals to feel a sense of control over late-stage PD by maintaining daily activities, medication regimes and interests. It is centred on ‘adapting’ foundations that were situational and ensure continuity with the past and stability in present routines. As such this stage was the main focus of people’s experiences of adjustment and adaptation for many years. Bridging the present was an active process of stabilising through ‘working things out’ and constructing a personal model of day-to-day adjustment and decision making. Day-to-day issues addressed in this way included communication difficulties, slowness of movement, involuntary movement and tremors, falls, fatigue, low mood, anxiety, spasms, limitations on mobility, eating and toileting and living with constant pain. Maintaining stability and constructing meaning were ‘worked out’ between the person with PD and their carer in daily life and constituted adjustment process or ‘Bridging’.

Taking control of routines was crucial to successfully Bridging the present and this involved participants developing expertise, especially understanding their patterns of symptoms and stabilising these using medication, whilst simultaneously seeking to re-build identity and meaning. The difficulties of stabilising and day-to-day managing of late-stage PD were captured by Joan and reiterated by all participants:

‘Very fluctuating – fluctuating quite a lot... from being off to being on. In the middle of
Participants’ experiences of their fluctuating symptoms made them ever more aware of the increasing encroachment of late-stage PD and the impact it had on their daily activities. In order to try and address this Bridging the present involved a range of ‘adapting’ processes that were evident at surface and deep levels (Figure 12).

Managing meaning

Finding meaning in the present involved participants establishing a personal pattern of responses to their PD symptoms. It was here that people integrated ‘Enduring’ and ‘Adjustment stages’ and built on their past. So, for example, Tom, with an occupational background in sales and management, was constantly engaged in ‘seeking patterns’ through the mapping of bar charts and symptoms, whereas Daniel and Jack utilized their past experiences as a confirming source for their identity in the face of changes imposed by PD such as dependence and reduced mobility. For the person with PD and their carer meaning was essentially constructed around the daily routine of managing symptoms and balancing these activities. As Charlotte notes, maintaining a degree of independence, however limited, was central: ‘So I do a little bit of shopping, go to Boots, go to the supermarket, do odds and ends like that, because it’s the only time I really feel I’m independent you know, just for about an hour or two’ (Interview 5, 2007).

In order to maintain a perception of independence a number of participants reported how they avoided seeing other PD patients with more advanced symptoms, such as in Parkinson’s Disease Society (PDS) meetings, for fear of what the(ir) future may hold. This tendency to largely live in the present was a critical feature of Bridging the present which involved little anticipatory planning or thoughts about future plans. However, those people who did attend PDS local meetings, such as Joan and Julie, found them largely supportive and a useful source of a shared sense of ‘fighting it’.

As the disease progressed meaning was constantly challenged by changes in a person’s symptoms such as the ‘horrible’ involuntary movements noted by Charlotte and an eroded sense of being a ‘survivor’. However, she sought to retain meaning by maintaining her interests of listening to music, watching television and reading poetry. Such strategies were widely utilised by people with PD and were anchors in their daily lives enabling people to retain a sense of ‘doing’, continuity and activity in day to day life. This meaning was often managed by a personal philosophy of both ‘accepting’ and ‘fighting’ the late-stage PD, as Jack summarised: ‘Something you have to live with’ that requires ‘making the best of what we got’ (Interview 2, 2007). Managing medication was, however, a critical process in both maintaining independence and making sense of their lives as part of being able to remain at Bridging the present.
**Figure 8: Building on the past as an enduring structure**

<table>
<thead>
<tr>
<th>Life History</th>
<th>Significant events</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sense of lived time</td>
<td>Past life as ‘resource’</td>
</tr>
<tr>
<td>Sense of story</td>
<td>Past life as ‘refuge’</td>
</tr>
<tr>
<td>Sense of meaning</td>
<td>Past life as source of contentment</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Identity</th>
<th>Relationships</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sense of ‘who I am’</td>
<td>Sense of purpose</td>
</tr>
<tr>
<td>Sense of ‘who we are’</td>
<td>Sense of connection (past)</td>
</tr>
<tr>
<td></td>
<td>Sense of being together (present)</td>
</tr>
</tbody>
</table>

**Figure 9: Coming to terms as an enduring structure.**

<table>
<thead>
<tr>
<th>Taking actions</th>
<th>Evaluating events</th>
</tr>
</thead>
<tbody>
<tr>
<td>Initial actions; noticing something’s wrong, finding out, seeking help information, losing control.</td>
<td>Re-examination of past life as ‘resource’</td>
</tr>
<tr>
<td>Later actions; getting control, seeking more advice.</td>
<td>Building on past storyline to support present coping.</td>
</tr>
<tr>
<td>Reflective actions; making sense of consequences, building control through experiential learning</td>
<td>Seeking sense of continuity.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Defining responsibility</th>
<th>Locating meaning</th>
</tr>
</thead>
<tbody>
<tr>
<td>Seeking to understand source of difficulty, ‘why me?’ in terms of PD and chronicity.</td>
<td>Locating and affirming (shared) sense of purpose.</td>
</tr>
<tr>
<td>Placing ‘why me?’ in the context of life history.</td>
<td>Placing events in an illness or life storyline</td>
</tr>
<tr>
<td>Working through responsibility for actions and reactions.</td>
<td>Joining up storylines around core approach; ‘accepting it’, ‘fighting it’, ‘rejecting it’ or ‘could be worse’.</td>
</tr>
</tbody>
</table>
Managing medication

The key to Bridging the present and managing symptoms meant addressing 3 questions: What medication? When to take it? and How often? Participants generally worked within the overall parameters set by the PDNS and the Consultant Geriatrician, but as they became ‘expert’ they ‘experimented’ with dosages or times to maximise the beneficial impact of medication on their lives and maintain ‘stability’.

“As I say I, I usually get about five, six hours out of one lot of medication, it only lasts about four now, I can feel it wearing off so then I’m sort of just hanging around as long as I can before I take the other one, the other, and then within about half an hour I’m back, I’m fairly, fairly good then” (Charlotte, Interview 10, 2008).

Such experimentation was supported by the PDNS and the Consultant and contact with them regarding medication regimes assumed enormous significance in daily life and was at the heart of stabilising activities, with the management of medication being pivotal to maintaining a sense of control.

The role of the PDNS at this time was seen as crucial, not only in helping to understand symptoms but also in gaining a sense of control over them through medication. The medication was reviewed by home visits either a review or on the request of people with PD or their carer. A continuing concern was the reduced impact of the medication in enabling people to ‘bridge the present’ and maintain stability in their daily life and keep their routines ‘safe’:

“But once this prescription wears, this medication wears off if I don’t take the tablets in good time I’m absolutely stuck, you know I’m like a pillar of salt really. Do you know the story about Lot’s wife, I wonder if she had Parkinson’s (laughing)” (Charlotte, Interview 9, 2008).

As the symptoms became more problematic how people protected their ‘time’ and routine by medication became increasingly difficult and complex. It often reliant on a variety of treatments and a strategy worked out through experience:

“So where the Apo (Apomorphine) – if the tablets are slow getting in the Apo’s supposed to fill that gap....as a rescue, but if the tablets are slow getting in and the Apo’s slow getting in you’re left with zero, and that’s when you really go down, so I have to have a couple of shots of Apo and then by that time hopefully the tablets are getting through and then the Apo will join it.” (Joan, Interview 6, 2008)

The reassurance about what, when and how medication should be used defined the relationship between people with PD, their carers and the Consultant and the PDNS. However people gauged the advice given by the PDNS’ according to a judgment made about the depth of ‘PD experience’ by the clinician combined with their own expertise. Changes in medication would be ‘tried out’ and evaluated by people with PD and their carers and their decision making was guided by their individual measures of how day to day life ‘worked out’ with a new regime or medication. They would inform clinicians retrospectively how ‘things worked out’ but often felt that this did not take place quickly enough and might take some months.

Maintaining stability

In late-stage PD Bridging the present involved constantly seeking and (re)affirming meaning and control, trying out new medication regimes and treatment options to manage shifting symptoms. Of central importance was ‘Maintaining Stability’ which required working with ‘time’ and being acutely aware of the relationship between time, medication and symptoms: “The tablets wear off I must have done the things I need...It takes much longer, what used to take half an hour now takes an hour”(Charlotte, Interview 7, 2008).
Whilst stability most often involved medication, other avenues were also explored. Tom, for example, constantly encountered problems with falling in his home and this led to his improvised use of ‘gardening knee-pads’ to cushion his falls. Whilst this looked ‘odd’ their use improved Tom’s quality of life and preserved his independence. For Charlotte, her bedroom had become a refuge from fatigue and falls and was as a place to retreat to later in the day: “Because I just can’t bear to be up any more. It’s my, my most relaxed time is when I’m in bed ... I either watch television or I read” (Interview 7, 2008).

It was evident that ‘Maintaining stability’ required constant work by people with PD and their carers and a process of re-building stability day-to-day. This involved adapting or as described by Charlotte ‘making the best of it’.

**Protecting routines**

Routines built into daily life were closely linked to medication taking, and provided ‘windows of time’ for activities, e.g. getting up, being able to wash and dress in the morning and arranging mealtimes. Each person with PD and their carer had their own routine for daily life that was modified as symptoms changed or there were ‘good days and bad days’. Routine was influenced by ‘Managing meaning’ and ‘Managing medication’ and supported ‘Maintaining stability’. Routines were focused on day to day activities, weekly events and routine focused on getting up, having a wash and being dressed, mealtimes, shopping, getting to bed and also occasional social events or appointments. As with stability the actions of ‘Protecting routines’ involved an acute awareness of time and using time effectively and efficiently before symptoms returned or overwhelming fatigue. Centre stage was the routines that surrounded medication which structured the day and defined the ‘windows of time’ for daily activities. The timing of when medication was taken in the morning was crucial in enabling the day to start, such as Julie who had to crawl ‘on all-fours’ to the toilet before they ‘kicked in’ and then she started to move around the house.

“So, adapting myself to this illness, I don’t think I ever will (laughs), I make the best of it. um, I look at it, I’ve got half a life, that’s how I look at it now, I’m not so bad in the morning, from about 4 o’clock in the afternoon I go down” (Interview 7, 2008).

Participants realised that improvement was a ‘remote’ possibility, and therefore managing their symptoms to ensure maximum functioning was their major goal. In addition to medication they often involved the use of routines.

Having a routine centred on completing activities was at the core of adjustment and underpinned ‘stability’ and *Bridging in the present*. Quality of life was often attached to particular activities such as going out for an hour for lunch even if it involved a complex routine of ‘getting the timing right’ and ensuring the wheelchair or electric scooter was in the car and extra medication was taken along in case a ‘boost’ was required.

Routine was protected against symptoms which resulted in ‘going down’ such as excessive fatigue freezing gait, the onset of stiffness, a tendency to fall or terrible tremors. The person with PD and their carer maintained an agreed view of priorities and established a shared routine and as Joan notes this was crucial for daily life to continue: ‘because a number of the items, um, the issues are shared issues and if one or the other goes their own sweet way with a shared issue then you’ve got a problem’ (Interview 5, 2007). However, routines were not static and evolved as symptoms changed, as Joan’s carer highlighted: ‘You’ve just got to, you’ve got to adapt and improvise’.

**Broaching Collapse**

The process of *Bridging the present* continued
to evolve over time but tended to result in a focus on ‘living for the present’ rather than thinking too much about the future. In fact there was an active process of not looking to the future or seeking to anticipate future needs. The future was addressed only in terms of having ‘hope’ that there would be some improvement or medication that might help. The relationship with the PDNS and the Consultant were crucial in retaining a sense of hope as people experienced greater instability as part of Broaching collapse. Joan noted how the Consultant was important in this respect:

“He never, he always left us with hope didn’t he, he never sort of said, just said ‘Goodbye’, he’d say well, you know, ‘See you next time and hopefully the problem has resolved itself’ or... he’d give you some kind of hope even on your lowest moments, you know, he’d pick you up. And he’d say ‘Oh don’t give up... ‘you know, ‘...we’ve got this, that and the other’, I’d say ‘I don’t want any more medication added’, ‘No, it’s not adding, we’ll take that away, put this in its place’(Interview 8, 2008).

Stability became increasingly difficult to maintain as critical events shifted people’s experiences from Bridging the present. As the disease progressed and change became more evident established strategies no longer worked as well or failed and future options, real or imagined had to be considered. Even the best maintained of routines could begin to ‘crumble, especially when medication was no longer able to maintain symptom stability and ‘living for the present’ was even more focused characterised by ‘living day to day’ as the dominant philosophy. The future often seemed to be ignored, or at least not given ‘centre stage’, until the ability to maintain stability in medication and routines began to move from crumbling towards collapse. This did not usually come about due to a sudden crisis but rather the slowly erosive effects of living with PD.

Figure 10: The Adjustment Stages

![Diagram of Adjustment Stages]

- **Critical Junctures**
- **Broaching Collapse**
- **Critical Junctures**

Building the present

Foundations

Adapting Processes

Reinforcing Processes

Reacting Processes

Fractured Bridging

Disease progression

Time
Figure 11: Critical junctures in the adjustment stages

Bridging Present ← Broaching Collapse

A number of events in:
- Illness trajectory
- Family trajectory
- Intersection between both
- Pace of events may be rapid or gradual.

Broaching Collapse ← Fractured Bridging

- A Key event in illness trajectory; sudden or significant symptom change – such as domains of movement, memory or the onset of an infection.
- Accumulation of events that weaken adjustment span
- Overwhelming of established coping thresholds
- Outstripping of coping resources (experiential).

The processes that began to operate as part of Broaching collapse were focused on ‘Crumbling managing strategies and routine’, ‘Collapsing stability’, ‘Coping fatigue’ and ‘Cracks in relationship’ (Figure 13). As with other stages the processes were interrelated. Indeed, the deep levels of ‘Coping fatigue’ and ‘Cracks in relationship’ were defined by a greater emphasis of ‘working apart’ by the person with PD and their carer and an overwhelming sense of fatigue by both partners. These will now be considered in some greater detail.

Coping fatigue

The longevity of PD as part of people’s lives extending to many years had established a pattern of adjustment embedded on Bridging the present. As a result of the shift to the Broaching collapse stage the keystone of ‘coping’ by ‘fighting it’ and ‘accepting it’ was weakened. The critical juncture of a change in the PD, the impact of other chronicity or an upset/crisis in family life defined a stage that was characterised by a sense of being overwhelmed by events and fatigue. The stress of daily routine became difficult to manage for both the person with PD and the carer in particular as a result of symptom change. This involved an increasing impact from existing symptoms or the development of new symptoms. In the case of John, Ben and Jack there was gradually impaired cognition and memory combined with immobility that resulted in ‘fatigue’ in their and the carers coping strategies. The modified situation did focus the attention of people with PD and their carers on exploring ideas about future strategies or plans but largely these were based on affirming the wish to stay at home, ‘see it through’ or consider the possibility of moving to different accommodation. Overall there was a sense of options ‘closing down’ and limited opportunities for changing the situation. As the situation continued the above difficulties began to lead to ‘cracks’ in previously good relationships and difficulties in maintaining established coping strategies. People experiencing this situation were reluctant or unable to consider ‘opening up’ other options and remained focused on attempting to maintain the patterns of Bridging the present despite a process of collapse exacerbated by struggling to support routines and fatigue.
Figure 12: *Bridging the present as an adjustment stage*

<table>
<thead>
<tr>
<th>Surface level</th>
<th>Deep level</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Managing medication</strong></td>
<td><strong>Protecting routine</strong></td>
</tr>
<tr>
<td>* Balancing medication regime and dosage</td>
<td>* Working together as ‘team’</td>
</tr>
<tr>
<td>  • Balancing medication regime and dosage</td>
<td>  • Managing time and defending ‘windows’ of time</td>
</tr>
<tr>
<td>  • Experimenting with medication type, timing and benefit</td>
<td>  • Valuing medication</td>
</tr>
<tr>
<td>  • Getting advice and new options</td>
<td>  • Noticing pace of change</td>
</tr>
<tr>
<td>  • Holding on to control of symptoms</td>
<td>  • Seeking sense of continuity</td>
</tr>
<tr>
<td>  • Noticing pace of change</td>
<td></td>
</tr>
<tr>
<td>  • Seeking sense of continuity</td>
<td></td>
</tr>
<tr>
<td>  • Advice and new options</td>
<td></td>
</tr>
<tr>
<td>  • Holding on to control of symptoms</td>
<td></td>
</tr>
<tr>
<td><strong>Managing meaning</strong></td>
<td><strong>Maintaining stability</strong></td>
</tr>
<tr>
<td>* Making sense of symptoms</td>
<td>* Building routines in daily life</td>
</tr>
<tr>
<td>* Managing continuity</td>
<td>* Working with symptoms</td>
</tr>
<tr>
<td>* Managing purpose (getting through it / fighting it)</td>
<td>* Working around change</td>
</tr>
<tr>
<td>* Seeing personal work</td>
<td>* Working with others</td>
</tr>
<tr>
<td>* Seeing shared work</td>
<td>* (i) Professionals  (ii) Family</td>
</tr>
<tr>
<td>* Managing feelings and hope</td>
<td></td>
</tr>
<tr>
<td>* Building (and Re-building) acceptance</td>
<td></td>
</tr>
</tbody>
</table>
Cracks in relationship
The relational stability of partnerships was weakened by the combination of the sometimes fragile relationship between partners due to the health of carers, the increasing impact of ill-health the contribution of other chronicity, increasing falls, the excessive disturbance to sleep and the emergence of memory problems. The ‘crumbling’ of routines and overwhelming tiredness forced people to start to work apart in daily life with a shift in the responsibility and dependency. It was evident that there was a denuded sense of ‘working as a team’ and the person with PD and the carer started to experience life with PD much more ‘separately’ with the carer seeing daily life as a series of tasks to complete and the person with PD struggling to maintain a sense of control and autonomy. For those experiencing this stage the difficulties with speech and communication and fatigue exacerbated the situation and the person with PD became more isolated within the relationship. There was also an awareness of future decline and attempts to plan ahead by ‘broaching’ the future choices or options that would be best for their partnership. However discussions...
were not followed up or acted upon and the emphasis was upon ‘struggling on’. The relationships were actively maintained by reference to the past and further engagement in Building on the past in order to seek and identify points of connection and a shared sense of ‘being together’ despite the PD and a clearer demarcation of roles as the ‘carer’ and ‘cared-for’. Attempts were made to retain important activities which were done ‘together’, such as going out for lunch even if this caused immense difficulties as in the case of John who had speech difficulties, very poor mobility, experienced repeated falls, increasing memory/cognition problems and difficulty eating and drinking.

Crumbling managing strategies and routine

At the centre of Bridging the present was routine and the increasing exhaustion evident from many carers’ accounts during the Broaching collapse stage resulted in previously held routines being prone to collapsing and breaking down. At the centre of the ‘crumbling’ process was the fact that medication no longer provided stability and there was a weakened sense of control by both the person with PD and their carer. The process of ‘crumbling’ strategies and routines varied according to personal and relational thresholds as well as the availability of additional support from within families or the extended networks of friends and neighbours. The variety of challenges posed by PD and other chronicity weakened established strategies, such as the combined effect of falls, overall frailty, fatigue, poor memory and increasing mobility problems. Also the ‘windows of time’ provided by medication became more difficult to maintain and diminished even though medication was modified in terms of dosage, when to take it or which medication or combination could be used to best effect. As noted by Joan: “No, Parkinson’s affects every bit of your life, yeah. I said to myself ‘Right, it’s got a piece

of my life but it’s not having any more’, but of course it doesn’t listen, it slowly takes another bit and you think ‘Well, OK, I’ll give in, you can have that bit’ (laughs), but I’m keeping some for me... and that’s why I sit with a needle for hours trying to thread it (Interview 6, 2008).

As the ‘windows of time’ to complete tasks or activities were reduced the effort to engage in activities increased, required greater time, effort and organisation: “The tablets wear off I must have done the things I need...It takes much longer, what used to take half an hour now takes an hour” (Charlotte, Interview 12, 2009). The person with the PD and the carer increasingly engaged in ‘working apart’ on their own strategies to manage the situation and daily life.

Collapsing stability

The recognition that there was an inability to manage symptoms through medication resulted in a perceived and actual loss of stability in people’s adjustment patterns. The process was largely gradual and was defined by the milestones of people’s shrinking ‘windows of time’. There was a sense of poor control over symptoms that was characterised by a feeling that there were limited choices now that established and new medication no longer ‘worked’ in maintaining routines. Furthermore, the situation was perceived as being very much ‘closed’ with little that could be achieved other than to ‘fight on’ and ‘seeing it through’. There was some discussion by people experiencing this stage regarding seeking alternative options of more support or different future options, such as moving to a bungalow or into care. However these ‘alternatives’ were not acted upon and there was a poorly developed sense of knowing what options were available, any external facilitation to enable people to see outside the immediate concerns of the present situation and seek alternative choices or strategies. ‘Collapsing stability’ was underpinned by an ‘acceptance’ of the situation and relying on ‘hope’ for improvements in medication or a ‘new’
medication. The difficulties posed by this approach was indicated by the advent of ‘patches’ for delivery of medication during the course of the study which were initially perceived as new medication and a source of hope for re-establishing the ‘windows of time’ experienced in Bridging the present stage. Charlotte described how she still was experiencing decline despite increasing the strength of the ‘patches’ and that her sense of hope was now evaporating and her identity of a survivor from her past experiences in 2007 no longer equipped her to ‘fight on’ in 2009 leading to a feeling of despair and seeking the alternative option of suicide.

Increasingly for those experiencing the stage of Broaching collapse there was a delicate interplay between failing memory and cognition with movement difficulties. These combined with ‘cracks in relationships’, and the increasingly evident failing health for both parties, which together resulted in ‘Collapsing stability’ whereby the process of bridging became difficult to maintain. The growing ‘awareness’ of the fragility of the situation varied among partnerships and at times was transformed into plans for future care provision, moving to a bungalow or getting more help. However it was only following a severe crisis that such plans were acted upon or realised and required ‘trusted’ partnerships, such as family members and/or the PDNS/other professions allied to medicine.

**Fractured Bridging.**

The final stage was evidenced by the examination of changes in a number of case examples (n=3) during the course of the study and the shift from ‘collapse’ to ‘fracture’. This was itself not a linear process but characterised by an increasing weakening of bridging that maintained people at Broaching collapse until they ‘slipped’ into Fractured bridging with its complete lack of stability. However it seemed that people (in particular carers and family) were able to endure tremendous stress and difficulties even at this stage of being ‘overwhelmed’. This seemed to be connected to personal linkages to Building on the past and established ways of Coming to terms. At this point the shift towards ‘being together’ rather than having a clear separation of ‘being me’ and ‘being us’ became the main focus and ‘seeing it through’ and based on achieving good and home based care for the person with PD. The dynamics of moving from Broaching collapse to Fractured bridging was clearly demonstrated by the case Joan and husband Peter who moved back and forth during the last few months of the study as poor stability was challenged by the further stress of additional events, such as recovering from a stroke then having to manage a colostomy in addition to difficult PD symptoms and a failing memory. In contrast John and his wife Catrin had moved to a permanent stage of Fractured bridging for 6 months before the end of the study with an increasing process of decline. John’s wife Catrin recounted during several interviews crying in the bathroom with her husband on the floor after another fall and asking ‘what are we going to do now’, as his recurrent falls become much worse, as did his other symptoms of failing communication, severe memory and movement difficulties (Interview 3-6). However, because couples and individuals generally did not proactively ‘broach the future’ or address a declining situation other than ‘struggle on’ the processes of fracturing often reached crisis point before action was even contemplated. The situation required access to external facilitation but this was ‘ad hoc’ such as in the case of John. There was some informal discussion during a Speech and Language Therapist visit and the opportunity to fully comprehend the situation by the PDNS visit was not fully realised due to a focus on a review of medication and’ the resistance of the carer in acknowledging the depth of crisis and the advent of severe memory problems.

The processes underpinning the stage of Fractured bridging was characterised by a series of ‘fractured’ relationships in the following areas:
Disease- There was a separation in understanding the disease process and the sense of what PD meant for people was challenged for both the person with PD and the carer. In particular the advent of dementia or memory-related problems was difficult for people to accommodate in their framework of understanding PD and they sought explanations, such as ‘getting older’. Also the range of symptoms being increasingly experienced and their severity undermined people’s ‘sense of meaning’ and ‘knowing their PD’.

- People- The increasing and alternating levels of stress and strain for carers and the frustration experienced by people with PD fractured the partnership arrangements established over many years. There was a struggle not only in maintaining routines but also daily relationships, in particular if there were difficulties during night-time. A sense of partnership and ‘working together’ was replaced by ‘working apart’. There was an increasing involvement by family members who had been present on the periphery of daily life but were now increasingly required to maintain daily routines and sustain day-to-day life. There was a weakening of relational stability and emphasis upon past achievements.

- Past and present life- A dissonance and tension developed between present life and people’s individual and shared sense of a past life. There was a shift towards emphasising ‘affection’, ‘attachment’ and ‘respect’ by the carer for the person with PD rather than ‘partnership’, ‘love’ and ‘admiration’ as part of changes in people’s relational stability.

Even though there were ‘fractures’ apparent in people’s sense of control and relationships this stage was also characterised by the following:

- Resilience – It was evident that despite acknowledging decline or difficulties people with PD and their carers appeared resilient and sought to manage the difficulties they encountered, despite fatigue or a lack of support.

- Independence – The pattern of partnerships ‘working together’ over a prolonged period of time as part of their biography and more recently with PD continued with a sense of independence being asserted and a resistance to asking for help, citing poor experiences in the past or as Daniel’s wife noted there was the recurrent theme from interviews that “I can still manage at the moment” (Interview 4).

- Isolation – The combination of resilience and independence developed a greater degree of isolation as symptoms became more difficult and people with PD became chair and house bound. The opportunities to be away from the house for carers or both the carer and the person with PD became increasingly limited.

Nonetheless, the processes of Fractured bridging (Figure 14) were characterised by an overwhelming weakening of bridging that resulted in the fractured sense of stability and lack of control. These will now be described in further detail.

Inability to cope

The carers identified a subjective feeling of ‘complete fatigue’ as events and daily life eroded their struggling abilities to cope with change and manage daily life. There was a loss of hope and little expectation that there would be any improvement in the overall condition of the person with PD, the control of symptoms and the ability of professionals to intervene to alter the situation. Relational stability was weakened with a shift away from episodes of ‘Being me’ and ‘Being us’ to the dominant pattern of ‘Being together’ and focused on life with PD. Coping was focused on ‘accepting’ and struggling to maintain a past identity of how the person with PD was before becoming worse, focused on a positive portrayal.
**Figure 14: Fractured bridging as an adjustment stage**

<table>
<thead>
<tr>
<th>Surface level</th>
<th>Deep level</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Failure of established/new strategies and routine</strong></td>
<td><strong>Loss of stability</strong></td>
</tr>
<tr>
<td>• Physical frailty overwhelms routines:</td>
<td>• Sense of failure in the control of symptoms</td>
</tr>
<tr>
<td>• Movement difficulties/frailty/falls</td>
<td>• Lack of options for regaining control</td>
</tr>
<tr>
<td>• Swallowing, speech and articulation</td>
<td>• Situational/daily struggle to maintain stability</td>
</tr>
<tr>
<td>• Memory difficulties/behaviour</td>
<td>• Lack of support for:</td>
</tr>
<tr>
<td>• Weight loss, emaciation</td>
<td>— ‘talking through events’</td>
</tr>
<tr>
<td>• Infections/chronicity</td>
<td>— Physical help</td>
</tr>
<tr>
<td>• Extreme fatigue, weakness and low morale</td>
<td>— Guidance and ‘road mapping’</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Inability to Cope</strong></th>
<th><strong>Recurrent Crisis/collapse in relationship</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>• Caregiver complete - fatigue</td>
<td>• Shift to Being us to the detriment of Being Me</td>
</tr>
<tr>
<td>• Loss of hope</td>
<td>• Affirming the importance of past self</td>
</tr>
<tr>
<td>• Coping and complete loss of Being Me and domination of Being Us</td>
<td>• Separation between past and present selves</td>
</tr>
<tr>
<td>• Being Together as key objective</td>
<td>• Empathy and focus on ‘fighting on’</td>
</tr>
</tbody>
</table>
Despite an inability to cope it was notable that additional support was not requested or if requested not followed up by carers until prompted by family or friends. There was an observable level of need, stress and strain yet a resistance to seeking additional help, in particular if previous requests had not been followed up. It was evident that as the situation became more difficult carers became focused on managing day-to-day and seemed unable to seek help or assistance from professionals unless there was a regular contact. The inability to cope was not acknowledged openly or easily and in many respects ‘kept hidden’ as the aim was to ‘struggle on’ and stay at home.

**Recurrent crisis/collapse in relationship**

The recurrence of small but frequent crisis in daily life resulted in an increasing pattern of a collapsing relationship which in defence of the present built upon a positive affirmation of the past. The ‘Enduring structures’ of Building on the past and Coming to terms were of paramount importance in constructing and re-constructing meaning in daily life and reinforcing relational stability. The ‘collapse’ of relationships were lessened if the ‘outer’ network were involved in supporting the situation, such as John’s son who helped his mother at night when his father became ill, agitated or fell over. However, such support was episodic as the son also had family demands and his mother Catrin had to struggle on in a constant state of crisis.

There was an emphasis on seeing the past life as a ‘refuge’ and ‘resource’ in the face of difficulties and affirming a past life as the source of empathy and respect for the person with PD. The relationship centred on ‘Being together’ and ‘seeing it through’. This was evident in the case of John who was deteriorating with significant memory, behaviour, communication, eating and drinking as well as mobility problems in 2009.

**Failure of established/new strategies and routine**

The onset of frailty in the condition of the person with PD signalled the failure of established routines combined with the impact of weakened relational stability.

Established routines and strategies failed in the face of less effective medication and a complex range of symptoms to manage day-to-day. The impact of repeated chest or urinary infections, such as in the case of John and Jack combined with weight loss, memory difficulties and extreme fatigue. It was a cumulative impact on strategies and routine, however despite periods of crisis during Fractured bridging the situation was dynamic and could be returned to Broaching collapse if particular issues were addressed, such as in the case of Jack and his infections.

**Failure of established/new strategies and routine**

The onset of frailty in the condition of the person with PD signalled the failure of established routines combined with the impact of weakened relational stability. Established routines and strategies failed in the face of less effective medication and a complex range of symptoms to manage day-to-day. The impact of repeated chest or urinary infections, such as in the case of John and Jack combined with weight loss, memory difficulties and extreme fatigue. It was a cumulative impact on strategies and routine, however despite periods of crisis during Fractured bridging the situation was dynamic and could be returned to Broaching collapse if particular issues were addressed, such as in the case of Jack and his infections.

Nonetheless the impact of decline continued to undermine established routines, strategies and ‘new’ initiatives, such the involvement of a dietician and physiotherapist with Jack.
Loss of stability

At the core of Fractured bridging was the erosion of stability. The emphasis on seeking, achieving and retaining ‘control’ in earlier stages could no longer be maintained and there was a sense of loss in the control of symptoms. The opportunities for regaining control were felt to be limited and the search for stability was focused on daily life and tasks such as getting up in the morning, washed, dressed and mealtimes. For Herbert’s wife the struggle was getting him up to his wheelchair so that he could be in the living room. Despite the lack of stability there were limited opportunities to talk through options, gain more physical help or obtain guidance on a ‘road map’ to the future from professionals. In many respects the fracturing of stability seemed to be hidden and take place within the ‘inner’ relationship of the spousal partners, with some involvement by the ‘outer’ family and friends network but limited engagement by professionals until a key event required hospitalisation, such as in the case of Herbert and John. Yet even at these critical points the degree of instability, crisis and fractured strategies were seemingly not recognised and in the case of John the crisis continued following discharge. Herbert died in hospital.

Relational Bridging: partnerships and networks of support

The processes of ‘Bridging’ identified the importance of relationships as part of adjustment work in late-stage PD. This was described as being located as part of the identity of people living with PD as carers and cared-for, respectively as people had both a sense of ‘Being me’ and also ‘Being us’. This focused on an individual sense of identity (‘Being me’) and a shared sense of identity built upon partnership with a common past (‘Being us’).

In their biography people recalled significant life events and careers that defined who they were as individuals, such as formative experiences by Jack and Daniel during war time as well as a joint-biography of marriage, children and older age. The nature of these ‘inner’ relationships were defined by the recall of past life and events. This link to Building on the past was central to spousal relationships and relevant in the limited cases of filial relationships in the data.

However the significance of relationships extended beyond close spousal or ‘inner’ relationships and involved a wider network of family, friends and neighbours. As part of adjustment in late-stage PD the nature and extent of a wider ‘outer’ network of relationships was important in supporting or weakening people’s bridging through the ‘Adjustment stages’. The conditions underpinning the strength or weakness of relational stability will now be described in greater detail.

It was clear that both the person with PD and their carer had a separate sense of identity, their own biography and sense of self (‘Being me’). However there was an intersection between their individual identity and shared parts of their past and present life that produced a shared sense of ‘Being us’. The central feature of relational stability was the maintenance of both aspects of people’s ‘inner’ relationship with sufficient opportunity to engage in both ‘Being me’ and ‘Being us’ (Figure 15). The importance of such opportunities underpinned relational stability, (represented as a sufficiently ‘broad’ base in Figure 15), and this was evidenced in how people described stability as part of Bridging the present. As part of this stage the person with PD and their carer had opportunities to express and experience ‘Being me’ as well as ‘Being us’. For instance, although Herbert was chair-bound (living each day from a wheelchair or bed) and experienced extreme fatigue, communication difficulties and required constant care he had maintained ‘Being me’ by watching football and sports on the TV. In the case of Ben his wife and carer fought to
obtain social support in order to complete a part-time course for an afternoon once a week to maintain a sense of ‘Being me’. In the same way people retained an identity of ‘Being us’ by maintaining routines, such as ‘outings from the house’. For John and his wife this involved going to a local area for lunch despite the practical difficulties that were involved and the limited ‘windows of time’ or for Julie and Tudor attending their ballroom dance social events to keep contact with shared friends.

The importance of a sense of ‘Being me’ and ‘Being us’ were not only rooted in Building on the past and expressed in daily life and carried through the stages of bridging. Building on the past enabled sources of relational stability to be identified: ‘love’, ‘admiration’, ‘partnership’ ‘affection’, ‘respect’ and ‘attachment’. These were maintained, re-built and relationships re-aligned in Bridging the present as well as during other stages. Relational stability consisted of a series of dynamic dimensions that were associated with experiences as people journeyed through ‘Adjustment stages’. Relational stability maintained ‘contentment’ within relationships and was expressed in activities of daily life. Contentment was central to stability but was modified and re-defined through stages as symptoms and frailty emerged as part of decline.

A third part to relational stability was ‘Being together’ with PD. People with PD and their carers described a relationship with PD as part of their lives, a feature that resonated through the ‘Adjustment stages’ as noted by Charlotte: “I think the main thing is that as you have got this illness you will not get better, is to see some good in it” (Interview 3). In late-stage the impact of PD was apparent in daily life and its earlier ‘backstage’ role following diagnosis was now ‘frontstage’ focused upon adjustment, adaptation and coping between the partners in the ‘inner’ relationships.

‘Being together’ centred on recognising a relationship with PD as a part of their shared life.

**Being me-Being us - Being together**

As the experience of PD changed over time the impact on relational stability was important and influenced the nature of adaptation within the ‘Adjustment stages’. In the case of partnerships (couples or spousal) where such relationships were denuded and put under severe stress it could result in a loss of ‘Being me’ (individual identity) and the dominance of ‘Being us’ (a shared sense of identity). For those experiencing increasing decline there was a further shift towards the dominance of ‘Being together’ where the carer and the person with PD lost their sense of a personal identity (‘Being me’) and the nature of a shared identity (‘Being us’) and the focus was life with PD. For the carer this focused on the need to ‘fight on’ on behalf of the person with PD, carrying forward a sense of continuity but very much working at bridging alone. As part of ‘Being together’ daily life was defined in terms of managing the symptoms of PD, relationships were constructed clearly as ‘carer for’ and ‘carer’ with a shift in the balance of responsibility and decision making towards the carer and a pattern of ‘working alone’ on adjustment.

The ‘inner’ relationships within partnerships (spousal and filial) were supplemented and supported by relational links with an ‘outer’ set of relational networks based on families and professionals. The interviews highlighted the centrality of these varied range of ‘outer’ networks that supported people with late stage PD and their carers. The network of friends and/or neighbours linked to the person with PD or their partner were ‘hidden’ and not initially apparent (or discussed during interviews) but maintained the ‘inner’ relationships by providing additional sources of relational stability in their lives. These family members, friends and neighbours provided additional support in terms of
someone to talk to, gain advice, companionship or assist with shopping and transport to hospital or GP surgeries. However the extent of support varied with some participants (n=3) having an extensive network or being isolated with a small or minimal network (n=10). The extent of networks and were central to the overall outcome from the process of decline and its impact on relational stability, reducing the opportunities for ‘Being me’ and ‘Being us’.

The dynamic between the extent of support networks and maintaining relationships became important as the person with PD experienced continued decline with an increase in the range of symptoms, their severity or chronicity. The pressure of change linked to its complexity and pace had an impact on the relationship between the person with PD and their carer (Figure 16). The range of the ‘outer’ support networks was important in enabling the ‘inner’ relationships of ‘Being me’ and ‘Being us’ to be supported in daily life and strengthening bridging activities.

**Professional roles and 'Bridging apart’**

The defining feature of how people with PD and their carers adjusted to the experience of late-stage Parkinson’s was ‘Bridging’ and its associated stages, processes and actions. The subjective experience of living with PD focused on managing its symptoms and coping with the transitions brought about by changes in their condition and other chronicity. As part of their ‘lived experience’ (defined as day-to-day life with PD) people with PD and their carers identified a number of professionals that contributed to ‘bridging’. As already indicated earlier, the role of the PDNS and the Consultant at the MDC were central in maintaining bridging, in particular **Bridging in the present** with its foci on medication and stability. The continuity provided by longstanding relationships were pivotal in the sense of support experienced by people with PD and their carers even though the level of contact was usually every 6-12 months (unless there was a community visit). A substantial amount of trust was embedded in these relationships and access to these two professionals were paramount in managing day-to day life even if such contacts were not utilised between clinic visits.

Although the roles of the PDNS and the Consultant were consistently seen as central by people with PD and their families there was a dissonance between the reported accounts provided in clinic or to the PDNS by people with PD and their carers and the ‘lived experience’. The accounts in the case-notes and nursing notes captured the career of the disease and core symptoms but the ‘fine grain’ experience of people was notably different. This ‘lived experience’ was not captured in standard assessments, observations, the completion of standard ADL function or cognitive tests or as part of an informal discussion during a visit or consultation about how people were managing.

It was evident that people with PD and their carers relayed the minimum amount of information to professionals and such information was dependent on the questions asked. As a result many issues remained ‘hidden’ until they emerged due to a problem or following specific probing, such as memory difficulties, hallucinations or adjustment strategies or gaps in future planning. The professional account of people’s adjustment were ‘thumbnail sketches’ in the notes and contrasted in focus and detail to the concerns voiced in people’s interviews. In this sense there was a ‘Bridging apart’ which seemed to increase as people journeyed further into late-stage PD. ‘Bridging apart’ consisted of differences in the interpretation between the professional and patients and carers perspective in the following areas:

- The experience of PD as a chronic and enduring illness;
The experience of adjustment at the level of daily life.

For people with PD and their carers in late-stage the experience of PD was constructed as an enduring and chronic illness that involved daily adjustment and was understood as focused on a sense of identity (biography), a sense of building and re-building day to day life (situational), a sense of having to slowly (or at times rapidly) adapt to and cope with changes over time (continual). At its core was the importance of relationships (relational) in maintaining all aspects of adjustment. In contrast to the ‘lived experience’ of patients and their carers the professional perspective focused on managing (1) symptoms, (2) medication and coping with (1) symptoms and (2) medication being taken. This represented a professional (MDT) ‘clinical experience’ of PD.

During the early stages of PD and initial bridging by people with PD and their families (focused on developing Bridging the present) there was a close alignment between the ‘lived experience’ and the ‘clinical experience’ of PD. This was based on a shared interest in symptom management using medication and coping underpinned by medication. As people continued their life over many years with PD and during late-stage PD there appeared an increasing tension as ‘Bridging apart’ became more pronounced. The professional ‘clinical experience’ of PD retained its focus on (1) symptoms, (2) medication and (3) coping with (1) and (2), whereas people with PD and their carers became more centred on their ‘lived experience’ of PD. This was highlighted in the case of Daniel and John who experienced increasing complexities and frailty but due to limited opportunities for improving symptoms, medication or coping with (1) and (2) received increasing stress in their ‘lived experience’ but also an increasing sense of ‘Bridging apart’ from professionals.

The involvement of the PDNS or Consultant was seen by patients and their carers as only necessary when a problem arose but they noted the lack of ‘anyone else’ to provide support, answer queries or engage in problem solving. There were communication links via telephone message to supplement clinic or home visits but these were at times problematic. It was notable that the MDT was fragmented and displaced in the community with a difficult system of access for people with PD and their carers unless there was a crisis and clear channels of referral. There was an absence of physiotherapy, occupational therapy and Speech and Language Therapy intervention unless there was a crisis and a period of intense rehabilitation was provided. However as in the case of Jack people required less intensive physiotherapy and more longitudinal support to address their movement and physical functioning. Speech and Language Therapy was rarely provided and when it was given people felt that the intervention was of little benefit other than having a personal advocate, such as in the case of John and Catrin. Professional intervention by therapists tended to follow a pattern of episodic or intense visits and professionals leaving written information. However people with late-stage PD and their carers considered such information of limited value as they had difficulty integrating it into their day to day ‘lived experience’ with PD.
The role of Community Nurses, GP’s and social carer were in most cases very limited in both scope and duration. In particular, the Community Nurses had a narrow range of involvement and provided a limited scope of advice or treatment, such as ‘ad hoc’ tissue viability care in the case of Herbert. The use of social care was surprisingly underutilised and carers focused on ‘managing’ the situation and had poor experiences of suitable respite care other than Ben and his involvement with the memory clinic. There were incidents in the data when a wider circle of formal caregivers were involved such as in the case of Joan following a crisis following a stroke. Yet for most people the periods of contact with these practitioners were episodic or limited despite people with PD and their carers identifying significant areas of need during interviews.

There was a notable resistance to asking for help or assistance from formal services. This was reinforced if people encountered any poor experiences, such as seeking respite care for John, any repeated requests for advice from the PDNS and GP which resulted in a strengthened resistance and unwillingness to involve the MDT. In cases such as John and Catrin participants developed an acute sense of ‘Bridging apart’ and felt ‘on their own’ and resisted further support.

The area of memory and cognitive impairment was an issue that was a feature of the ‘lived experience’ for many participants. The impact on ‘lived experience’ and day-today life in late-stage PD was far greater, complex and more subtle than assessments documented in case or nursing notes. The models of intervention and adaptation provided by a memory clinic, such as the one Ben attended were not utilised and people with PD and their carers developed strategies of their own. Yet they were unaware of the substantial information and practical advice available though dementia-based services such as memory clinics and the Alzheimer’s Disease Society.

‘Bridging apart’ and the PDS
The majority of participants were involved with the PDS at an earlier part in their life with PD, with some exceptions such as Tom
who did not want to ‘see others’ with PD worse than himself. Even though participants were active within the local PDS branch and network at an early stage in their PD, during late-stage PD there was ‘Bridging apart’ from the PDS as people were no longer able to maintain links and relationships and became more isolated.

Overall, there emerged in late-stage PD a fragmented form of MDT support that underpinned ‘Bridging apart’. At the centre of ‘Bridging apart’ was a separation between informal and formal networks of support. The ‘centre stage’ activity of adjustment was focused on bridging and relationships as part of spousal, partnership-based support and the informal, hidden network provided by family and friends. It was apparent from the data that the support provided by the PDNS and Consultant was important for people with PD and their carers, however it consisted of a distant form of support through the vehicle of clinic attendance or if required/check up home visits. There was a feeling of ‘background support’ if required but this was constructed as a reactive rather than an active process often with a limited range of possible remedial options.

The other community based MDT were only involved in episodic or limited contact or support and were therefore seen as ‘remote’. The process of living with decline was focused on supportive work between people with PD, their carers and their ‘hidden’ network as part of bridging. The separation between this work and the MDT became the dominant feature of ‘Bridging apart’ in late-stage PD resulting in a sense of isolation.

**Parkinson’s Disease Nurse Specialist**

At the centre of life and adjustment to PD was the role of the PDNS. However the role was complex and in the two case exemplars involved in the study there were contrasting models that emerged with both costs and benefits. In many respects the ‘best fit’ was combining the elements of the two models and embedding the PDNS within a MDT and a clear community-based network with particular attention to the development of the PD Support Worker and wider social support.

The centre stage diagrams constructed by the two PDNS highlighted the complex tensions in the role of the PDNS. Their role included case-work with people with PD and their families from early to late stage, as well as education with the MDT, working with support groups, improving referral patterns with GP’s and research work. This mix of work clustered in the centre stage diagram highlighted the tension between ‘patient contact’ and other related work with a significant caseload. The nature of the geographical spread of patients resulted in substantial travelling for home visits for both PDNS. In addition the patient caseload included not only those being seen in the local MDC but also by neurologists in the Walton Centre. The most experienced PDNS provided mentoring, support and clinical supervision to recently appointed PDNS. This was highly valued and involved ongoing support, problem solving and creating a form of informal clinical supervision.

In the case of ‘PDNS 1’ the role had been focused on structural innovation to services that centred on skilling community hospital staff, establishing telephone clinics as well as home visits and clinics. As part of this model ‘patient contact’ and relationships were organised around the separation of the role into achievable components, using allocated time for telephone-contact. However there were at times difficulties in following up late stage cases and the degree of involvement, relationship and contact was ‘surface’ in nature.
Figure 16: The impact of decline in relational stability

The ‘outer’ support networks vary in size and closeness (proximity- resulting in lesser or greater degrees of support for the ‘inner’ relationships and the process of relational instability, such as family members living far from the area.

Increasing PD symptoms with variable complexity and pace

Increasing chronicity presents additional stressor

Greater relational instability

Increasing pace and complexity of change

Journey with PD

Time
In the case of ‘PDNS 2’ there was a relationship-based model that characterised the role and it created tensions in attempting to ‘join up’ structural work and maintaining contact and relationships with people with PD and their families. The demands of addressing those with earlier stage PD and late-stage PD resulted in similar difficulties to ‘PDNS 1’, however the contact had greater ‘depth’ in terms of involvement and relationship. It was apparent that even though maintaining contact was problematic there was a ‘sense of involvement’ and reassurance that ‘backup’ was available by people with PD even if the PDNS was not always easily contacted.

Management of treatment regimes and medication provided the bulk of the late-stage work for the PDNS. This was highly valued by people with PD and their families as it was instrumental to maintaining stability and Bridging the present. Combined with the other aspects of the role there were limited opportunities to engage in other psychological and social adjustment work. This weakness became increasingly important as people experienced greater decline and a collapse or fracture in their stability. In general there was limited engagement in addressing coping stress, memory loss or addressing couple-based or family-based adjustment strategies. The work required with memory and cognitive problems was complex and required a high level of skills. People with PD and their carers/families occupied positions of resisting or accepting memory or cognitive impairments that resulted in a response of consensus or conflict. The skills and established relationships of the PDNS were underutilised and there were missed opportunities for acknowledging and developing the role of the PDNS in order to intervene and engage people in consensus not conflict-based work. The role of the PDNS was fundamental in facilitating rapid referrals or acute problem solving but there was difficulty in continued engagement in adjustment work with people with PD and their families.

At the end of the study the role of the PD support worker emerged in practice. This presents an opportunity to develop some aspects of the supportive role required in maintaining bridging strategies and provide an additional link to the PDNS and the MDT as part of ‘Scaffolding’.

Scaffolding

The notion of ‘scaffolding’ emerged from the analysis of the dataset and was theoretically sampled (Glaser, 1978) during the final stage of the study. Scaffolding itself is not a new concept and is well established in the educational evidence-based highlighting is cardinal feature as being centred on learning. Of particular note is its usage in advancing problem solving and making judgements in everyday life and also identifying the need for guidance and support in knowledge building activities of learning, in particular within a collaborative environment (Pata et al, 2006). In general ‘scaffolding’ refers to joint problem solving between learner-teacher and originates from the metaphor used to describe effective problem solving between parents and their children (Wood et al, 1976). The underpinning thesis by Woods et al (1976) was that children needed a partial understanding of the task but had an inadequate level of skill to perform the activity remedied by scaffolding or building up a series of actions. Key components of scaffolding are providing support at the right skill level requiring a sensitive assessment of abilities and the ‘fading out’ of assistance as competence increases (Pata et al, 2006). Belland et al (2008) highlight the utility of the scaffolding metaphor in understanding how best to design a curriculum to advance novice problem solvers using a variety of scaffolding models. They indicate a divergent range of models in the scaffolding evidence base and the variety of scaffolds that can be used to support learning and activity. At its heart scaffolding attempts to provide temporary
support to enable tasks that cannot be performed unaided to be completed in order to develop competency. It requires a diagnostic and supportive approach utilising a range of techniques, strategies and skills (Belland et al., 2008; Ge and Land, 2004; Rasku-Puttonen et al., 2003). However the concept of scaffolding has also been used beyond the educational environ, including narrative-based therapy (Brimhall et al., 2003).

Social scaffolding

In the present study the data analysis identified the importance of different forms of learning and support that facilitated ‘bridging’ for people with PD and their families. Simply, ‘Scaffolding’ was focused on preparing and managing transitions over time based on accessing a range of sources for support underpinned by a learning process. The defining feature of ‘Scaffolding’ was that people engage in adjustment as a learning process and support is focused on people providing assistance at the most appropriate level. This involved some physical help but was mainly about acquiring information, experiential learning (to adjust) and learning who to ‘work with’ or contact in terms of supporting life with PD. The process involved not only family, friends and a network-based support structure but also current professional support services and was dynamic.

‘Scaffolding’ had implications for how adjustment was best supported based on a construction of support that was not initially focused on physical care. Rather ‘Scaffolding’ started from the basis of learning and the involvement of physical aspects of care was a secondary, later consideration. Arguably, recognising that people ‘scaffold’ as part of their couple and/or family-based adjustment is central in designing services that work with people’s ‘Bridging’ strategies and a pattern of coping with PD. In the present study particular areas of ‘Scaffolding’ were identified. These ‘Scaffolding’ areas in adjustment were supported by a range of activities. The ‘Scaffolding’ areas provide a framework for developing practice and support ‘Bridging’. The generated framework centred on the interaction between ‘Learning’, ‘New skills’, ‘Peer support’, ‘Specialist advice’ and ‘Top up skills’.

Learning

- **About PD** - Gaining an understanding about PD and seeking to understand why it has occurred to them as individuals.

- **About its impact** – Through a reflective process people located the diagnosis of PD in their life story and sought to understand how it would impact on their day-to-day lives.

- **About what to do** - Based on learning about PD (in general and in their lives) people learned strategies for seeking to adjust, adapt and cope with symptoms.

- **Learning** involved talking and listening to partners, friends and professionals.

New skills

- **Seeing the need** – This focused on recognising that new skills were required and could be useful in adjusting to the symptoms of PD and that existing skills and knowledge were insufficient. People had personal/couple-based thresholds and generally struggled before seeking out help and developing new skills.

- **Gaining information and skills** – Once there was a recognition that other skills and associated knowledge was required, people with PD and their carers became aware that there was a need to identify where best to find such information and who would provide the necessary information or skills. This was a difficult area as people with PD and their families did not know about the possible options available and required signposting. This was usually done through the PDNS but again people did not quickly ‘recognise the need’ and often delayed in seeking-out information.

- **Supported** – The development of core
skills such as medication management were supported by the PDNS and learning involved testing competency. Other skills such as movement and ambulation involved an initial set of tuition by the MDT but was delivered in a package of time-limited activity. These were supported by paper-based leaflets that were largely ineffective in reinforcing what to do and did not facilitate motivation to engage in these skills. There were no broad range of skills taught to people with PD and their families, such as coping with changes to ADL (dressing and dexterity), coping with pain, managing ‘on and off’ periods, dealing with low-mood, managing sleep or managing memory loss.

- **Self-taught and life as experiment** – The majority of people with PD and their families engaged in experiential learning and developed their own skill-base after much experimentation. The learning process was often difficult, time consuming and the lessons/skills learnt by others were rarely transferred and only utilised if they were part of a PDS group. Professionals seemed largely unaware of these self-taught/experiential skills.

**Peer support**

- **Finding understanding** – Gaining peer support was important in avoiding isolation and this was relevant within families and within a wider network, such as the PDS branch meetings/group. Those who had engaged with the PDS had benefited from the experience but as they deteriorated found this difficult to maintain. A key feature in peer support was finding people that understood PD, the symptoms and had a supportive approach.

- **Finding information and support** – Some people had not been able to find information and support outside their own family partnerships and remained isolated. The majority had a network of friends and neighbours who sustained them informally and attempted to act as advocates. Professional signposting and liaison was also useful in finding possible sources of support but there was limited involvement by the MDT. In general, opportunities for gaining peer support was limited and social care options, such as day centres were judged to be unacceptable due to a narrow range of activities offered to people with PD and their carers. Web-based resources were not accessed and information-seeking activities were often very limited in focus despite the availability of a broad range of material (e.g. PDS resources).

- **Keeping it up** – If people with late-stage PD and their carers were able to access information and a wider network of support it was often difficult to maintain. This was due to increasing decline and symptom change. People with PD and their carers had difficulties in maintaining peer support as they became increasingly housebound.

**Specialist advice**

- **Getting on with it and hanging on** – People had a tendency to struggle before seeking advice or specialist input. Previous negative experiences in terms of effectiveness with some interventions resulted in a weariness in asking for therapies, such as SLT or physiotherapy. A habitual pattern of ‘getting on with it’ (as part of ‘Bridging the present’) prevailed.

- **Getting the right help at the right time** – Difficulties existed in that the main contact point was mainly the PDNS or/and the Consultant for advice and often people with PD and their families would wait until their appointments (every 6 or 12 months) prior to seeking advice. The PDNS would only be contacted by phone at exceptional times. When the PDNS was involved the interventions included the modification of medication or a referral to other professionals. Often the right help did not occur at the right time as people kept ‘hanging on’ and the professional focus was focused and narrow rather than looking at a broad range of issues and examining how they could ‘scaffold’ a number of problems.
Figure 17: Scaffolding: an emerging model

Scaffolding up

Scaffolding Areas

Scaffolding Activities

- Top up skills
  Advice

- Specialist
  Advice

- Peer Support

- New Skills

- Learning

Access

Acquiring

Acknowledging

Reinforcing knowledge, building on skills, adapting skills

Consultant, PDNS, physiotherapist, SLT, memory, clinic, other professional

Family, PDS, friends, neighbours

Medication management, moving, coping, memory, specific issues.

Talking about, talking through, listening to, doing, reflecting

Communication ← Contact ← Continuity

Scaffolding Across
• **Limited options** – The difficulty that was presented by people with PD, their families and professionals was the limited range of options for support.

*Top up skills*

• **Moving and handling** – The difficulties with moving and falling resulted in a need for ‘top up’ skillling which occurred infrequently. Aids were provided following consultation with professionals but simple skills were overlooked that actually made a contribution to day-to-day success, such as skills helping in walking and recovering from freezing.

• **Experimenting with medication** – The PDNS (and Consultant) provided a constant access point for managing medication and enabling people with PD and their families to experiment to find the most suitable balance of medication for them. This was done via clinic or by organising home visits or telephone advice. This was highly valued.

• **New ideas and seeing issues** – The focus of ‘topping up skills’ was limited and did not include developing new ideas or areas for skill or knowledge acquisition. As the PD became increasingly characterised by a complex range of symptoms there were few examples of ‘seeing issues’ differently by people with PD, their carers or professionals and recognising the need for additional skills. This was particularly evident in dealing with decline, managing memory/cognitive problems, adapting to behavioural changes and aspects of palliative care.

• **Getting other people in** – Connected to ‘new ideas and seeing issues’ there was a lack of recognition by people with PD, their families and professionals that a wider group of people including a range of MDT professionals, voluntary agencies and family/friends were required to support the situation when problems occurred and decline became significant. The professionals involved with particular people with PD and people with PD and their carers accepted a process of ‘struggling on’.

As part of ‘scaffolding’ there were two basic processes identified from the data, respectively **scaffolding up** and **scaffolding across**. These were important as they identified how best to support people as part of ‘Bridging’ and adjustment through a dynamic process of ‘Scaffolding’. These consisted of areas that were required for effective ‘Scaffolding’ in day-to-day life.

*Scaffolding up*

• **Acknowledging** - This involved recognising and gaining insight into life with PD. Through learning about PD people identified areas which required the development of skills and knowledge.

• **Acquiring** - This involved moving beyond ‘acknowledgment’ that PD was now part of their lives. It focused on recognising that there was a need for support not only within the family but also across a wider network of friends, neighbours and MDT professionals.

• **Access** - This involved recognising, seeking and attempting to secure access to specialised clinical advice regarding the management of symptoms, any changes in the coping abilities, the effectiveness or side effects of medication and the need for new or updated skills.

*Scaffolding across*

• **Communication** - The **scaffolding up** activities required communication between a range of people, in particular close partners, family and friends and core professional such as the PDNS or Consultant. This required both ability and opportunities to communicate effectively which presented difficulties in a life with late-stage PD.

• **Contact** - To have effective communication required maintaining and developing opportunities for contact with key people, in particular specialised services such as the PDNS, Consultant, Speech and Language Therapy and physiotherapy. The core issue for people with late-stage PD was keeping in contact with professionals which became increasingly difficult. When contact did occur it was limited to specific
issues (mainly medication) and did not include a broad review (focused on overall coping) or problem solving a particular difficulty. Participants felt that more regular contact would facilitate ‘Scaffolding’ issues such as re-learning or gaining new skills. Contact was also relevant to how people with PD and their carers were able to maintain communication and links with family, friends and their wider network.

- **Continuity** - The issue of continuity was particularly important and the nature of the relationship with professionals resulted in advice, information and guidance given being seen as trustworthy and credible. Family and friends also provided continuity and they were judged as being credible on the same basis of an enduring relationship.

The emergent model of ‘Scaffolding’ (Figure 17) included the areas, activities and the processes of scaffolding across and scaffolding up and supported people’s efforts at bridging as part of their lives with late-stage PD. The interrelationship between the scaffolding up and across activities focused on acknowledging, acquiring and access related to the requirements of communication, contact and continuity. For instance acknowledging that is focused on learning required communication with a range of people engaging the family about PD and its impact as a prelude to developing new skills.

The areas of ‘Scaffolding’ were dynamic and interrelated for instance, the need to acquire peer support was built upon (scaffolded) a process of learning and gaining new skills. Furthermore acquiring with peer support provided opportunities for access to specialist advice and top up skills. The difficulties described in the data was directed at maintaining the scaffolding up and scaffolding across process. Initial communication required the further ‘Scaffolding’ of contact and continuity and it was the maintenance of ‘Scaffolding’ that remained particularly difficult. People become isolated and restricted in their abilities to acquire or access specialist advice and especially top up skills in late-stage PD. Indeed as the nature of people’s life with PD was over a long period of time (Williams and Keady, 2007). The weakness of the current service and practice model was its difficulty in recognising the need for ‘Scaffolding’ activities and once these were established how to maintain these over a prolonged period of time.

The importance of ‘Scaffolding’ was its focus on different aspects of adjustment to life with late-stage PD, directed towards managing learning, engaging with support that was not instrumental or physical in its orientation.

The activities of ‘Scaffolding’ required partnership working and a process of increasing the intensity in scaffolding up and/or scaffolding across in response to people’s worsening condition and circumstances. Having good working relationships and a knowledge of how people ‘bridge’ (such as Building on the Past, Bridging the Present) was important in enabling ‘Scaffolding’. The importance of relationships within ‘Scaffolding’ could not be underestimated and its focus on relationships within partnerships and family, and relationships with professionals, mainly the PDNS, Consultant and other therapists.

In the data good working relationships were crucial as people ‘bridged’ difficulties over time. In the study as contact diminished or became distanced with the MDT professionals there were few sources of support. In these scenarios access to scaffolding up became limited and there were insufficient access to specialist advice and top up skills and the peer support became increasingly weak as people were unable to maintain previous/existing contact, such as PDS Branch Meetings or clubs. The PDNS was seen as very important in providing or underpinning ‘Scaffolding’ but the PDNS was seen as ‘overstretched’.

As a result there were long periods without contact and incomplete continuity resulting in an increased sense of weakness in ‘Scaffolding’ activities, including those that had been established earlier in their life with PD, such as a lack of top-up skills.
4. Recommendations

Moving Forward Assessment and intervention: ‘Bridging’ and ‘Scaffolding’ in practice

The development of ‘Bridging’ and a ‘Scaffolding’ model presents an opportunity to inform assessment and encourage a broader range of interventions in practice. ‘Bridging’ highlighted the importance of biographical knowledge, adjustment re-built on a situational day-to-day basis and the importance of responding continually to change in late-stage PD that was underpinned by a network of relationships. These areas were part of the ‘lived experience’ of people with late-stage PD and informed how adjustment worked in their own area of adaptive ‘practice’ and coping.

Scaffolding

‘Scaffolding’ focussed on supporting the process of learning to adjust and manage life with late-stage PD. Arguably, these provide scaffolds for practitioners to utilise in practice and bridge the ‘gap’ between the ‘lived experience’ of people with PD (and their carers) and the MDT ‘clinical experience’.

The data from the study and the mapping of ‘Bridging’ provides a platform to identify potential areas for intervention based on a broader assessment process. Such areas are linked to biographical and relational knowledge and focus on practitioners engaging in a narrative-led process of information gathering as part of assessment and planning actions.

It was evident that as part of ‘Bridging apart’ there was a dissonance between the perspectives of people with PD (and their carers) and the MDT. In late-stage the experience of PD for people was constructed as an enduring and chronic illness that involved daily adjustment. It was understood as being focused on a sense of identity (biographical), a sense of building and re-building day to day life, a sense of having to slowly (or at times rapidly) adapt to changes over time and maintain significant relationships. In contrast to this ‘lived experience’ of people with late-stage PD (and their carers) the MDT professional perspective focused on managing symptoms, medication and coping with symptoms and medication. This represented a contrasting MDT ‘clinical experience’ of PD. During late-stage PD there was an increasing tension as ‘Bridging apart’ became more pronounced and people with PD and their carers became more centred on their ‘lived experience’. The data developed tools that could provide a number of cueing questions to inform a review of coping strategies focused on the areas of biographical life history and relational life with PD (Appendix 1).

The area of relationships, adjustment and coping could be assessed in greater depth using a more structured tool. The Relational Assessment in Parkinson’s Disease (RAPiD) and Life History Questionnaire aims to provide a trigger for further assessment or intervention by identifying weak or strong relational stability.

As Ollerenshaw and Creswell (2008) suggest subjecting people’s narrative accounts to analysis provides insight that facilitates the development of problem solving. The narrative-based assessment tools may enable the development of a closer connection between the ‘lived experience’ of people with PD and their carers and the multidisciplinary ‘clinical experience’ in order to reduce ‘Bridging apart’.

Palliative care: Integrating Social and Physical ‘Scaffolding’

The area of palliative care in late-stage PD emerged as a significant area of concern in the study. It was associated with people’s experience of greater decline and poor stability from existing medication and well established strategies. It did not have a clear
‘trajectory’ but was associated with the later stages of ‘Bridging’ and was distinct from the period when there was ‘end of life’ care.

Palliative care of people with late-stage PD centred on living with decline and focused on the need to support the collapse in ‘Bridging’. Palliative care involved both social and physical aspects of care and ‘Scaffolding’. In the study palliative care involved the interrelated areas of contentment and comfort.

The area of contentment focused on ensuring a sense of continuity between people’s past and present, building and maintaining stability in relationships, providing access to favoured activities even within the limitations imposed by the process of decline and importantly ‘being at home’.

The related area of comfort was directed at the physical degree of comfort around activities of daily life, such as being able to move around using aids, comfortable sitting places (for prolonged periods of time) and the ability to be able to rest and lie down. Pressure area care was a rather neglected area of comfort but important for the person with PD and their carer as was managing night-time and having support to problem solve difficulties in movement, at times behaviour and again physical comfort. Being able to have comfort in eating and drinking and going to the toilet required adaptation and developing management strategies.

The description of contentment and comfort and the transition from palliative to end-of-life (terminal) care requires further research and practice innovation.

Conclusion

Overall, ‘Bridging’ and ‘Scaffolding’ highlight the importance of developing an integrated support system for people with late-stage PD and their carers. The grounded theoretical account of ‘Bridging’ describes and defines the complex social processes of adjustment, adaptation and coping. ‘Scaffolding’ provides a framework for interventions in a practice centred approach focused on learning through good communication and accessing learning resources, building support strategies through appropriate contacts with the MDT and a wider community-based network. Finally ‘Scaffolding’ in palliative care is focused on building upon established learning, communication and contacts and ensuring continuity in the provision of information, knowledge and a network of support.
5. Discussion

“We conclude that, above all else, people with PD have psychosocial needs that are currently insufficiently met, and this may be the major challenge for the next millennium” (Chesson et al 1999 p. 129).

The development of ‘Bridging’ and ‘Scaffolding’ has sought to contribute to understanding how the psychological and emotional aspects of care identified by Cheeson et al (1999) may be better understood and addressed. As Simpson et al (2006) highlight the relationship between social support and psychological outcomes are complex but still requires attention in order to minimise distress and promote happiness. A key feature of maintaining lower levels of depression, anxiety and stress was the nature of support, its quality and the number of close relationships (Simpson et al, 2006). In the present study ‘Bridging’ is centred on relationships and delineates how people construct support as part of a complex dynamic between ‘Enduring’ structures and ‘Adjustment’ stages, consisting of a range of categories and properties.

Psychological Adjustment

The emergence of the ‘Bridging’ contributes towards the evidence that emphasises the centrality of psychological adjustment and the need for interventions (Secker and Brown, 2004). Hobson (2008) identified the narrow focus of clinical interventions on the person with PD and despite acknowledging the carer’s needs there are few interventions. Furthermore, it was recognised by Ellgring et al (1993) over a decade ago the positive impact of psychological interventions for people with PD and their carers. The development of ‘Scaffolding’ as well as ‘Bridging’ facilitates seeing adjustment in late-stage PD as a complex process but one that has many opportunities for interventions. Such interventions are based on engaging clinicians and services in supporting people’s own adjustment (Bridging) and engaging in ‘Scaffolding’ support. It is clear from the evidence base that psychological adjustment is crucial in ability to maintain relationships, remain emotionally balanced and manage symptomology (Brod et al., 1998). It is therefore important to avoid ‘Bridging apart’ and work with people to strengthen ‘weak bridging’ and reinforce ‘strong bridging’. PD evolves over time and as Schekman et al (2002) identified the importance of identifying the most important issues for people with PD and how they change over time and how perceptions influence the course of their disease. Arguably, ‘Bridging’ and ‘Scaffolding’ provides a platform for starting to address these issues.

Family based care

The area of family based adjustment and coping in PD has been increasingly recognised in the literature but has tended to focus on cross sectional studies and early to mid stage changes (Lyons et al, 2004). The longevity of PD as a chronic illness has particular consequences in heightening carer strain as indicated by Lyons et al (2004) uncovering a decline in physical and emotional health over a 10 year period. Lyons et al (2009) notes that the evidence base regarding family care-giving has focused on dementia and older people whereas the gradual onset and progression in PD has resulted in few studies about how the process adjustment evolves over time (Lyons et al, 2009). Again, the account of ‘Bridging’ maps some of the complex social processes that underpin carer strain but also highlights a dynamic lived experience of adjustment, adaptation and coping with PD. Understanding the social processes of adjustment and coping provide a platform for moving practice forward as part of the ‘clinical experience’ of the MDT.
Relational Practice
At the centre of ‘Bridging’ and ‘Scaffolding’ is relational work or what has been termed relational practice. In the literature it has been defined as professional activities that are ‘necessary to develop and sustain interpersonal relationships’ based on an understanding of individuals’ circumstances and their contexts (Parker, 2008). As such MDT relational practice with patients and their families requires:
• Accessibility of professionals.
• Boundary management involving emotional connections with patients, but also avoid being overloaded.
• Connection with people and the ability to create engagement/empathy and demonstrate emotional authenticity.
• Collaboration with all parties need to share information and be involved in relational work.
• Continuity – the ability to relate past and present experiences.

Parker (2008) argues that individual ‘relational’ practice should be extended to group interactions. The King’s Fund (Firth-Cozens and Cornwell, 2009; Goodrich and Cornwell, 2008) note that compassion is expressed with and towards others and that it has the capacity to alleviate pain. The contact people with PD and their carers had with PDNS and others, including the consultant contributed towards alleviating people’s adjustment beyond symptom control. In late-stage PD this became of greater importance and value but was more difficult to access. It was evidenced in the study of late-stage PD that relational practice was central to successful ‘Bridging’ and underpinned ‘Scaffolding’. As Goodrich and Cornwell (2008) note such forms of practice involves practitioners in a ‘real’ dialogue with patients based on honesty and courage.

Palliative Care
In Wales and in the UK a range of policy and advisory documents are directed towards developing Palliative Care (DoH, 2008; NCPC, 2007; WAG, 2006; WAG, 2005; NICE, 2004). Increasing attention is also now being directed towards developing palliative care (PC) in PD, including a number of possible approaches (Bunting-Perry, 2006). This discussion is embedded in a critical appraisal of how to address quality of life in PC and develop end-of-life care in non-cancer and neurodegenerative conditions (Ying et al, 2009; Catteral, 2008; Coventry et al, 2005). For instance, the ability of community nurses to support PC and the role of specialist PC practitioners or services (Shipman et al, 2008). A wider review of PC has been undertaken within the PDS community as well as within the research literature (PDS Consultation Document, March 2009). The operational framework provided by The National Council for Palliative Care (2004) and NICE (2004) focus upon PC as being underpinned by the provision of ‘supportive-care’. A ‘supportive-care’ model resonates with the findings from the present study. In PD the issue of PC was rooted in people’s ‘Bridging’ stages and activities and cannot be separated as a discrete phase in contrast to end-of-life care. However, the areas of contentment and comfort were delineated as particular dimensions or aspects of PC as people experienced increasing decline. Also ‘Scaffolding’ provides a framework for engaging in MDT ‘supportive-care’ (NICE, 2004) for people with late-stage PD living in the community. Of particular importance is not only linking PC to ‘Bridging’ but also being aware of ‘Enduring structures’.

Policy and practice
The development of the National Institute for Health and Clinical Excellence (NICE) clinical guideline 35 (Parkinson’s disease) (NICE, 2006) sets out a more proactive, co-ordinated and focused multi-disciplinary approach to services for people with PD and their families. The NICE (2006) guidelines
identify that PD results in extensive disability and costs to health and social care, and has a substantial impact on family carers. Yet the report produced by the Parkinson’s Disease Society (PDS, 2008) argues the service inequalities that exist and there is a need for services to reach out to family carers. A key recommendation by the report (PDS, 2008) was the commissioning of more Parkinson’s Disease Nurse Specialists (PDNS) in primary and secondary care in order to better manage the distressing symptoms of the condition.

The evidence supports the importance of the PDNS role and its ‘particular contribution’ (Reynolds et al, 2000, page 337). The findings from the present study highlights the central role of the PDNS but also the difficulties of ‘overstretch’. In particular as part of a multifaceted role and its associated range of expectations. As suggested in the recommendations of the report there is a need for a wider base of support that is network-focused, the use of a structured educational programme, the strategic development of the PD Support worker role and re-orientation of what constitutes ‘social support’. Also the skills of the PDNS may also need to address a wider range of therapy, including memory and cognitive based work.

Memory and Cognition

As part of the experience of PD the issue of memory, cognitive problems and dementia was significant. As reported by Foltynie et al (2004) memory-related problems and cognitive impairment is a notable issue in PD. To date, the weight of research focus in Parkinson’s disease dementia (PD-D) has been in the advancement of its: neurological impact (Emre, 2003), association with dementia with Lewy Bodies (DLB) (Sellal, 2006); and diagnostic and management considerations (Hobson and Meara, 1999; Waldemar, Dubois, Emre, Georges et al., 2007).

In the main, this focus has been necessary to provide guidance to clinicians and practitioners as, prior to Emre et al’s (2007) groundbreaking work, there had been no specific or operationalised criteria to diagnose dementia associated with Parkinson’s disease (PD). It could be argued that people with PD-D have been sheltered under the umbrella term ‘dementia’ and their specific needs not fully explored, addressed or acknowledged. On the other hand, as expressed in the National Institute for Health and Clinical Excellence (NICE) clinical guideline 35 (Parkinson’s disease) (NICE, 2006), working with people with cognitive impairment as a consequence of their PD could be ascribed to a dedicated role for specialist PD nursing staff, particularly in the provision of psychological support and counselling to help with confusional states (MacMahon and Thomas, 1998; MacMahon, 1999; Handley, 2006).

This specialist approach to support may also fall under the remit of the community mental health nurse in dementia care (Keady, Clarke and Adams, 2003; Keady, Clarke and Page, 2007) and extend out to dedicated dementia care teams.

This development would appear particularly important bearing in mind Schrag, Jahanshahi and Quinn’s (2000) findings that cognitive impairment in PD is firmly aligned to a poor quality of life, and therefore cognitive rehabilitation interventions aimed at the onset of PD-D would seem a natural first step in providing help and support. It would seem that supporting families of people with PD-D would help to alleviate the patterns of stress due to the longevity of the movement disorder and the subsequent disabling impact of cognitive impairment as identified in a number of case examples in the study of late-stage PD.

Participatory methods

The method of ‘centre staging’ was developed during the study to enable a participatory
approach to constructivist grounded theory to be utilised. Ironside et al. (2003) emphasised the importance of co-creating a shared understanding of the lived experience of chronic illness and uncovering this ‘touchstone of meaning’ (Ironside et al., 2003 p.180). Centre stage storylines were embedded in a narrative-based approach. This was significant in recognising the importance of exploring 'life patterns' in order to understanding meaning that extend beyond personal accounts to demonstrate community experience and meanings (Plummer, 2001). Moreover, a narrative enables an individual's understanding of self and the construction of identity that is shaped by a degree of purpose and unity (McAdams and Janis, 2004) to be uncovered.

The use of centre stage storylines and a narrative approach reflects Clandin and Connelly’s (2000) approach that builds upon people's personal experience and learning and interaction with others in order to discern a story of lived experience. This involves identifying ‘interaction’, ‘continuity’ and ‘situation’ across the dimensions of personal, social, past, present, future and place. The development of diagramming and narrative in the study has in part addressed the challenge set out by Charmaz (2000) in attempting to engage people as active participants. Charmaz (2000) argued that constructivist grounded theory “recognises the interactive nature of both data collection and analysis .. through the study of experience from the standpoint of those who live it” (p.522).

**Conclusion**

In the study it has been possible to explore the experiences of people living with late-stage PD using a participatory approach to grounded theory. It was important to secure the RCBC funding to be able to examine this under researched area. The theoretical work of ‘Bridging’ and the ‘Scaffolding’ framework present a conceptual model for augmenting good practice and identifying areas for health and social care intervention. The importance of supporting and reinforcing relationships within partnerships, as part of local networks and with professionals (such as the PDNS) is central to positive adjustment to living with PD as a long term condition.

The study has highlighted areas that present both opportunities for developing practice and services in order to support community-based care for people with PD and their families, centred on the concept of ‘Scaffolding’. It is clear there are also challenges in maintaining and developing community support systems for people with PD as they experience greater decline and disability. It is hoped that the study conducted as part of the Fellowship has contributed to ‘fleshing out’ some of the hidden issues and identified areas for practice development in late-stage PD. It could also be argued that ‘Bridging’ and ‘Scaffolding’ may have fit, work and relevance (Glaser, 1978) in other long term conditions and present opportunities for research and transferring good practice to other clinical areas.
6. Fellowship Programme

The RCBC post-doctoral Fellowship was focused on understanding adjustment in late-stage PD. The purpose of completing the empirical study as an integral part of the post-Fellowship award was:

1. To extend and enhance the advanced research skills, management and international network of the applicant and establish a programme of work.
2. To conduct a robust empirical study that would enable the achievement of (1) and fill an important gap in the evidence required to inform change in practice and improve outcomes for patients and their families in the area of PD.
3. To develop a grounded theory account of complex adjusting processes in PD and develop implications for practice in order to improve outcomes for patients and their families.
4. To develop and test methodological innovation that engages people living with long term conditions as partners in the research process in order to enhance the evidence-base.
5. To map best-practice in chronic disease management as part of an existing programme in North Wales.
6. To disseminate findings from empirical study and the implementation of change through All-Wales, UK and international networks.

The achievement of these aims during the course of the Fellowship will now be examined in greater detail.

1. To extend and enhance the advanced research skills, management and establish a programme of work

As part of the Fellowship programme a substantive contribution to personal development has been made through self-directed learning, engagement with the supervisory team Professor Jane Noyes, Professor John Keady and Professor Bob Woods and attendance at formal RCBC Wales study days. A reflexive framework (Romm, 1998) was utilised to guide personal learning and the scrutiny of targets, actions and gains from the conduct of the research study and the overall fellowship programme. Romm (1998) affirms the importance of engaging in interdisciplinary reflexivity in order to understand ‘different vantage points’ and challenge ‘source discipline’ boundaries and develop ‘options for actions’ (p.63). Importantly, such reflexivity engages with different ways of knowing and reflects upon personal styles of knowing and working acknowledging ‘disjunctions and inconsistencies highlighted in different domains of inquiry ... ambiguity and paradox’ (p.64).

As part of the Fellowship programme I focused on engaging not only other disciplines from the clinical and research community but also the perspective of lay advisors and those participants that were at the heart of the inquiry. Using Romm (1998) as a heuristic framework I identified areas of self-learning that focused on developing advanced skills gained the course of the fellowship programme. These advanced skills were focused on project design and management, engaging key policy making stakeholders, archiving research data, managing media as part of dissemination and finally developing techniques to establish theoretical sensitivity.

Project design and management- As part of the Fellowship I gained additional skills in developing a longitudinal research design including the development of a participatory project design. The skills required to manage a research project were developed by working with the supervisors, respectively Professor Keady, Professor Noyes and Professor Woods. I gained additional technical and interpersonal skills in order to manage the ethics and governance processes and
implement the design of a longitudinal grounded theory study. Furthermore, the supervisory meetings with Professor Noyes and Professor Keady were instructive in identifying areas for future and identifying gaps in knowledge and skill development. For instance an initial plan to involve a Lay Advisory Group throughout the project was identified as problematic in the first year following a discussion with lay advisors. This was due to the emergence of some distressing results from the fieldwork which challenged their own constructions of life with PD and their anticipated futures. In essence a particular finding from the data was that people with PD held the future ‘in abeyance’ and focused on the present (‘Bridging the present’) until changes forced them to re-consider and manage decline. Following a supervisory meeting I re-aligned the role of the Lay Advisory Group to informing the development of the research question and its study aims and objectives. However one lay advisor felt able to contribute as an ongoing lay advisor and based on discussions with the supervisors Alison Underwood continued to comment upon the ongoing study reports, outputs and provide a critical appraisal of the findings detailed in the final report. The role of lay advisors as part of project management in degenerative long term conditions is currently the focus of a journal publication.

Engaging key policy making stakeholders, archiving research data, managing media as part of dissemination- During the course of the Fellowship programme a range of study days were used to further enhance personal development and resulted in additional skill gains. The study days provided an opportunity to listen and discuss research practice with a wide variety of subject-specialists as well as introducing a range of skills, in particular managing the media as part of research dissemination strategies and ESDS: archiving research data. These contributed towards extending the scope of personal and professional learning with such a range of research based topics being discussed within the Community of Scholars meetings. The attendance of study days at the Welsh Assembly Government and Community of Scholars Away Days were particularly useful in introducing a broad number of issues that influenced the conduct of research and providing skills for engaging key policy-making stakeholders.

Developing techniques to establish theoretical sensitivity -The development of techniques to augment theoretical sensitivity centred on involving lay people as advisors in the project design. This commenced with the planning stages prior to engaging the study participants in co-constructing their experience of living with PD. The approach I sought to develop attempted to build reflexive skills and techniques to engage lay people as advisors and actively contribute to a research design process. This was an important facet of the research design as it could be argued that the central tenets of grounded theory are the development of ‘theoretical sensitivity’ by the researcher in order to underpin the building of ‘conceptual ideas’ and its relationship to ‘theoretical sampling’ as the strategy to discover emerging concepts to build theory (Glaser and Strauss, 1967; Glaser, 1978).

Theoretical sensitivity requires an openness to the phenomena, a ‘personal and temperamental bent’ and an ability to have theoretical insight and ‘make something of it’ (Glaser, 1978 p.46) and I developed techniques to uncover ‘local concepts’ and ‘insight’ (Glaser and Strauss, 1967; Glaser, 1978). As part of this process I recruited five lay advisors to act as part of the advisory group in partnership with the PD Nurse Specialist in the MDC.

I found the most effective technique was informal work with each of the five patients and their carers independently in their own homes in order to examine the research question and the research design. I developed a technique that engaged advisors in
discussing a thumbnail sketch of their ‘life theories’ that generated ‘insight’ about what PD meant to them and its impact as a chronic illness. This enabled the study’s research question to be embedded in a reflective discussion with advisors building on their ‘lay expertise’ and exploring their ‘life theories’. At the heart of this technique was engaging lay advisors to gain thick descriptions of their experiences of life with PD and seeking ‘authentic emotional understanding’ (Denzin, 1989) based on entering the person’s experiential world and ‘felt experiences similar to those felt by the other’. This technique challenged my own research-based approach which was based on ‘emotional-cognitive understanding’ and could have resulted in my perspective as the researcher present an “unwillingness to enter into another’s point of view” (Denzin, 1989). The thumbnail sketch was followed up by providing each of the advisors with a basic framework identifying the key concepts and terms drawn from the research proposal. I asked advisors to critically appraise the key terms: Parkinson’s disease, adjustment, coping, carer and care-giving (as indicated in table 1). They spent a few weeks exploring their ‘mental constructions’ (Guba and Lincoln, 1989) and four people with PD and their respective families outlined their interpretations using ‘thick’ and narrative-based descriptions. Importantly, their conceptual definitions were constructed through a ‘storied’ narrative of their experiences and described what these concepts and terms meant to them. This included the views of the person with PD and commentaries by their carer. I repeated the process as part of my reflexive analysis of the research question and ‘grounded’ a review of these same key concepts and terms in my own life history and theoretical perspectives situated in the health sciences literature. For instance, this involved responses to PD that were based on impressions gained in the past as a nurse in the Acute Care of the Elderly Unit, Day Hospital, a research officer in a community-based project and a gerontological nurse lecturer. It included reflexively taking account of models and theories that informed the researcher’s ‘mental constructions’ (Guba and Lincoln, 1989) and sensitivity to social constructions regarding PD, chronic illness and chronicity in older people. The final stage of this reflexive technique was the integration of both sets of constructions and representing them diagrammatically (Appendix 5). The modified research proposal was further modified following a final discussion with the lay advisors. As one advisor commented this technique enabled me as the researcher to see ‘cracks in the pavement’ that others wouldn’t notice.

The lay advisors and the researcher’s perspective however differed in its sensitivity to significant inter-relationships. The lay advisors generated a far more complex account of how PD may be understood as it was experientially sourced rather than the researcher’s view drawn from a reading of the literature (Abudi et al., 1997; Playfer, 2002).

2. To conduct a robust empirical study that would enable the achievement of (1) and fill an important gap in the evidence required to inform change in practice and improve outcomes for patients and their families in the area of PD.

The completion of the study into late-stage PD developed additional evidence about the experiences of people living with PD and their families. The findings from the study resulted not only the emergence of a grounded theory account of adjustment in late-stage PD but also delineated the importance of ‘Scaffolding’ as a way to address some of the underpinning difficulties experienced by people with PD and their families.

As a result the ‘Scaffolding’ framework may present a platform for addressing the needs of people with PD and their carers in the community, building upon the theoretical work of ‘Bridging’.

58
<table>
<thead>
<tr>
<th>Key concept/term</th>
<th>Guidance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parkinson's disease</td>
<td>When the term/description is used what does it mean to you as an individual and family?</td>
</tr>
<tr>
<td>Adjusting And Coping</td>
<td>Adjusting to life with Parkinson's and the symptoms</td>
</tr>
<tr>
<td></td>
<td>Coping with day to day life and the symptoms of Parkinson's</td>
</tr>
<tr>
<td>Symptoms in Parkinson's disease</td>
<td>Such as tremor, walking, mood, vision and which are the most troublesome symptoms</td>
</tr>
<tr>
<td>Disability in Parkinson's disease</td>
<td>The effects of Parkinson's on your daily life and doing daily tasks</td>
</tr>
<tr>
<td>Support in Parkinson's disease</td>
<td>How people and their families are assisted in their daily lives, this can range from physical to emotional support</td>
</tr>
<tr>
<td>Carer And caregiving</td>
<td>A person providing assistance/help to another person as part of a relationship/a family member</td>
</tr>
<tr>
<td></td>
<td>What the carer provides</td>
</tr>
<tr>
<td>Transition or change in Parkinson's disease</td>
<td>This may involve the changes from one stage to another, such as before/to after starting medication, how changes happen in Parkinson's and how much change is experienced as part of daily life</td>
</tr>
<tr>
<td>Movement Disorder Clinic</td>
<td>The clinic setting where the doctors and day hospital team are seen, such as physiotherapy and nursing</td>
</tr>
</tbody>
</table>
The completion of the study on late-stage PD has also provided the basis for further work in partnership with other colleagues. Initially a collaborative bid with Northumbria and Newcastle University is being prepared for submission in late 2009/10 in order to develop an evidence base for improving communication in people with severe difficulties in PD. The data gained from the study has enabled the development of assessment tools (RAPiD and Life History Questionnaire) to identify sources of support required to maintain relationship-centred care in community dwelling people with PD. This relational index will be subject to further piloting and scrutiny as a basis for assessing stability in relationships for people with PD and their families in order to prevent crisis and/or collapse in relational stability. This work is being completed in partnership with Professor John Keady (University of Manchester) and with Dr. Ingrid Pretzer-Aboff (Associate professor) University of Delaware, USA.

3. To develop a grounded theory account of complex adjusting processes in PD and develop implications for practice in order to improve outcomes for patients and their families.

A substantive outcome from the study has been the development of a grounded theory of adjustment in late stage PD built upon ‘Bridging’. It maps the complex social processes of adjustment, adaptation and coping to PD and identifies how best to support people during periods of transition and decline. The grounded theory has utility as it not only underpins the ‘Scaffolding’ framework but also provides an account of adjustment authored with participants as part of their ‘lived experience’ of managing a chronic and debilitating condition. The development of targeted journal publications (see Appendix 6) has facilitated dissemination to practitioners and builds on the series of seminars at Bangor University, University of Manchester, Northumbria University and conference presentations in Cardiff and Washington (USA) which highlight not only the theory but its implications for enhancing practice and the care of patients and their families.

4. To develop and test methodological innovation that engages people living with long term conditions as partners in the research process in order to enhance the evidence-base.

The design of the grounded theory study involved reviewing the substantive literature and seeking to develop innovative approach to constructivist grounded theory. This resulted in the development of centre stage storylines with Professor John Keady as part of the supervisory relationship.

Despite the criticism of Glaser (2002), the case made by Charmaz (2000) for constructivist grounded theory is compelling. An underlying concern of Charmaz (2000; 2006) in constructivist grounded theory is gaining a ‘grounded’ account of patients’ experiences and the researcher’s role in allowing that to emerge. This was a key aim in uncovering the experiences of people living with late-stage PD.

The starting point for centre stage storylines was challenging the researcher’s role as the ‘interpreter’ for subjective experiences and the arbitrator of developing constructivist grounded theory. The focus on ‘storied meaning’ by Charmaz (2000) directed towards developing a method of gaining and maintaining a more egalitarian model of working in order to develop and ‘ground’ grounded theory based on narrative work and through that a constructivist approach. It was a short conceptual leap from ‘storied meaning’ to ‘storylines’ as it was crucial to find a link and way of approaching collaborative data collection and analysis.
from a position that ‘made sense’ to those being asked to engage in generating constructivist grounded theory. In its lay construction, people living with late-stage PD could see the sense in searching and describing the main storylines of their lives, and it was from this simple point of connection that centre stage storylines were developed.

Storylines have been used extensively in narrative-based work such as by Sandelowski (1991), Plummer (2001) and Strauss and Corbin (1998). This emerges from the basic element of ‘story’ in narrative traditions and the development of its presentation and disclosure through storylines, plots and themes (Plummer, 2001). These may be a feature of the narrative-as-told by research participants or the narrative-as-interpreted by the researcher to enable the story to be organised and developed into a pattern with an embedded meaning (Plummer, 2001). The narrative-based researcher has a repertoire of conceptual ‘tags’ to organise people’s storied lives, including seeking out nuclear episodes, plots with epiphanies, a thematic cluster of episodes and the literary device of a beginning, middle and end (Plummer, 2001). Storylines, plots and themes in many respects are closely linked in narrative-based work as part of its architecture supporting the analysis of complex dynamics in stories and delineating how events, incidents and characters of a life story are organised, disclosed, have agency and act as part of the uncovered (narrated) story (Williams and Keady, 2008).

In grounded theory, Strauss and Corbin (1998) describe the use of storylines as a stage or device in data analysis ‘to facilitate identification of the central category and the integration of concepts’ (p. 148). The storyline enables the researcher to identify the story from the raw data and obtain a general sense of what is being described in the data and ‘stand back’ in order to question what are the main issues in the data, what is ‘striking me over and over’ and ‘comes through’ even if implicitly (Strauss and Corbin, 1998). In this way the storyline is a technique for identifying a story, drawing out what is the description that consists the story and developing an analytical account defined as a ‘storyline memo’. At its core the device of a storyline focuses the researcher towards the raw data, and mapping out any connections and relationships in order to have an explanatory story.

Narrative was central to the development of centre stage storylines as a method of data collection and analysis of storied meaning within constructivist grounded theory (Charmaz, 2000; 2006). The aim of using storyline is consistent with the technique outlined by Strauss and Corbin (1998) but embraces the call of Charmaz (2000) to re-engage with the raw data. Rather than ‘stand back’, it enables the participant to move forward and stand with the researcher in moving from identifying the story, defining the descriptive story and formalizing a ‘storyline memo’. A ‘narrative turn’ (Roberts, 2002) enables this egalitarian use of storyline to be successfully adopted supported by the use of diagramming and a dramaturgical frame of reference. In the study the storyline was based on the basic starting point of it being a central theme, a meta-narrative (Ostakue et al., 2004) or as described by Glaser (1992): ‘The storyline is just the core category which accounts for most of the variation in the pattern the participants call a problem’ (p.77).

However, in the study, the storyline is not solely restricted to the researcher as ‘analyst’, rather it involves participants in co-constructing the[ir] storyline in the area under study. Glaser (1992) argues that grounded theory and identifying a storyline is based on ‘persistence, patience and emergence’ (p. 78). However, in the present study partnership is central to this act. Furthermore, in contrast to
a traditional usage of storyline in the analytical stages of grounded theory, the storyline (based on narrative work) was placed at the start of the theoretical journey and the initial immersion in the data obtaining a ‘general sense’ and seeking out the descriptive story and then subsequently revisited on an ongoing basis and subject to constant comparative analysis. Writing the storyline at this initial stage using the centre stage device is a shared endeavour to define the ‘gut sense of what the research is all about’ (Strauss and Corbin, 1998, p.148). The centre stage storyline was situated within an interview that had a biographical account and provides a way to explore the complexities and map out the relationships between selfhood, identity and the social world that are core aspects of any narrative (Roberts, 2002; Bruner, 2004).

Therefore, the ‘storyline’ is built around a literal device of a ‘centre stage’ diagram and describes a temporal account of life with living with a long term condition. It is an approach that has its roots in examining early adjustment to living with Alzheimer’s disease, PD and stroke (Keady and Williams, 2007). The centre stage storyline is focused on facilitating people to be reflexive about their lived experience with their long term condition with a ‘narrative diagram’ since ‘we organise our experience and our memory of human happenings mainly in the form of narrative’ (Bruner, 1991, p.4). The role of graphic devices are well documented in the narrative field, however their organisation, structure and constituent elements have a variety of functions (Drucker, 2008). The arrangement of images, their scale or size in relation to each other, ordering of space, sequences and hierarchies has a narrative effect and is a representation of complex and interconnected narratives. Furthermore, diagrams use arrows, overlapping and directional orientation ‘tell a story’ of complex events and a temporal sequence (Drucker, 2008, p.130).

Centre stage storylines rely on the act of diagramming. Diagramming has an established role in grounded theory work (Glaser and Strauss, 1967; Strauss and Corbin, 1998; Charmaz, 2006). Arguably, the key attribute being ‘diagrams should flow, with the logic apparent without a lot of explanation’ (Strauss and Corbin, 1998, p.152). In the study of late-stage PD this activity allowed engagement with participants’ subjectivity as stated by Charmaz (2000, 2006). The views of Strauss and Corbin (1992) that diagramming enables the researcher to gain distance ‘forcing him or her to work with concepts rather than with details in the data’ is turned on its head. Rather, the process of centre stage diagramming involves participants and the researcher gaining ‘closeness’ to the data and engaging in conceptual work with participants from an early point. Furthermore, unlike Strauss and Corbin’s (1992) vision of diagrams as valuable tools for integration, that centre-stage diagrams are central to ‘uncovering’ and later the ‘integration’ of the emergent theory.

The simplicity of diagramming was based on using ‘chapatti’ or Venn diagrams as part of centre staging as the circles denote different sizes in symbolic relationships to each other. Mikkelsen (1995) describes their utility in depicting participants sense of relations as well as events and the ability to ‘weight’ allocated to individuals or groups stating ‘it is a subjective, not an objective, delineation’ (p.80). However, in centre staging, the use of Venn diagrams is modified by using the notion of a ‘stage’ and asking participants to not only use size and weighting, but also the centrality of issues, people or events in being ‘centre stage’.

These storylines are ‘fleshed out’ by additional descriptions, additional diagrams or commentaries as part of the interviews. The additional storylines based on the centre stage diagrams identify iii) how [is the centre stage
storyline supported/accomplished) and iv) when [does the centre stage storyline occur]. It was important that the diagramming was situated within the interview and was both informed by and informs the foci, conduct and content of the interview. The development of this approach is currently being detailed in a journal paper with Professor John Keady.

5. To map best-practice in chronic disease management as part of an existing programme in North Wales.

The conduct of the study has enabled further mapping of best practice in chronic disease management by focusing on late-stage PD as a case example. As part of the findings the attributes of ‘Bridging’ and ‘Scaffolding’ may well be transferrable to a range of conditions and present an opportunity to develop a more substantive and formal aspect of theory (Glaser, 1978) in the area of adjustment to transitions in long term conditions. The existing programme of work is currently investigating adjustment in stroke, early stage PD and COPD.

6. To disseminate findings from empirical study and the implementation of change through All-Wales, UK and international networks.

The findings and methods from the study have been disseminated widely within the UK and at two International conferences. Furthermore the dissemination strategy involves further dissemination of the Summary Report to local Health Boards, the PDS and the completion of seminars and meetings with the PDS local branch meetings. Presentations have been completed for the RCBC Wales, the College of Health and Behavioural Sciences, University of Manchester, Northumbria University and local Community Health Council. The initial journal paper (see Appendix 6) provides a platform for a number of publications to ‘flesh out’ particular aspects of the study and its findings, such as ‘Scaffolding’.

The project has involved developing a partnership working with multidisciplinary team members at Northumbria University, Newcastle University and the University of Manchester. As part of such collaboration I have gained valuable experience in working with Dr Anna Jones (Northumbria University), Dr. Nick Miller (University of Newcastle), such as the development of a multi-site bid for NHS funding focused on speech and language difficulties in PD. This includes a research design integrating preliminary grounded theory work as part of a RCT. In brief the complex design seeks to assess the effectiveness, cost, acceptability and relevance of speech and language therapy for people with PD who have impaired communication. During the course of the project I have been able to meet and liaise with the movement disorder clinical teams working in Newcastle and discuss the findings as part of the prior to dissemination. It is has been useful to gain a critical perspective on the work.

Outputs

The project has resulted in a number of presentations at international and national conferences and a series of seminar presentations to highlight the methodology and findings from the study. A journal paper has been published (see Appendix 6) describing ‘Bridging’ in late stage PD. In addition a number of publications are in preparation elaborating on the initial publication that provided an outline of the emerging grounded theory and detailing the use of ‘centre-staging’ as part of a constructivist grounded theory. The further publications continue to detail the grounded theory focused on ‘Bridging’ and the ‘Scaffolding’ strategy also the methodological innovation, including the development of centre-staging techniques. In brief the outputs are as follows:
Publications (Accepted)

Publications (Submitted)

Publications (in preparation)
Williams, S. and Keady, J. Resisting and accepting: two case exemplars from the experiences of people living with late-stage Parkinson’s disease and memory loss. Journal: Ageing and Mental Health
Williams, S. and Keady, J. Bridging: Understanding the dynamics of adjustment in late stage Parkinson’s Disease. Journal Health and Social Care in the Community.


Conference Papers (Presented)

2009 Keady, J. and Williams, S. and Roberts, S. Centre stage storylines: giving vulnerable people a voice in researching their experiences and co-constructing grounded theory. RCN International Nursing Research Conference, 24-27th March, Cardiff City Hall, Cardiff.


Invited Presentations


Williams, S. and Keady, J. (2009), Northumbria University Bridging’: a linking scheme to explain adjustment in the lived experience of late-stage Parkinson’s
disease 27th April.

Future Projects

I have secured funding from the RCBC Wales (£140,000 for 2 year project) to continue the research work on adjustment in long term conditions, commencing in April 2010. The Senior Career Fellowship will provide an opportunity for developing not only a ‘substantive’ but also a more ‘formal’ grounded theory (Glaser, 1978) in adjustment and transitions. This application builds upon the RCBC post-doctoral fellowship centred on chronic disease management and is focused on the development of practice in Chronic Obstructive Pulmonary Disease (COPD).

Despite the significance of COPD (RCP, 2004) very little is known about how patients and their family carers adjust to their condition and how best to support them (Bergs, 2002; Fraser et al, 2006). The Department of Health (Do H) estimate that only 2% of those who need pulmonary rehabilitation have access to such programmes and COPD care has often been found to be fragmented with a lack of co-ordinated care management, including the management of transitions from one care sector to the other at different stages of the illness (CMO, 2005). The empirical study seeks to examine how community and hospital-based support maintains stability and manages the decline of people with COPD (and their families). Furthermore, it explores the role of the multidisciplinary team (MDT) in providing pulmonary assessment, intervention, rehabilitation and palliative care as people attempt to adapt to life with COPD. It seeks to identify the development of adjustment, shared decision making (SDM) and self management.

Building on the Fellowship project work on late-stage PD the study will use a modified grounded theory approach (Glaser, 1978; Charmaz, 2000; Keady et al, 2007; Keady and Williams, 2007; Williams and Keady, 2008). This innovative approach utilizes centre stage storylines and engages participants as partners in the research enterprise. However it will also utilise a change management process based on the PARiHS framework (Kitson et al 2008; Rycroft-Malone, 2004) to engage in knowledge transfer with the participating NHS Trusts. As part of the PARiHS framework the implementation process will focus on ‘evidence’, ‘context’ and ‘facilitation’ (Kitson et al, 2008).

The study will seek to develop the grounded theory of adjustment and will be integrated with existing published sources of ‘evidence’ (NICE, 2004; WAG, 2007) on managing transitions and supporting people with COPD, developing SDM and self management. The development of the grounded theory will result in ‘conditional statements’ (Charmaz, 2000, p. 524,) that enable shared constructions to be drawn together. The empirical work focused on NHS respiratory services will enable patient/family preference, clinical expertise and local insight (Glaser, 1978) to be utilised. Furthermore, the empirical work with 3 case exemplars enable relevant ‘context’ to be identified seeking to clarify the role of culture, transformational leadership, team configuration and evaluation of performance. The researcher (SW) will initially utilise the findings to engage in ‘facilitation’ and identify local facilitators to enable sustainable reflection on positive exemplars, innovative practice and modifications required to ways of working, thinking or service design. The process will consist of modelling intervention(s), workshops to guide implementation of local action plans and establishing modes of evaluation.
References


Charmaz, K. (1990). Discovering chronic illness: using grounded theory. Social Science and Medicine, 30: 1161-1172


Pata, K.; Lehtinen, E. and Sarapuu, T. (2006) Inter-relations of tutors and peers scaffold;ding and
decision making discourse acts. Instructional Science. 34, 313-341.


PDS (2005) Palliative Care and Advanced Stage Parkinson’s Disease. London, PDS.


WAG (2007) Designed for people with chronic conditions: service development and


Appendix 1

Semi-structured Interview Guide: People with PD and their carers

Semi-structured Interview Guide

The interview guide is designed to be divided into a series of interviews to discuss each discrete area where necessary.

Background to the study
Aims
Reaffirm consent procedure
Reaffirm consent to tape record interview
Right to stop the interview/life history at any time and withdraw from the research
Confidential nature of the research interview

1. Life History

I would like to start by asking you a few questions about your past life history.

i. Tell me about your life story. Begin wherever you like and include whatever you wish.
ii. What were the most important turning points in your life?
iii. Tell me about the happiest moments in your life.
iv. What about the saddest moments.
v. Who has been the most important person in your life?
vi. Who are you closest to now?
vii. What does your life look like from where you are at now?
viii. If you had the opportunity to write the story of your life, what would the chapters be about?
(Probe about the last chapter).

ix. Self
How would you describe yourself when you were younger?
How would you describe yourself now?
Have you changed much over the years? How?
What is your ‘philosophy’ of life? That is, what is the meaning of life to you?
2. Finding out

I would like to ask you about how you first found out you had Parkinson’s disease.

i. What did you or your family first notice?
ii. How did you feel/your family feel about your symptoms?
iii. Why did you decide to find out what the matter was?
iv. When did you decide to find out what these symptoms meant?
v. Did you do your own research on symptoms, such as through the library/internet or family and friends?
vi. Who did you go and see about your symptoms?
vii. How did you or your family feel about the diagnosis?

3. Your symptoms

I would like to ask you a bit more about your symptoms as they are now.

i. What are your symptoms now?
ii. How would you describe your symptoms?
iii. Which symptoms are the most difficult to manage?
iv. Why are these symptoms difficult?
v. Which symptoms are the easiest to manage?
vi. Why are these symptoms easier to manage?
vi. How do you feel about your symptoms? (Also family)
viii. Have you had any new symptoms recently?

4. Life with your illness

I would like to ask you about your life living with your illness day-to-day.

i. As a story what would be the ‘chapters’ of your life?
ii. How would you describe a good day?
iii. How would you describe a bad day?
iv. What would an average day be like?
v. Do you have help? (if yes from whom?)
vi. How often do you attend the Movement Disorder Clinic/Day Hospital?
vii. When are you there who do you see?
viii. What happens when you attend the Clinic/Day Hospital?
ix. How would you describe the experience?
x. Does going to the Clinic make a difference to your day-to-day life with your symptoms?
xi. Do you go to any other local hospital (community) or day centres?
   If yes, who do you see when there?
   If yes, how often do you go?
If yes, how was that organised and when?

xii. How easy has it been to find information about benefits or agencies that can help?

5. Explore additional issues raised by people with Parkinson’s disease and their families

i. Are there any issues or ideas that you would like to raise that we haven’t discussed so far?

ii. Are there any issues or ideas that we have mentioned before/earlier that you would like to discuss again?

Thank the person for their time and contribution
Appendix 2: Semi-structured Interview Guide: Movement Disorder Clinic Practitioners.
Appendix 2

Semi-structured Interview Guide: Movement Disorder Clinic Practitioners

Semi-structured Interview Guide

Background to the study

Aims

Reaffirm consent procedure

Reaffirm consent to tape record interview

Right to stop the interview at any time and withdraw from the research

Confidential nature of the research interview

1. The Movement Disorder Clinic

I would like to start by asking you a few questions about the Movement Disorder Clinic

i. How would you describe the Clinic?

ii. What are the aims of the Clinic?

iii. How does the Movement Disorder Clinic work?

iv. Would you change the Movement Disorder Clinic?
   a. If no, why not?
   b. If yes, how would you change it?
   c. Why has this not happened?

2. Your work

I would like to ask you about your work with people with Parkinson's disease at the Movement Disorder Clinic.

i. How would you describe your work?

ii. How did you come to work with people with PD?

iii. How would you describe your present role in the Movement Disorder Clinic?

iv. At what stage in their condition do you see people with PD?

v. Do you discuss cases regularly as a multidisciplinary team?

vi. Do you liaise with other community teams members about patients from the MDC?
3. Your work with the person with Parkinson's disease

I would like to ask you a bit more about your work with (participant) at the moment..

ix. What are his/her symptoms now?

x. How would you describe the symptoms?

xi. Which symptoms are the most difficult to manage?

xii. Which symptoms are the easiest to manage?

xiii. How do you feel he/she and the family is dealing with the symptoms?

xiv. How could the symptoms be managed better?

4. Life with Parkinson’s disease as a chronic illness

I would like to ask you about how you see (the participant) managing their illness from day-to-day.

xii. How do you think they manage their illness from day-to-day?

xiii. How did you get a ‘picture’ of how they manage?

xiv. Do they receive help? (if yes from whom?)

xv. How often do they attend the Movement Disorder Clinic?

xvi. When they are here who do you see? (person with Parkinson’s disease and which family member?)

xvii. Does going to the Clinic make a difference to their day-to-day management of their condition?

5. Explore additional issues raised

v. Are there any issues or ideas that you would like to raise that we haven’t discussed so far?

vi. Are there any issues or ideas that we have mentioned before/earlier that you would like to discuss again?

Thank the person for their time and contribution
Appendix 3: Gantt Chart: Preparatory Stage
# Preparatory Stage

<table>
<thead>
<tr>
<th>Activity</th>
<th>2006</th>
<th>2007</th>
<th>2008</th>
<th>2009</th>
<th>Involvement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Set up Lay Academic Advisory Group (LAG)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>People with PD (n=9) SW, JN, JK, BW</td>
</tr>
<tr>
<td>Prepare Protocol, COREC, R&amp;D</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>LAG, SW</td>
</tr>
<tr>
<td>Submit/Modify Protocol, COREC, R&amp;D</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>SW</td>
</tr>
<tr>
<td>Recruit patients/families</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>SW, Clinical Team</td>
</tr>
</tbody>
</table>

### Key:
- **▲** Start: SW – Dr Siôn Williams
- **▼** End: JN – Professor Jane Noyes, Bangor University
- **▼** Target End: JK – Professor John Keady, Manchester University

- BW – Professor Bob Woods, Bangor University
- PDS – Parkinson’s Disease Society
- MDC – Movement Disorder Clinic
## Fieldwork Stage

<table>
<thead>
<tr>
<th>Activity</th>
<th>2006</th>
<th>2007</th>
<th>2008</th>
<th>2009</th>
<th>Involvement</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>S</td>
<td>O</td>
<td>N</td>
<td>D</td>
<td>F</td>
</tr>
<tr>
<td>Interview MDC team</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Interview Patient/Family Dyads (Group 1 - n=10)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Recruit further Patients/Families (Group 2)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Approached n=10</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Consented n=4</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Interview Patient/Family Dyads (Group 2 – n=4)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>LAG Review</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Interview Patient/Family and Diagramming (Group 1 – n=9)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Interview Patient/Family and Diagramming (Group 2 – n=4)</td>
<td></td>
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<td></td>
<td></td>
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</tr>
<tr>
<td>LAG Review</td>
<td></td>
<td></td>
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<tr>
<td>Liaise with Reference Group coordinators MDC</td>
<td></td>
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<tr>
<td>Formal Consultation with Internal &amp; External Reference Groups: MDC Team</td>
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<td></td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>

### Key:
- ▲ Start
- ▼ End
- ▼ Target End

**SW – Dr Siôn Williams**  
**BW – Professor Bob Woods, Bangor University**  
**JN – Professor Jane Noyes, Bangor University**  
**PDS – Parkinson’s Disease Society**  
**JK – Professor John Keady, Manchester University**  
**MDC – Movement Disorder Clinic**
### Reporting/Dissemination Stage

<table>
<thead>
<tr>
<th>Activity</th>
<th>2006</th>
<th>2007</th>
<th>2008</th>
<th>2009</th>
<th>Involvement</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Activity</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Report Writing</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>SW</td>
</tr>
<tr>
<td>Complete Report.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>SW, LAG, PDS, rcb</td>
</tr>
<tr>
<td>Presentation/Dissemination</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>SW</td>
</tr>
<tr>
<td>De-brief/Visit all cases in</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Group 1 and 2</td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>

**Key:**

- **Start**: SW – Dr Siôn Williams
- **End**: JN – Professor Jane Noyes, Bangor University
- **Target End**: JK – Professor John Keady, Manchester University

BW – Professor Bob Woods, Bangor University
PDS – Parkinson’s Disease Society
MDC – Movement Disorder Clinic
Appendix 4: Sampling frame
### Appendix 4

#### Sampling frame

**Table 1: Sampling Frame: overview of study participants**

<table>
<thead>
<tr>
<th>Name</th>
<th>Age of person with PD</th>
<th>Diagnosed</th>
<th>Interviews</th>
<th>Date</th>
<th>Brief Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Joan and husband Peter</td>
<td>Joan aged 65 years</td>
<td>1994</td>
<td>Interview 1</td>
<td>28.5.2007</td>
<td>In the autumn of 2007 Joan suffered a stroke with right hemi-paresis. Hypersalivation and facial stiffness. Poor mobility. Swallowing difficulties. Extreme fatigue, spasms and pain.</td>
</tr>
<tr>
<td>Jack and wife Sarah</td>
<td>Jack aged 89 years</td>
<td>2001</td>
<td>Interview 1</td>
<td>3.7.2007</td>
<td>Some swallowing difficulties (requires soft food) and low volume in speech. Very poor mobility and chair-bound for most of day.</td>
</tr>
<tr>
<td>John and wife Catrin</td>
<td>John aged 78 years</td>
<td>1988</td>
<td>Interview 1</td>
<td>5.6.2007</td>
<td>Severe PD. Very poor balance, communication difficulties and frequent falls. Mostly chair-bound requiring assistance with ADL.</td>
</tr>
<tr>
<td>Name</td>
<td>Age of person with PD</td>
<td>Diagnosed</td>
<td>Interviews</td>
<td>Date</td>
<td>Brief Comments</td>
</tr>
<tr>
<td>-----------------------</td>
<td>-----------------------</td>
<td>-----------</td>
<td>-------------------------------------------------</td>
<td>---------------</td>
<td>-------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Stephen and wife Grace</td>
<td>Stephen aged 84 years</td>
<td>1990</td>
<td>Interview 1, Interview 2, Interview 3, Interview 4, Data collection discontinued</td>
<td>3.9.2007, 18.9.2007, 2.10.2007, 11.12.2007</td>
<td>Wife as carer also has been diagnosed with PD. Poor mobility. Registered blind. Bilateral symptoms with generalised dyskinesia. Mother had PD. Contact maintained with telephone but no active data collection due to condition and focus on managing day to day.</td>
</tr>
<tr>
<td>Name</td>
<td>Age of person with PD</td>
<td>Diagnosed</td>
<td>Interviews</td>
<td>Date</td>
<td>Brief Comments</td>
</tr>
<tr>
<td>-----------------------------</td>
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<td>-----------------------------------------------------------------------------</td>
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<td>-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Dafydd and daughter Sally</td>
<td>Dafydd aged 66 years</td>
<td>1999</td>
<td>Interview 1 Interview 2 Interview 3 Interview 4</td>
<td>11.9.2007 16.10.2007 24.1.2008 4.3.2009</td>
<td>Suffered series of bereavements. Suffers depression and high levels of anxiety. Lives at home with daughter. Father had PD</td>
</tr>
<tr>
<td>Herbert and Mary</td>
<td>Herbert aged 78 years</td>
<td>1999</td>
<td>Interview 1 Interview 2 Interview 3 Interview 4 Interview 5</td>
<td>11.6.2007 22.6.2007 20.7.2007 7.9.2007 25.9.08</td>
<td>Very severe PD with poor balance and immobile. Sialorrhoea. Son was also interviewed on 22.6.2007. Repeated telephone contact maintained during deterioration in condition and period in hospital. Wife interviewed following bereavement.</td>
</tr>
<tr>
<td>Huw and wife Margaret</td>
<td>Huw aged 70 years</td>
<td>2000</td>
<td>Interview 1 Interview 2 Interview 3 Interview 4 Interview 5 Interview 6</td>
<td>7.6.2007 11.7.2007 24.9.2007 28.1.2008 4.3.09 22.6.09</td>
<td>Mild general dyskinesia. Mobility deteriorating and requires help with cutting up food at times.</td>
</tr>
<tr>
<td>David and wife Jane</td>
<td>David aged 61 years</td>
<td>2001</td>
<td>Interview 1 Interview 2 Interview 3</td>
<td>8.6.2007 26.6.2007 5.11.2007</td>
<td>Mild dysarthia. Sialorrhoea.</td>
</tr>
<tr>
<td>Ben and wife Vivien</td>
<td>Ben is aged 83 years</td>
<td>1996</td>
<td>Interview 1 Interview 2 Interview 3 Interview 4 Interview 5</td>
<td>4.6.2007 18.6.2007 23.7.2007 6.10.08 12.6.09</td>
<td>Attends Memory Clinic Day Hospital has planning and organisation difficulties, poor short term memory and confusion. Poor mobility. Reduced periods of contact due to severe memory loss.</td>
</tr>
</tbody>
</table>
Appendix 5: Understanding Parkinson’s Disease: Lay Insight Diagrams
Appendix 5
Understanding Parkinson's disease

Lay Insight Diagrams
Adjustment and coping

Balancing drugs and symptoms

- Being stable
- Emotional rollercoast
- Life history
- Confidence
- Partners
- Emotional support

Help and support

- Inside/outside worlds
- Symptoms change
- Experiment what & when
- What works for you
- Keeping it going
- Sliding down (hill)
- Being down
- Depression & chronic sorrow

Stress

- Information for support
- 'Shade and light'
- Challenging stress paradigm
- Rolland's model

Relationship

- Life history/narrative
- Psychosocial models of adjustment
- Embodiment & fatal embrace

Lay advisors

- Depression & chronic sorrow
- Keeping it going
- Sliding down (hill)
- Being down
Appendix 6: Journal Publication
‘A stony road... a 19 year journey’: ‘Bridging’ through late-stage Parkinson's disease
Sion Williams and John Keady
Journal of Research in Nursing 2008; 13; 373
DOI: 10.1177/1744987108095160

The online version of this article can be found at:
http://jrn.sagepub.com/cgi/content/abstract/13/5/373

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http://jrn.sagepub.com/cgi/content/refs/13/5/373
‘A stony road… a 19 year journey’: ‘Bridging’ through late-stage Parkinson’s disease

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Abstract  Studies reporting the lived experience of late-stage Parkinson’s disease are sparse. Using constructivist grounded theory and centre-stage storyline generation as the methodological approach, this study reports on 69 interviews with 13 people with late-stage Parkinson’s disease and their family carers who were recruited from the caseload of two specialist Parkinson’s disease nurses working in North Wales and one consultant geriatrician. The interviews were conducted longitudinally between June 2007 and April 2008, and all participants were diagnosed with late-stage idiopathic Parkinson’s disease using Brain Bank clinical criteria. All interviews and the subsequent sharing, modification and testing of the results of data analysis were conducted in the person’s home and with their participation as partners in the research process. From this process, bridging emerged as the centre-stage storyline in adjusting to life with late-stage Parkinson’s disease, and this consisted of three temporal stages, namely: 1) building on the past; 2) bridging the present and 3) broaching the future. These three stages were underpinned by three linked sequential foundations, namely biographical, situational and crumbling. These stages, foundations and properties of bridging have important implications for the understanding of late-stage Parkinson’s disease and informing the nursing role in developing and providing appropriate supportive interventions.

Key words  adjustment; bridging; constructivist grounded theory; late-stage Parkinson’s disease; lived experience
Introduction
Although Parkinson’s disease (PD) occurs in people of all ages, it is most common in older people, that is, those aged over 65 years (Bell, 2003). Bell (2003) suggests that such individuals present with a complex range of symptoms that become increasingly more difficult to control as the disease advances, especially motor complications, fluctuations in the effectiveness of therapeutic treatment and dyskinesias (see also: Verhaegen, 2002; Stocchi, 2003). Moreover, cognitive changes experienced late on in the condition may lead to a diagnosis of Parkinson’s disease dementia (PD-D; Emre, et al., 2007) with the concomitant challenges that this diagnosis brings (Emre, 2003). The incidence of dementia is common affecting approximately 40% of people with PD (Emre, 2003). Within the United Kingdom, there are estimated to be 120,000 people living with PD (Holloway, 2007), and worldwide the Working Group on Parkinson’s Disease (2003) suggests that this figure is around 6.3 million.

In the United Kingdom, the development of the National Institute for Health and Clinical Excellence (NICE) clinical guideline 35 (Parkinson’s disease; NICE, 2006) acted as a catalyst stimulating more proactive, coordinated and focussed multidisciplinary services for people with PD and their families. This was necessary as a recent comprehensive report produced in the United Kingdom by the Parkinson’s Disease Society (PDS) (PDS, 2008) highlights the service inequalities that exist for this group and the need for services to reach out to family carers. One potential solution recommended by the report (PDS, 2008) was the commissioning of more Parkinson’s disease nurse specialists (PDNS) in primary and secondary care who use a family-centred approach to better manage the distressing range of psychomotor and physical signs and symptoms that are a hallmark of the condition. However, to develop such services, there is a need for a more complete understanding of the experience of living with late-stage PD for those affected and their families.

This article outlines some of the initial findings of a 2-year qualitative, longitudinal study conducted in North Wales, where the first author (SW) undertook repeated interviews during 2007–2008 with 13 people with late-stage PD and their close family supporters, usually a spouse. Using a combination of constructivist grounded theory (Charmaz, 2000) and centre-stage storyline generation (Keady and Williams, 2007; Keady, et al., 2007), we report on the emergence of bridging and its supporting properties and processes as a way of understanding adjustment and decision-making in day-to-day living with late-stage PD. Before this, we briefly outline the literature on PD with an emphasis on its middle and late stages to place the study within an appropriate context.

Late-stage Parkinson’s disease: an overview
PD is recognised as a neurodegenerative and incurable chronic illness that has a major impact on health and requires substantial personal and social adjustments (Playfer, 2002). PD results from the death of the dopamine-containing cells of the substantia nigra, and diagnosis is made based on the history and examination (NICE, 2006). After stroke, it represents the leading cause of neurological disability and is the second most prevalent neurodegenerative condition after Alzheimer’s disease (Thomas, et al., 1999), with a prevalence of 1% in the population over 60 years with an incidence of 4–20 per 100,000, the number being higher in men (NICE, 2006). Progression is unpredictable, with fluctuations in rate and severity of symptoms (Holloway, 2007). Quality of life is influenced significantly by perceptions of social and family support,
characteristics of the person and life experiences during the disease, coping strategies and socio-economic factors (Klepac, et al., 2007).

To date, and perhaps understandably, the vast majority of PD research has focused upon medical treatment and drug therapy in the attempt to alleviate symptoms and thereby improve the quality of life of people living with the condition (Abudi, et al., 1997). Recently, there has been greater interest in exploring subjective experiences, the range of coping strategies used by people with PD and their families and their accounts of their quality of life (MacCathy and Brown, 1989; Hermann, et al., 1997; Brod, et al., 1998; Carter, et al., 1998; Hobson, et al., 2001; Happe and Berger, 2003). Habermann (1996) identified the range of day-to-day demands faced by people living with PD, including emotional issues, changes to relationships with one’s body and its image, changing identity and living with unpredictability.

Holloway (2007) has described the inherent difficulties of living with PD because of its uncertain progress and highly variable and fluctuating symptoms that belie the simple view of it as the ‘shaking disease’. She notes the stigma and disadvantage experienced by people with PD and their carers, including mobility, personal care, communication problems, anxiety, restricted social life, loneliness and isolation. Holloway (2007) characterises PD as involving family members being caught up in its spiralling effects, but notes that their needs are often misunderstood by both the wider community and professionals. Macht, et al. (2005), in their qualitative study, also highlighted variation and complexity in the degree and type of psychological problems experienced in PD and the related stress experienced not only by the person with PD but also by their family (Klepac, et al., 2007; Wressle, et al., 2007). The NICE (2006) guidelines note that PD results in extensive disability and costs to health and social care and has a substantial impact on family carers.

However, despite growing awareness of such difficulties, there has been limited attention paid to the experiences of older people with PD and their families during late-stage disease, particularly from a longitudinal perspective (Hobson, et al., 2001). Addressing this deficit was the main aim of the study reported here.

**Study design**

**Aims and sampling strategy**

The study examines the experiences of older people (over 60 years) with late-stage PD and attempts to understand the transitions experienced by patients and their families as they encounter greater disability. The overall aims of the study are to:

- map the experiences of people with PD and their families as they manage and adjust to living with late-stage PD;
- identify coping and decision-making strategies used by people with PD and their families and how these change over time;
- explore how therapeutic strategies used by multidisciplinary professionals may support people with late-stage PD and their families;
- recommend changes to practice based on the study findings.

To operationalise these aims, members of a Movement Disorder Clinic (MDC) in North Wales, comprising professionals, namely two PDNS, a consultant geriatrician, occupational therapist, physiotherapist, psychologist researcher and two MDC nurses, cooperated fully with the primary researcher (SW). The inclusion criteria for the
study were twofold. First, participants had to have a diagnosis of PD using Brain Bank clinical criteria (see Gibb and Lees, 1988) and be assessed as having late-stage disease using the Hoehn and Yahr (1967) scale – indicating disabilities that influence the older person’s potential to be independent. Second, participants had to be living at home with the support of a family carer. Participants who met the inclusion criteria were given a letter by the consultant geriatrician explaining the study and were invited to take part. Subsequently, 15 people with late-stage PD and their families requested additional information, and 13 consented to take part in the study. One carer has also been diagnosed with PD. Table 1 describes the participants (all participants’ names have been changed to protect anonymity).

As the study involved repeated interviews with vulnerable older adults, the principles and values of process consent were adopted (Dewing, 2002) and consent to participate in the study was gathered at each encounter. Ethical approval to conduct the study was obtained from the relevant University Research Ethics Committee and the NHS Research and Development Committee in North Wales.

Data collection and analysis

As the aim was to generate new theoretical insights that have the potential to inform practice, a grounded theory approach was adopted. However, a key criterion was that the method should also engage with participants as equal partners. Charmaz (2000, 2006) argues that contemporary approaches to grounded theory need to extend beyond Glaser and Strauss’ (1967) original goal of being understandable to both researcher and participant, and she contends that meaning should be achieved through negotiation to reach a shared understanding. It was such an approach that we sought. Charmaz (2000) therefore promotes a vision of theory development that involves the mutual creation of knowledge by the viewer and viewed (p. 510). Although we endorse such a philosophy, Charmaz (2006) does not fully explain how this mutual creation of knowledge can be achieved. Therefore, to operationalise our goal of partnership working, the primary researcher (SW) adopted a research approach that involved the use of diagrams and other visual artefacts to identify centre-stage events that highlight the most important storylines for those living a life with late-stage PD. In order to place this within an appropriate temporal analysis, the whole approach was underpinned by a biographical perspective. The centre-stage diagrams generated in this way are both interactive and literal, with the middle of the page representing the centre-stage storyline with other issues being placed close to or far away from the centre to represent their perceived importance at a given moment (for a more complete discussion of the approach, see: Keady and Williams, 2007; Keady, et al., 2007).

Consequently, the centre-stage storyline technique goes beyond simply labelling life events chronologically (Gergen, 1988) and, instead, uses the storyline as a thread linking together the life course and life events thereby helping to make sense out of people’s lives (Sandelowski, 1991). It also generates insights into the way human beings understand and enact their lives through stories (Sandelowski, 1991, p. 163) within a frame of reference that has autobiographical and temporal dimensions. Centre-stage storylines generated in this way were constantly compared across the data set, with the on-going analysis being discussed with each participant until shared understanding was reached. Of central importance were agreeing what symptoms were centre-stage, who was centre-stage in managing these symptoms and how this
Table I  Sampling frame: overview of study participants

<table>
<thead>
<tr>
<th>Name</th>
<th>Age of person with PD</th>
<th>Diagnosed</th>
<th>Interviews</th>
<th>Date</th>
<th>Brief Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Joan and husband Peter</td>
<td>Joan aged 65 years</td>
<td>1994</td>
<td>Interview 1</td>
<td>28.5.2007</td>
<td>In the autumn of 2007, Joan suffered a stroke with right hemiparesis.</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>Interview 2</td>
<td>14.6.2007</td>
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<td></td>
<td></td>
<td></td>
<td>Interview 3</td>
<td>28.6.2007</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Interview 4</td>
<td>1.8.2007</td>
<td>Hypersalivation and facial stiffness. Poor mobility.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Interview 5</td>
<td>6.9.2007</td>
<td>Swallowing difficulties. Extreme fatigue, spasms and pain.</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>Interview 6</td>
<td>5.2.2008</td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td>Interview 7</td>
<td>25.2.2008</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Interview 8</td>
<td>15.4.2008</td>
<td></td>
</tr>
<tr>
<td>Jack and wife Sarah</td>
<td>Jack aged 89 years</td>
<td>2001</td>
<td>Interview 1</td>
<td>3.7.2007</td>
<td>Some swallowing difficulties (requires soft food) and low volume in speech. Very poor mobility and chair-bound for most of day.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Interview 2</td>
<td>17.7.2007</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Interview 3</td>
<td>4.9.2007</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Interview 4</td>
<td>11.9.2007</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Interview 5</td>
<td>24.9.2007</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Interview 6</td>
<td>12.11.2007</td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td>Interview 7</td>
<td>8.1.2008</td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td>Interview 8</td>
<td>11.2.2008</td>
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<td></td>
<td></td>
<td></td>
<td>Interview 2</td>
<td>20.6.2007</td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td>Interview 3</td>
<td>18.7.2007</td>
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<td>Interview 4</td>
<td>18.9.2007</td>
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<td>Interview 5</td>
<td>3.10.2007</td>
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<td></td>
<td></td>
<td></td>
<td>Interview 6</td>
<td>7.12.2007</td>
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<td></td>
<td></td>
<td></td>
<td>Interview 7</td>
<td>30.1.2008</td>
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<td></td>
<td></td>
<td></td>
<td>Interview 8</td>
<td>2.4.2008</td>
<td></td>
</tr>
<tr>
<td>John and wife Catrin</td>
<td>John aged 78 years</td>
<td>1988</td>
<td>Interview 1</td>
<td>5.6.2007</td>
<td>Severe PD. Very poor balance, communication difficulties and frequent falls. Mostly chair-bound requiring assistance with Activities of Daily Living (ADL).</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Interview 2</td>
<td>17.7.2007</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Interview 3</td>
<td>27.9.2007</td>
<td></td>
</tr>
<tr>
<td>Tom and wife Julie</td>
<td>Tom aged 70 years</td>
<td>2000</td>
<td>Interview 1</td>
<td>4.7.2007</td>
<td>Poor balance and gait disturbance. Severe realistic dreams, postural hypertension and mild dyskineasia. Memory difficulties.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Interview 2</td>
<td>11.7.2007</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Interview 3</td>
<td>5.9.2007</td>
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<td></td>
<td></td>
<td></td>
<td>Interview 4</td>
<td>24.10.2007</td>
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<td></td>
<td></td>
<td></td>
<td>Interview 2</td>
<td>20.6.2007</td>
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<td></td>
<td></td>
<td></td>
<td>Interview 3</td>
<td>18.7.2007</td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td>Interview 4</td>
<td>19.9.2007</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Interview 5</td>
<td>24.10.2007</td>
<td></td>
</tr>
<tr>
<td>Stephen and wife Grace</td>
<td>Stephen aged 84 years</td>
<td>1990</td>
<td>Interview 1</td>
<td>3.9.2007</td>
<td>Wife as carer also has been diagnosed with PD. Registered blind. Bilateral symptoms with</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Interview 2</td>
<td>18.9.2007</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Interview 3</td>
<td>2.10.2007</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Interview 4</td>
<td>11.12.2007</td>
<td></td>
</tr>
</tbody>
</table>

(continued)
was accomplished. An illustration of the method of centre-stage storyline diagramming is shown in Figure 1.

As Table 1 suggests, the life story and centre-stage diagramming were developed over a series of visits, initially every month or 2 months with some participants. This methodological approach to developing and refining ideas enabled co-construction (Charmaz, 2000) and the emergence of a shared constructivist grounded theory on adjustment and decision-making in late-stage PD. In total, data gathering and analysis to date has involved 69 interviews with 13 participants and their carers. We report here on the overview of the analysis to date and present an emerging grounded theory of the experience of living with late-stage PD that will be subjected to further refinement in the light of future data collection and analysis.
Findings
Centre-stage storyline: bridging

Bridging emerged as being central to the process of adjustment in late-stage PD. As a concept, bridging is not new and has been used as a metaphor in a variety of settings to describe a process of consolidation or reaching out from one place to another; for example, bridging the gap in social care and education (Higginbotham, et al., 2000; Small, 2005), bridge at the crossroads (Alzheimer’s Disease International, 2005) and part of a single bridge in the development of social and health care services. It was the image of a bridge as a means of spanning, linking and moving across or over an obstacle or difficulty that resonated with participants in this study, with bridging here being an active, on-going process by which they attempted to manage the effects of late-stage PD. Bridging is, therefore, a dynamic, transcending process in late-stage PD and has multiple meanings and qualities, as Joan explains:

And then the bridging you see, you can’t bridge if you haven’t built a structure of some kind you can’t get over it, its just like the Eiffel Tower if you like.

(Interview 7)

The participants agreed that bridging was centre-stage and necessary to adjustment and decision-making in their day-by-day lives. By working closely with each of the participants over the duration of the study, three stages emerged with bridging forming the link between their past, present and potential future. These three stages were named: 1) building on the past, 2) bridging the present and 3) broaching the future. The nature of peoples’ contact with professionals also proved important in supporting the processes that helped them to successfully negotiate their lives with late-stage PD. During the course of the interviews, three properties or foundations underpinning
bridging at each stage emerged, namely: biographical, situational and crumbling. Figure 2 displays the trajectory of the emerging model.

We will now briefly describe each of these stages and their associated properties and processes.

**The foundations of bridging: building on the past**
The first stage of living with late-stage PD, building on the past, emerged initially from an earlier study (Keady and Nolan, 1999), which highlighted the importance of previous events and the nature of previous relationships in determining the current context of care in the field of dementia. Similarly, here building on the past provides the biographical foundations on which current bridging activities are built. As such, everyday events are shaped by the past and have to be continually recast and reconstructed in the light of PD. As Table 1 indicates, most participants had received their diagnosis some time ago and thereby all were well versed in the impact that PD had upon their lives. However, in order to make sense of their present, they needed to build upon the past by engaging in continual life review involving the following processes:

**Life history**
Participants with late-stage PD worked with their life history and engaged in storying past experiences with their carer. This storied life emphasised connections and continuity and represented an accepted and shared storyline. For both individuals, this

![Figure 2](image-url)
process of revisiting, reviewing and re-building life history to construct a coherent storyline for life with PD was a situated and cyclical process that was repeated regularly as the disease progressed.

**Significant events**

This continuing review of life history helped to identify personal and shared significant events. Such key events influenced the relationship of the person with PD and their carer and were central in mapping a storyline based on previous lives, such as the shared experience of raising a family. Within this context, the diagnosis of PD represented a highly significant past event, which, as Joan noted, had been ‘a stony road … a 19 year journey’ (Interview 3).

**Relationships**

Maintaining a sense of closeness and relationship between the person with PD and their carer required both parties to construct and re-construct their life history together to take account of significant events. This occurred both when relationships had been longstanding, such as with Daniel or Joan, but also where relationships had been more recent, such as in Ben’s case. All the above factors influenced the current identity of the person with PD.

**Identity**

Biography and previous life experiences helped individuals to shape their identity in the face of PD. For example, Charlotte had a strong sense of being a survivor of hardship following key events in her life, such as the loss of her husband and surviving the war years in Germany: ‘bombed out we had only the things we had on … we lived in the cellar for three years’ (Interview 3). Equally, Jack and Daniel had lived through a series of extraordinary events during the war in Europe and Asia.

However, identity was not only based on extraordinary events but was linked to personality. John and Julie and their carers had a sense of being determined and always worked hard to make a life and bring up their families. This sense of a shared and collective identity was built on the foundations of the past and was crucial in shaping a new life, understanding what was happening and what to do with their new body in the light of PD. As the disease progressed, identity was not only (re) negotiated between the person with PD, their partner/carer and their family but also with practitioners, such as the PDNS and their general practitioner (GP). Consequently, continually framing and re-framing the meaning of past events helped to support existing relationships by providing a shared sense of identity and continuity both between partners and, to a more limited extent, those professionals involved. This building on the past provided the foundations upon which bridging was built.

**Bridging: stage 2: bridging the present**

The stage of bridging the present captures the need for individuals to feel a sense of control over late-stage PD by maintaining daily activities, medication regimes and interests. It is centred on situational foundations that ensure continuity with the past and stability in present routines. With a solid past to build on, bridging the present is
an active process of stabilising through working things out and constructing a personal model of day-to-day adjustment and decision-making. Day-to-day issues addressed in this way included communication difficulties, slowness of movement, involuntary movement and tremors, falls, fatigue, low mood, anxiety, spasms, limitations on mobility, eating, toileting and living with constant pain.

Taking control of routines was crucial to successfully bridging the present, and this involved participants developing expertise, especially understanding their patterns of symptoms and stabilising these using medication, whilst simultaneously seeking to re-build identity. The difficulties of stabilising and day-to-day managing of late-stage PD were captured by Joan:

Very fluctuating – fluctuating quite a lot…..from being off to being on. In the middle of doing things I sort of fade away……just like a rag doll and won’t be able even to get out of the chair or…..reach a drink or…..anything, not even to speak sometimes.

(Interview 3)

Participants’ experiences of their fluctuating symptoms made them ever more aware of the increasing encroachment of late-stage PD and the impact it had on their daily activities. In order to try and address this, bridging the present involved the following situational processes:

Managing meaning
Finding meaning in the present involved participants establishing a personal pattern of responses to their PD symptoms. It was here that people built on their past. Hence, for example, Tom, with an occupational background in sales and management, was constantly engaged in seeking patterns through the mapping of bar charts and symptoms. For the person with PD and their carer, meaning was essentially constructed around the daily routine of managing symptoms and balancing these activities. As Charlotte notes, maintaining a degree of independence, however limited, was central:

‘So I do a little bit of shopping, go to Boots, go to the supermarket, do odds and ends like that, because it’s the only time I really feel I’m independent you know, just for about an hour or two’

(Interview 5)

In order to maintain a perception of independence, a number of participants reported how they avoided seeing other PD patients with more advanced symptoms, such as in PDS meetings, for fear of what the(ir) future may hold.

This tendency to largely live in the present was critical to the third stage broaching the future and is an issue we return to later. However, those people who did attend PDS local meetings, such as Joan and Julie, found them largely supportive:

It’s useful – I think so because, before I didn’t know anybody else that had got it or how it affected them, you know, but um, going there you see different ones you see.

(Interview 5)

As the disease progressed, meaning was constantly challenged by changes in a person’s symptoms such as the horrible involuntary movements noted by Charlotte. However, she sought to retain meaning by maintaining her interests of listening to music and reading poetry. This meaning was often managed by a personal philosophy of both accepting and fighting the late-stage PD, as Jack summarised: ‘Something you have to live with’ that requires ‘making the best of what we got’ (Interview 2). Managing
medication was, however, a critical process in both maintaining independence and making sense of their lives.

Managing medication

The key to bridging the present and managing symptoms meant addressing three questions: What medication? When to take it? and How often? Participants generally worked within the overall parameters set by the PDNS and the consultant geriatrician, but as they became expert, they experimented with dosages or times to maximise the beneficial impact of medication on their lives and maintain stability. The challenges this posed were vividly described by Charlotte:

But once this prescription wears, this medication wears off if I don’t take the tablets in good time I’m absolutely stuck, you know I’m like a pillar of salt really. Do you know the story about Lot’s wife, I wonder if she had Parkinson’s (laughing).

(Interview 5)

Such experimentation was supported by the PDNS and the consultant, and contact with them regarding medication regimes assumed enormous significance in daily life and was at the heart of stabilising activities, with the management of medication being pivotal to maintaining a sense of control. The role of the PDNS at this time was seen as crucial not only in helping to understand symptoms but also in gaining a sense of control over them through medication.

Maintaining stability

In late-stage PD, bridging the present involved constantly seeking and (re)affirming meaning and control, trying out new medication regimes and treatment options to manage shifting symptoms. Maintaining stability required working with time and being acutely aware of the relationship between time, medication and symptoms:

As I say I, I usually get about five, six hours out of one lot of medication, it only lasts about four now, I can feel it wearing off so then I’m sort of just hanging around as long as I can before I take the other one, the other, and then within about half an hour I’m back, I’m fairly, fairly good then.

(Charlotte, Interview 4)

Although stability most often involved medication, other avenues were also explored. Tom, for example, constantly encountered problems with falling in his home, and this led to his improvised use of gardening knee pads to cushion his falls. Although this looked odd, their use improved Tom’s quality of life and preserved his independence. For Charlotte, her bedroom had become a refuge from fatigue and falls and was as a place to retreat to later in the day:

Because I just can’t bear to be up any more. Its my, my most relaxed time is when I’m in bed … I either watch television or I read.

(Interview 4)

Participants realised that improvement was a remote possibility, and therefore managing their symptoms to ensure maximum functioning was their major goal. In addition to medication, they often involved the use of routines.
Protecting routines

Routines built into daily life were closely linked to medication taking and provided windows of time for activities, for example, getting up, washed and dressed in the morning and arranging mealtimes. For Joan and her carer, maintaining an agreed view of priorities and establishing a shared routine was crucial for daily life to continue: ‘because a number of the items, um, the issues are shared issues and if one or the other goes their own sweet way with a shared issue then you’ve got a problem’ (Interview 5). Protecting routines and managing medication were closely linked. However, routines were not static and evolved as symptoms changed, as Joan’s carer highlighted: ‘You’ve just got to, you’ve got to adapt and improvise’.

By and large, the process of bridging continued to evolve over time but tended to result in a focus on living for the present rather than thinking too much about the future. However, as the disease progressed, this was not always the best strategy.

Bridging: stage 3: broaching the future

At the current stage of the study, broaching the future, which is about considering future options, real or imagined, is the least well developed of the phases conceptually. However, it is apparent from the data that eventually even the best maintained of routines begin to crumble, especially when medication was no longer able to maintain symptom stability. The future often seemed to be ignored or at least not given centre stage, until the ability to maintain stability in medication and routines began to crumble. This did not usually come about due to a sudden crisis but rather the slowly erosive effects of living with PD.

The following processes begin to operate as crumbling became evident.

Coping fatigue

Interviews with John, Ben and Jack suggested that gradually impaired cognition and memory combined with immobility resulted in fatigue in their coping strategies, occasioning the need to broach the future. For example, John is living a life with possible PD-D, cognitive deterioration, immobility and falls, which have removed his sense of control over his life, and care home provision is currently being considered. On the contrary, for Ben, it is the memory difficulties combined with his longstanding diabetes that pose the greatest challenges:

Well my Parkinson’s mainly, shakes all over (pause), my diabetes is not too bad now and...but I can’t stand very long, you know, and I can’t walk very far, I get tired and um, I’ve got to get a hand to get my clothes on in the morning and my wife and (unclear) um, usually I’m tired most of the day um (long pause), I get fed up at times you know, but um, I’ve just got to struggle on so.

(Interview 3)

Ben’s wife struggles to manage his memory difficulties and depression:

…the last two or three years its come on. And then he’s been mithered about losing his memory haven’t you? {directed towards her husband}, because you can’t remember things.

(Interview 2)

The above difficulties began to lead to cracks in previously good relationships.
Cracks in relationship

A combination of the sometimes fragile relationship between partners, the health of carers, the increasing impact of ill-health contributing to chronicity and the emergence of memory problems resulted in a crumbling of routines, which forced people to start to plan ahead by broaching the future. Our data indicate that this is a fraught and difficult time.

Crumbling: managing strategies and routine

Increasing exhaustion was evident from many carers’ accounts and previously held routines were prone to collapsing and breaking down. At the centre of the crumbling process was the fact that medication no longer provided stability, and there was a weakened sense of control. Personal thresholds differed as to when the growing awareness of the fragility of the situation was transformed into plans for future care provision and who should be involved at an early stage, such as family members and/or the PDNS/other professions allied to medicine. The point at which individuals began to broach the future was determined by a delicate interplay between failing memory, movement difficulties, cracks in relationships and failing health for both parties, which together resulted in collapsing stability whereby the process of bridging could no longer be maintained.

John’s wife Catrin recounts crying in the bathroom with her husband after another fall and asking ‘what are we going to do now’, as his recurrent falls become much worse, as did his other symptoms of failing communication, memory and movement difficulties (interview 3). However, because couples generally did not proactively broach the future, the situation often reached crisis point before action was even contemplated.

Discussion

In the study of long-term conditions, the focus of researchers has often been on the stress coping model (Nolan, et al., 2003; Aldwin and Park, 2004), with coping methods having been described as involving cognitive, behavioural and avoidance strategies (Hobson, et al., 2001). Our data indicate that such concepts may not fully capture the insider experiences of people with PD and their families, which involves more subtle and nuanced tactics. Corbin and Strauss (1987) identified the importance of biography in the process of accommodation to a long-term condition, and this was very evident in our study, with the meaning of relationships, between spouses or with adult children, continually being framed and re-framed from a biographical perspective. The strategies used to bridge from the past to the present provide new insights in the experiences of living with and creating meaning in late-stage PD. However, the reluctance of those actively involved to broach the future meant that established strategies were put under increasing strain. It is here that the PDNS could play a fuller part.

The impact of PD on the daily life of partners and family has been recognised (Wressle, et al., 2007), and the role of the PDNS in sustaining quality of life and biographical connectivity in living with a progressive long-term condition is at the forefront of developments in primary care and secondary care, as well as being a key role for MDCs (Whitney, 2004). Initially introduced in 1989 through the support of the PDS, the PDNS role has been the subject of rigorous study as to its effectiveness (see
Jarman, et al. (2002), impact on promoting positive quality of life for people with PD (MacMahon and Thomas, 1998) and cost effectiveness (Hobson, et al., 2001). Arguably, the PDNS is central to care (particularly medicines management), but our study suggests an important but as yet underdeveloped role in broaching the future when PD-D (Emre, et al., 2007) may be a feature of life. In addition, the roles of the PDNS, consultant geriatrician and GP should be considered within a broader network of support services, including a dedicated multidisciplinary MDC, and closer working with memory clinics to support adjustment to memory loss for people with PD and their carers. In our study, the support offered, especially day care, did not seem to match people’s requirements, and a more proactive approach to the provision of respite care is required.

In terms of the work of MDC, access to a structured programme of education and support is also potentially important in helping people with PD and their families to (re)construct relationships during bridging the present (Sunvisson, et al., 2001). Charlton and Barrow (2002) highlighted the importance of a self-help group for people with PD, and the availability of such support helps people with PD to positively (re)construct relationships. Although the literature emphasises the importance of people’s subjective experience and symptom management (Abudi, et al., 1997; Habermann, 2000; Hobson, et al., 2001; Holloway, 2007; Wressle, et al., 2007), from our work to date, it appears that reciprocal relationships are central to maintaining quality of life for both people with PD and their carers. Quality of life in PD is complex, particularly as older people with PD frequently have other chronic illnesses associated with age. The concept of frailty (Markle-Reid and Browne, 2003; Jo-Levers, et al., 2006) appears very relevant to understanding quality of life in late-stage PD, as do the ways in which stability and managing control are handled. From our data, we would suggest that stability, maintaining a sense of control, routines and medicine management are key dimensions that help people with PD and their families make bridges, from the past to the present. However, their ability and willingness to broach the future is less well developed, and this will be the focus of future exploration.

Of course, it is useful not to claim too much from the findings of one study that is limited to exploring the perspectives of people with late-stage PD receiving care within one MDC and restricted to three geographical and Local Health Board areas within North Wales. The authors recognise that there are a range of different service models that seek to address the needs of people with late-stage PD and their carers. However, our participants are drawn from people who receive care from two PDNS and potentially involve a wide number of health and social care practitioners within those three areas. An additional limitation of the study is that the participants recruited may not represent the wide diversity of symptoms that people with PD and their carers encounter. Nonetheless, we would suggest that participants experience a diverse and complex range of symptoms that are not atypical of late-stage PD.

Finally, although the observation by Chesson, et al. (1999) was made nearly a decade ago, it seems both appropriate and pertinent to revisit this once again:

We conclude that, above all else, people with PD have psychosocial needs that are currently insufficiently met, and this may be the major challenge for the next millennium (p. 129).

The authors recognise that bridging, as with all emergent grounded theory (Glaser and Strauss, 1967; Glaser, 1978), is subjected to further modification, and we will
continue to develop, test and refine the concepts provided in this paper, as well as explore the next experiences in peoples’ lives with PD.

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References


387


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Appendix 7: RAPID Checklist
The purpose of this checklist is to find out more about how you both live day to day with PD. Please read each sentence and indicate how much you agree or disagree with the statement by ticking the relevant circle: please only tick one circle per statement. There are no right or wrong answers and your responses will remain confidential and used to help develop the best support for you.

### 1. About our life

<table>
<thead>
<tr>
<th>Statement</th>
<th>We strongly agree</th>
<th>We agree</th>
<th>We are undecided</th>
<th>We disagree</th>
<th>We strongly disagree</th>
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<tbody>
<tr>
<td>We organise our day together.</td>
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<tr>
<td>We continue to show affection to one another.</td>
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<tr>
<td>Our relationship is based on mutual support and togetherness.</td>
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<td>We plan ahead.</td>
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<td>Over recent years we have grown closer as a couple.</td>
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<td>Members of our family show us care and support.</td>
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<td>We spend time together outside the home.</td>
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<td>We keep to a structured routine in our daily lives.</td>
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<td>We remain in love with one another.</td>
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<td>We draw on our past times together to help us through the day.</td>
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### 2. About Our Life with PD

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<tr>
<th>Statement</th>
<th>We strongly agree</th>
<th>We agree</th>
<th>We are undecided</th>
<th>We disagree</th>
<th>We strongly disagree</th>
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<tr>
<td>Over the years we have learned to control and adapt to the symptoms of PD.</td>
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<td>Finding stability in our lives is important to us.</td>
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<td>We are able to have a good night's sleep.</td>
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<td>We cope well with the changing symptoms of PD.</td>
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<tr>
<td>We attend a support group.</td>
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<td>We are content with our quality of life.</td>
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<tr>
<td>We are well supported by the Parkinson's Disease Nurse Specialist.</td>
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<tr>
<td>The prescribed medications help us get through each day.</td>
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<tr>
<td>We are able to overcome fatigue and tiredness brought about by PD.</td>
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<tr>
<td>We work together to solve any challenges we face.</td>
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