

**MAPPING SELF-MANAGEMENT
STRATEGIES IN PARKINSON'S
DISEASE: IMPLICATIONS FOR
PHYSIOTHERAPY PRACTICE AND
RESEARCH**

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This thesis is dedicated to my family - Alan, Charlotte and Alexander - and to the memory of my parents-in-law, Maurice and Dorothy Jones, whose battle with Parkinson's disease taught me more than they will ever know about the condition and life itself

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- the many other colleagues, friends and family who have shared this journey with me

ABSTRACT

The overarching purpose of this research was to find out about life with Parkinson's disease and to use that knowledge to inform physiotherapy management. The project aimed to explore current and alternative ways in which professionals could seek to understand the experience of life with Parkinson's disease; to explore the implications of resultant new knowledge; and to investigate how physiotherapy relationships should take account of new ways of understanding and new knowledge.

A spiral of research activity was undertaken comprising three successive cycles. The first two cycles were undertaken using case study methodology, focusing on the experience of life with Parkinson's disease from a group and an individual perspective. A wide range of qualitative and quantitative methods for both data collection (including interviews, disability and quality of life scales and activity monitoring) and data analysis were employed. The level and complexity of personal work undertaken by individuals to manage their condition was the principal theme to emerge from initial cycles. This insight led to the development of a tool – strategy mapping – to enable professionals to capture and use information about self-management in their interactions with individuals. The third cycle employed action research methodology to develop and evaluate the strategy mapping framework - centred on identifying strategies related to Self, Routines, Support and Involvement - in physiotherapy practice.

A number of perspectives were developed in relation to the project's aims. The methodological perspective highlighted the need for commitment to listening to the experiential narrative and hearing the story of self-management. The ontological perspective offered the potential for practice and research to build on existing self-management solutions. The epistemological perspective pointed to addressing power differentials between knowledge bases to promote collaborative therapy relationships. The full potential of a paradigm shift which attempts to increase the degree of alignment between the everyday lives of individuals with Parkinson's disease and physiotherapy practice, education and research remains to be uncovered.

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1 A spiral of research activity

1.1 Overview of chapter

The overarching purpose of this research project was to find out about life with Parkinson's disease and to use that knowledge to inform the physiotherapy management of the condition. This initial chapter will provide an overview of the aims and a brief summary of the outcomes of the project. The research process undertaken to produce the outcomes will be articulated using the research cycle model (Rowan 1981). This will enable the tracking of developing relationships between ideas and evidence over time. The individual phases of the three cycles that formed the spiral of research activity will be discussed, including their links with other projects within the research group's overall programme. This account will place considerable emphasis on my relationship, as a principal investigator, to the research process. This is particularly important as, although employing mixed methodology, the overarching inquiry paradigm guiding the study has been a qualitative one, and I acknowledge myself to be an instrument in the research process. Cross-reference will be made to subsequent sections of the thesis relating to specific phases of the research spiral to enable the reader to follow up links if desired. The final section of this chapter will detail the part each chapter of the thesis plays in telling the story of the outcomes of the research spiral.

1.2 Aims and outcomes

Because of the cyclical nature of the spiral of research activity undertaken in the course of this project, the aims of the research evolved over time, and this evolution forms part of the story to be told in this thesis. However for clarity the broad and related subsidiary aims of the project will be articulated here:

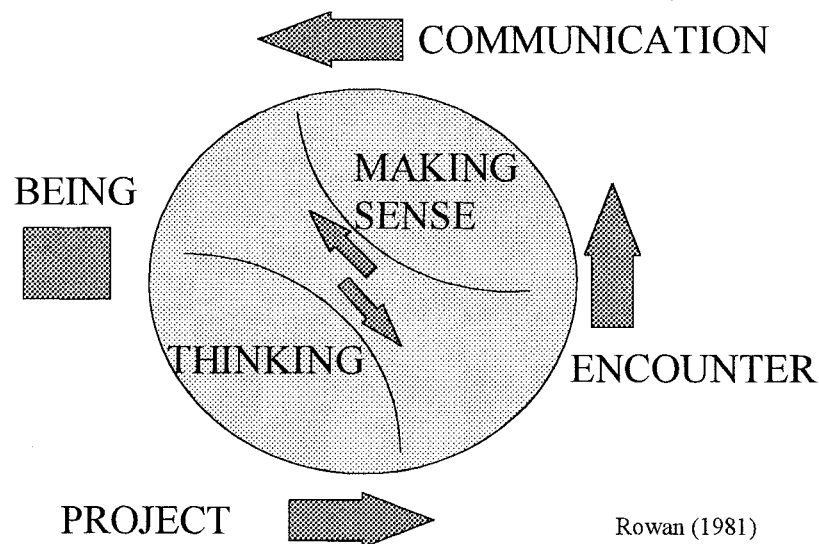
1. To explore the experience of living with Parkinson's disease from an individual perspective
 - To consider how health care professionals currently understand life with Parkinson's disease
 - To develop alternative ways of understanding the experience of life with the condition
2. To explore the implications of new knowledge generated as a result of alternative ways of understanding Parkinson's disease
 - for physiotherapy practice
 - for physiotherapy research
3. To investigate how the physiotherapy relationship can be structured to take account of both new ways of understanding and new knowledge in Parkinson's disease
4. To explore the interface between physiotherapy practice and research through personal exposure to the research process

The project has sought to examine four perspectives, three explicitly in relation to Parkinson's disease and physiotherapy management and one in relation to making links between physiotherapy practice and research in the context of the study. The developing methodological perspective has highlighted the need for commitment by professionals to listen to, hear, capture and act on individuals' experiential narrative in relation to life with Parkinson's disease to ensure meaningful intervention and evaluation. The developing ontological perspective has uncovered knowledge about the extent and nature of self-management, which has the potential to guide practice and research to ensure congruence with personal reality. The developing epistemological perspective points to a focus on addressing power differentials between knowledge bases to promote collaborative therapy relationships with mutual sharing of knowledge and learning. The developing practitioner/researcher perspective suggests that alignment of the research process to the practice process has the potential to bridge the perceived divide and enable the practice setting to become a rich environment for systematic inquiry. The research cycle model (Rowan 1981) has been central to the exploration of each perspective.


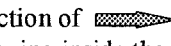
1.3 Links between cycles and spirals

The framework chosen to articulate the research process within the current project is the research cycle model (Figure 1.1). It is possible to apply this model to any research project, whether it be of experimental or collaborative design. What differentiates between the research cycle model used within different research designs is the extent to which the people involved in the research are taking part under the auspices of particular roles, such as researcher or subject, or are committed to the process as individuals, for example as collaborators at some or all phases (Rowan 1981). The phases of the model are: BEING (finding or being given a problem); THINKING (searching the literature and combining with existing knowledge to refine the problem); PROJECT (planning the research); ENCOUNTER (using relevant methods e.g. experiment, interviews to collect data); MAKING SENSE (analysing data appropriately e.g. statistical or thematic analysis); and COMMUNICATION (writing or presenting work); before returning to one's usual work (BEING).

Figure 1.1 Research cycle model



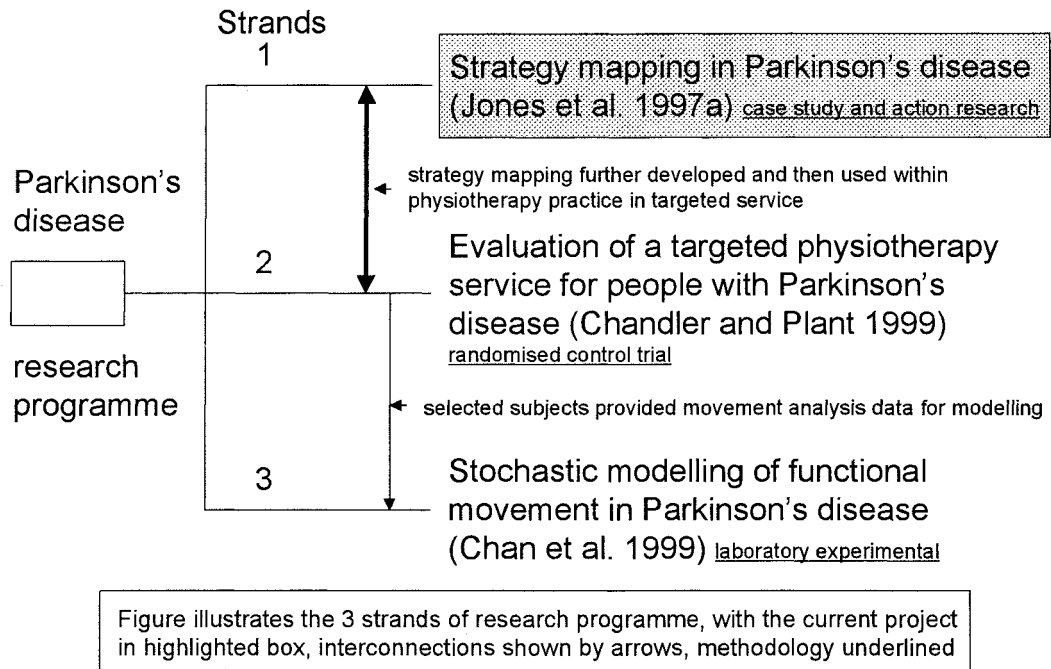
Rowan (1981)
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Cycle starts at  and follows direction of  starting inside the circle (small arrow), moving out for two phases, before moving inside the circle (small arrow) prior to last phase

In April 1994 I joined a research team investigating movement disorder in Parkinson's disease using a predominantly experimental approach (BEING). A research question had been identified from a literature review of existing work in the area of Parkinson's disease and function (THINKING) which would be amenable to study by building on developing experience and equipment (PROJECT). An experiment was planned in which repeated quantitative measures of movement parameters and functional outcomes would be taken over time, in addition to monitoring the effect of treatment in a number of participants (ENCOUNTER). Relevant statistical tests were to be applied to the data (MAKING SENSE) with results disseminated via conference presentations and academic papers (COMMUNICATION). The research would have proceeded through one research cycle, creating the possibility for further research cycles to address related research questions.

By contrast the project presented in this thesis used the components of the research cycle in an iterative, developmental way to produce a spiral of research activity, composed of sequential cycles, within a qualitative paradigm. This spiral of research activity was not a predetermined design. Rather, an active decision was taken to go into the field and allow the evidence that was collected to influence the shape of the research. Increasing familiarity with the literature of research methodology allowed the spiral shape to be superimposed onto, and help make sense of, the evolving research experience. The following sections chart the dialectical process of engagement within my personal, practice and research worlds that led to a departure from the planned project. The original project was subsequently developed into Strands 2 and 3 of the team's research programme (Figure 1.2), with both projects completed in one research cycle. Strand 1, the current project, can be seen to link into the experimental part of the overall research programme, with the experimental context providing valuable insights into the developing perspectives within the project. The following sections, which present the research activity within each phase of the research spiral in turn, will highlight links between Strand 1 and 2.

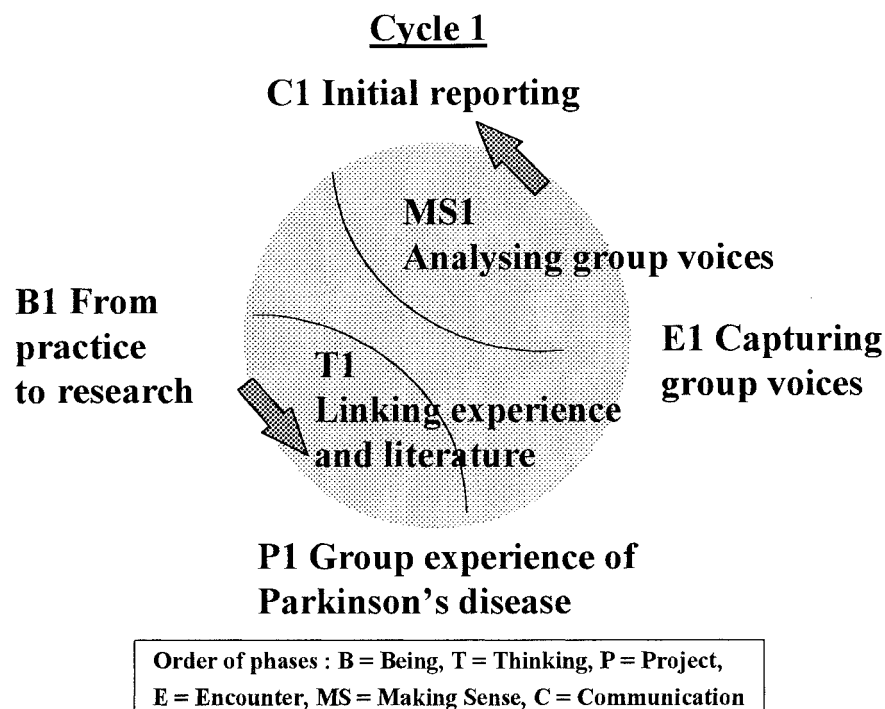
Figure 1.2 Parkinson's disease research programme at University of Northumbria (1994-2001)



1.4 First steps in research (Cycle 1)

Cycle 1 (Figure 1.3) charts my move from physiotherapy practice into research and my first encounter with each stage of the research cycle.

Figure 1.3 First steps in research: Cycle 1



1.4.1 From practice to research (BEING 1)

The BEING stage of the research cycle focuses on experience. BEING 1 represents the starting point for the dialectic and centres on developing conflicts within my practice experience. I undertook my physiotherapy training (1976-1979) as a mature student at a time when courses were at diploma level and opportunities for post-graduate study were scarce. The Open University (OU) provided me with a structure for continuing academic development. My physiotherapy training had been firmly situated within the medical model. Physiotherapy theory, which sought to explain physiotherapy practice, was based on key assumptions such as the primacy of the concepts of normality, scientific objectivity and reductionism (Roberts 1994). OU courses such as The Handicapped Person in the Community (Boswell et al. 1975) and Issues in Health and Disease (U205 Course Team 1985) sensitised me to the existence of alternative models of health - economic, social and geographical - and cultural and historical explanations of symptoms.

My first physiotherapy post was sited in an acute hospital setting where I became increasingly dissatisfied treating 'chests' on the medical wards and 'fractured necks of femur' on the orthopaedic wards. Reducing individuals to a 'chest' or a 'femur' was to reduce the relevance of the social and economic reality that led to the decision to smoke or which made a fall more likely. Neither did I feel part of the culture of the wards on which I was working, which was firmly in nursing control. I envied the nurses' ability to work with patients over the twenty-four hour period, seven days a week if necessary, and to be able to link care to encouraging function. I wanted to work with the nursing staff during dressing or bathing to encourage balance, confidence in moving and independence. It was difficult to see how rehabilitation could be seen as essential if it could be suspended over weekends.

I moved into an educational setting, working with children with severe learning difficulties, often accompanied by complex physical disability. With visibility of practice in an open classroom, and the long-term nature of the professional relationship, came increased accountability. Working to a professional agenda born of technical knowledge (Schon 1983) was not going to work in the same way it had appeared to in the brief therapeutic encounters within an acute hospital setting. Working in partnership with families, foster carers, care staff, teachers, classroom assistants, social workers, psychologists, nurses, dinner ladies and caretakers, I learnt that my professional input was but one small part of a complex whole. I needed to be sensitive to the context into which I was delivering my intervention. I began to comprehend the power of the social model of disability as I shared the stigma of the client group with whom I was working, being asked by a Fellow of the Chartered Society of Physiotherapy why I was wasting my skills on non-productive members of society. This type of comment bears out the worst fears of the disability lobby, who see rehabilitation as inextricably linked to social control (Oliver 1996), in this case as agents of the state to maintain a healthy workforce of, by implication, 'normal' citizens. Acknowledging this conflict, I have developed a personal philosophy based on thinking, speaking and acting, in my personal, professional, academic and research life, in ways that convey my beliefs about equality within society.

Later, working as a community physiotherapist developing a service for people with multiple sclerosis - a chronic, fluctuating neurological condition - I learnt from my clients

about living with uncertainty; about the need for honesty (when I didn't know immediately how to tackle a problem); humility (when what I tried did not turn out as expected); and humour. I had needed to 'reflect on' and 'research' my own practice in order to make a case for more resources. Initially this had been in terms of physiotherapy time, but later it was with a view to creating awareness of the need for integrated multidisciplinary management of the condition. Research was becoming increasingly important in the late 1980's as physiotherapy sought to evidence its knowledge base, and it was an area that I felt, as a practising professional, I needed to experience in some way. However I did not feel comfortable about learning my research skills through the medium of distance learning. Given the almost overwhelming clinical caseload I was carrying, I knew that studying research methods part-time at Masters degree level would prove unsustainable. The only option appeared to be a period of full-time research in the area of practice. In January 1994 I attended a Rehabilitation Study Group meeting at the Regional Rehabilitation Centre in Newcastle upon Tyne, where I heard about the programme of research into movement disorders at the University of Northumbria at Newcastle. I subsequently joined the research team - a novice researcher who was also a practitioner with a commitment to working in partnership, with a high tolerance of uncertainty and with a desire to see the world in all its complexity.

1.4.2 Linking experience and literature (THINKING 1)

The THINKING stage in a dialectical research cycle represents an inward movement into the cycle. Ideas from experience and the literature are processed and tried out against research problem templates for acceptability. The shape of the available templates reflects the researcher's socialised worldview, their personal way of seeing and understanding the world (Glesne and Peshkin 1992). My worldview, born in part out of the academic and professional experiences described in BEING 1, now confronted the experimental philosophy underpinning the original research concept. The issue at the centre of the dialectic at THINKING 1 was how cases (or subjects) in the research were to be viewed.

Ragin (1992a) suggests that we make sense of the evidence in the world about us by limiting it with our ideas, and we do this by means of 'casing'. He offers a framework for thinking about cases (Ragin 1992b) which involves two key dichotomies about how cases

are conceived: as empirical units (based on a realist ontology - cases are ‘out there’ to be found or objectified) or theoretical constructs (based on a relativist ontology - cases are consequences of theories or conventions); and as specific (developed in the course of the research) or general (external to the conduct of the research). Table 1 shows the four cells derived from a cross-tabulation of the two dichotomies.

Table 1.1 Understanding of cases

Cases understood as:	Ontology (nature of reality)	Case conceptions	
		Specific	General
Empirical units	Realist	1. Cases are found**** (cases real and bounded in course of the research)	2. Cases are objects* (cases real, defined by convention and manipulated in course of research)
Theoretical constructs	Relativist	3. Cases are made*** (cases constructed and theoretical significance demonstrated in course of research)	4. Cases are conventions** (cases are collective products of scientific community which structure ways of seeing and doing research)
* original research project ** PROJECT 1 *** MAKING SENSE 2 **** PROJECT 3			

Based on Ragin (1992b)

In the original research project cases had been conceived as general empirical units, the product of a realist ontological stance, with cases of Parkinson’s disease capable of being experimentally manipulated by investigators (Table 1.1, Cell 2). An objectivist epistemology was required, with the inquirer remaining distant from the subject. As a result of my experience described in BEING 1, I was used to thinking of clients as partners, to referring to their expertise and experience of managing their condition when making my contribution. I had been influenced by critical theoretical perspectives, which ensured a voice to those often marginalised in social processes. It was therefore not surprising that my instinct was to seek the views of the population I was to investigate in

order to ensure that PROJECT 1 had meaning for them as well as for the research team. My conception of the case under study at this point was at Cell 4 of Table 1.1. I thought of the study population as forming a theoretical category with the label of Parkinson's disease. My desire to get close to the subjects as opposed to remaining distant meant I favoured a subjectivist epistemology.

The dialectic within the research team resulted in a creative tension. A choice would have to be made between the relative certainty of a standard research cycle, in which analytical reasoning would break down cases into component parts as a basis for understanding, and the uncertainty of an evolving research spiral, which would attempt to capture the totality of an experience as a basis for understanding.

1.4.3 Group experience of Parkinson's disease (PROJECT 1)

The uncertain path was chosen. The methodological challenges this presented will be discussed in Chapter 3 and Chapter 4. PROJECT 1 used group case study methodology to guide the planning of entry into the field to ask groups of individuals about the experience of living with Parkinson's disease.

1.4.4 Capturing group voices (ENCOUNTER 1)

Group discussion, brainstorming and informal conversations were employed at ENCOUNTER 1 (4.2.2, p. 86). This was the only point in CYCLE 1 at which research participants were involved. The research cycle model (Figure 1.1) can be used to illustrate the points at which there is involvement of research participants in the research cycle and the degree of their involvement from fully collaborative to data source only (Rowan 1981; Reason 1988). Table 1.2 charts the growing commitment to involvement as the research spiral evolved. However the project never reached the status of true participatory research, an issue discussed in detail in relation to the limitations of the project (11.7, p. 284), as collaborative research was a concept I became more familiar with, and committed to, over the course of the spiral. As a correction to the reduced level of involvement of individuals at ENCOUNTER 1, the same individuals were included in COMMUNICATION 3 when they were presented with the results of the research spiral

and their comments sought. Increased commitment to involvement of research participants matched the move from a relativist general stance to a relativist specific one, Cell 4 to 3 of Table 1.1. As the focus of the research sharpened from the experience of individuals with Parkinson's disease to individual self-management strategies, cases were increasingly 'made' with the attendant need to verify their theoretical significance by reference to the individuals themselves. Increasing confidence in the categories of mapping self-management strategies (5.2, p. 128) meant that strategies were likely to be 'found' (Table 1.1, Cell 1), however verification remained essential, with both individuals and the group at large.

Table 1.2 Involvement between researcher and participants in research spiral

Research cycle stage(s)	Level of involvement		
	Fully collaborative	Somewhere in between	Data source only
First steps in research/ ENCOUNTER 1 ⁺			X
Charting a course/ ENCOUNTER 2 ⁺ & MAKING SENSE 2 ⁺		X	
Finding a focus/ THINKING 3*, PROJECT 3*, ENCOUNTER 3* ⁺ , MAKING SENSE 3* ⁺ , COMMUNICATION 3*	X		
* with physiotherapy- researcher + with individuals with Parkinson's disease			

Based on research mapping (Rowan 1981; Reason 1988)

1.4.5 Analysing group voices (MAKING SENSE 1)

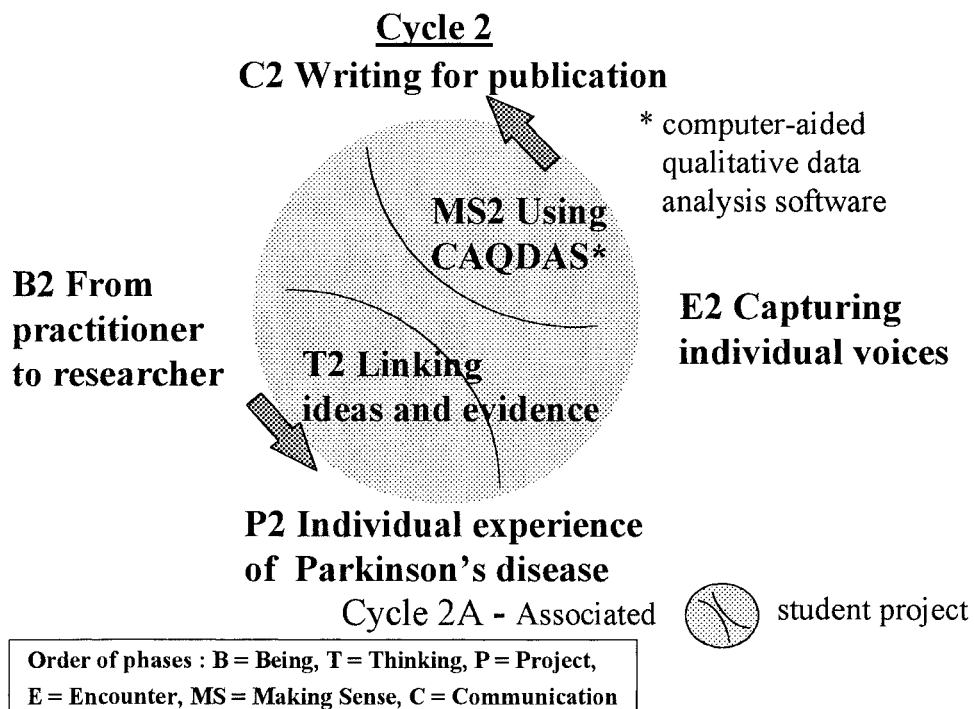
A wealth of qualitative data needed to be analysed at MAKING SENSE 1. My initial attempts to make sense of this data (4.3.1, p.88) showed clearly that I was still working within my practice framework, which had been heavily influenced by the medical model. My thinking was to evolve with the research spiral. As I moved further away in time from the practice arena and became sensitised to alternative ways of knowing, I began to hear a different story from my informants. Increasingly less influenced by the concept of cases

as conventions (Table 1.1, Cell 4), MAKING SENSE stages were marked by a move to ‘make’ cases in the course of the research (Table 1.1, Cell 3) through the interaction of ideas and evidence.

1.5 Charting a course (Cycle 2)

Having had my first experience of each point of the research cycle it was possible for me to be more focussed in charting the course of successive cycles (Figure 1.4), as the empirical world became more structured by theoretical ideas arising from Cycle 1 results (Ragin 1992a).

Figure 1.4 Charting a course: Cycle 2



1.5.1 From practitioner to researcher (BEING 2)

The transition from full-time clinical work to full-time research was for me a difficult one. At BEING 1 in community clinical practice with people with multiple sclerosis, the pressures had been constant - to visit, to treat, to record - and they were often also immediate - the need to communicate with other involved professionals. The outcomes in practice were largely tangible - a successfully (or unsuccessfully) co-ordinated hospital discharge; improved gait with the supply of an orthotic; pain relief; or the honest acknowledgement of all involved in the management of an individual that palliative care was appropriate. Professional relationships remained in a similar configuration - set within a uniprofessional team, treating a specific patient population in a community context. At BEING 2, involved in full-time research, the pressures fluctuated depending on the phase in the project - intense just before and during data collection, seemingly reduced during analysis, and often appeared distant, for example, deadlines to produce reports of the research for the University research quality exercise, which had comprised COMMUNICATION 1. The outcomes seemed nebulous. The contrast with clinical work made this a frightening experience. Research relationships had a different configuration, again depending on the phase of the research. At critical times contact with supervisors was intense; at times the main relationships were short-term, perhaps with research participants; and I was often alone with my data and the literature.

1.5.2 Linking ideas and evidence (THINKING 2)

Part of the uncertainty at BEING 2 was engendered by the knowledge that there needed to be another inward movement into Cycle 2 at THINKING 2 to combine the results of MAKING SENSE 1 with more theoretical ideas from the literature in order to plan PROJECT 2. THINKING 2 was heavily influenced by the notion of trying to capture the complexity of life with Parkinson's disease by triangulating evidence from a number of different sources (3.4.3, p.75).

1.5.3 Individual experience of Parkinson's disease (PROJECT 2)

In contrast to the group focus in PROJECT 1, PROJECT 2 took an individual focus on life with Parkinson's disease. A small number of case studies were planned to investigate

how individuals approach and manage life with Parkinson's disease (3.4, p. 67). Whilst case studies are inherently multi-method, this phase of the research spiral was particularly concerned with the philosophical basis of combining qualitative and quantitative methodologies (3.4.2, p. 73). Table 1.2 highlights the increased level of involvement of research participants at an increased number of stages in the research cycle.

1.5.4 Capturing individual voices (ENCOUNTER 2)

ENCOUNTER 2 used a variety of research methods, including in-depth interviews, disability and quality of life scales and ambulatory monitoring equipment (4.4-4.7, p. 96) to understand life with Parkinson's disease from an individual perspective and discern the usefulness of different tools for capturing its complexity (Table 2.7, p. 60).

1.5.5 Using computer-aided qualitative data analysis software (MAKING SENSE 2)

A qualitative data analysis software package – NUD*IST (Non-Numerical Data Indexing Searching and Theorising) (QSR 1994) - was researched and used for MAKING SENSE 2 (4.8.2 and 4.8.6, p. 110 and 118). In addition data collected during ENCOUNTER 1 was reanalysed using the software (4.3.2.1, p. 90). A long, lonely learning curve with only the software demonstration disk, the manual and an electronic mailbase bulletin board for support (QSR-forum 1996) marked this phase of Cycle 2. Computer-aided qualitative data analysis software (CAQDAS) is increasingly evident in published research (Kelle 1995) and I have no regrets about making the decision to use it, but I have to acknowledge the toll it took on my time. Far from distancing me from my data however, the technology allowed me to feel I could access it, and that it and my analysis of it could be accessible. Working in Cell 3 of Table 1.1, it meant that the cases I was making and how I was making them could be viewed and reviewed. The importance of self-management strategies began to emerge from separate and integrated analysis of qualitative and quantitative data sources (4.8, p. 108) and provided the central focus for the final cycle.

1.5.6 Writing for publication (COMMUNICATION 2)

Another major time challenge occurred at COMMUNICATION 2. I was approached with a view to co-authoring a book chapter on the management of Parkinson's disease. A consultant neurologist would write about the medical management and I would contribute the physical management section. Once more a steep learning curve faced me. The task was completed (Jones and Godwin-Austen 1998) and submitted on time, only to wait over two years for publication.

A commitment to dissemination has been a feature of the COMMUNICATION stages throughout the research spiral. Reed and Procter (1995) highlight the fact that 'insider' practitioner researchers have a particular commitment to dissemination, not just to the academic community but also to professional colleagues. They also exhibit a concern to transfer the findings of research into the practice arena. This focus was to heavily influence PROJECT 3. Appendix 1 gives details of publications and conference presentations arising from this research project and related work on physiotherapy and Parkinson's disease.

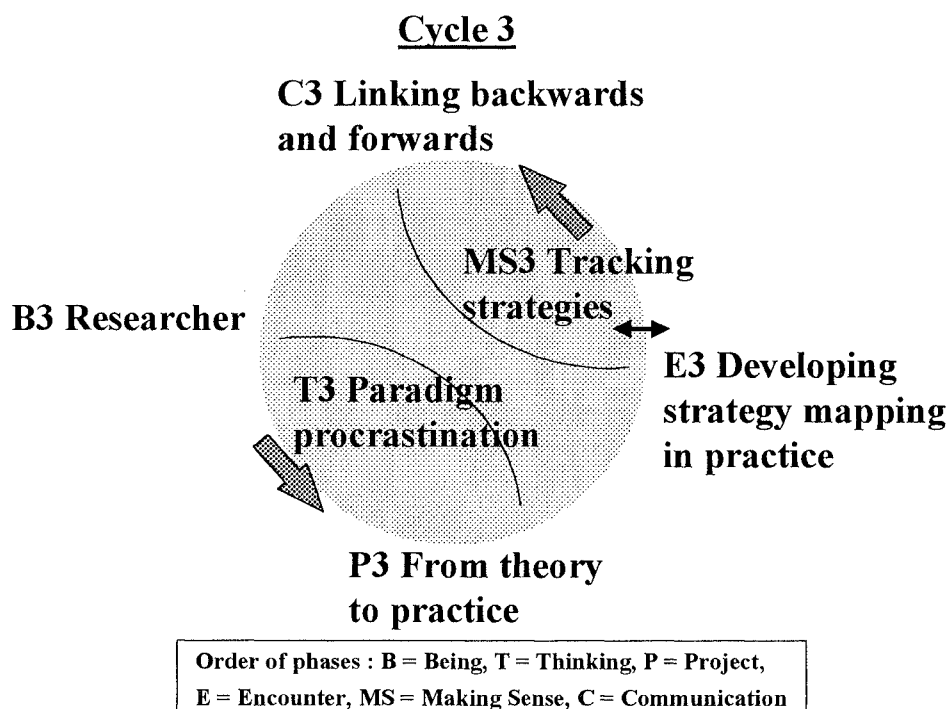
1.5.7 Physiotherapy in the management of Parkinson's disease (Cycle 2A)

At the same time as I was completing Cycle 2 of the research spiral, Ane Seglem Asbjornsen, an undergraduate physiotherapist studying for a BSc(Hons) Physiotherapy at the University of Northumbria at Newcastle, completed her research project within my project area, Cycle 2A in Figure 1.4. She interviewed senior physiotherapists (n=5) about their work with individuals with Parkinson's disease (Asbjornsen 1996). We worked together on all the stages of her research cycle and I subsequently performed a secondary analysis of her data (Jones et al. 1997b). Differences between hospital and community based therapists emerged, particularly in relation to the role of physiotherapy (Dawson 2000), with community based therapists making greater links between basic movement skills and their use to extend individuals' social and leisure activities to increase self-esteem and involvement. Insights from Cycle 2A informed THINKING 3 and PROJECT 3, however none of the data is included in this thesis.

1.6 Finding a focus (Cycle 3)

Rowan (1981) highlights the possibility that researchers can get stuck at points of the research cycle and for me that point was reached during Cycle 3 at THINKING 3 as I struggled to plan what I knew would be the final cycle of the spiral. Figure 1.5 charts the main stages of Cycle 3.

Figure 1.5 Finding a focus: Cycle 3



1.6.1 Researcher (BEING 3)

At BEING 3 I was adjusted to full-time research and actively promoting and participating in the research culture within the University, whilst having an awareness that I needed to address the issue of where I was going to make my professional contribution at BEING 4, the end of the research project.

1.6.2 Paradigm procrastination (THINKING 3)

I now needed to bring together evidence from two previous cycles with ideas from the literature to both produce results and plan one further cycle. Neither this phase nor the previous THINKING phase (THINKING 2) would have been necessary in the original research design. Results from the project, undertaken over one research cycle, would have been disseminated, critically appraised by practitioners with the time and skill to do so, and assimilated into practice if deemed relevant. Its linear approach would have had the potential to influence physiotherapy practice in Parkinson's disease indirectly, but would not have had the capability of itself to actively facilitate practice-related change. The cyclical approach of the actual research design however had the potential to move the research into the practice arena and promote and evaluate change (3.5, p. 76).

1.6.3 From theory to practice (PROJECT 3)

This stage comprised an action research project that involved collaboration at all stages of the research cycle between myself and a physiotherapy practitioner-researcher, Sheila Harrison (Table 3.4, p. 81). Sheila was setting up a targeted physiotherapy service for people with Parkinson's disease and their carers, which was to be evaluated using a randomised control trial design (Figure 1.2) (Chandler and Plant 1999). The time that she was planning her physiotherapy input coincided with the emergence of a strategy mapping framework from Cycles 1 and 2 of this project. This framework aimed to enable physiotherapists to capture the self-management strategies of individuals with Parkinson's disease and to build professional intervention on existing client work (5.3, p. 130). Congruence between Sheila's practice philosophy and that espoused by strategy mapping meant that it provided a potential framework within which she could work. It was agreed that she would use the framework in practice and we would develop it collaboratively on the basis of feedback, both from herself and the individuals she was working with. The only two points of connection between this study and the randomised control trial were development of client-centred practice with the physiotherapy practitioner-researcher based on strategy mapping, and the use of data routinely gathered by her as part of the trial from which to derive strategies. Because there was an active and a control group in the trial, it was possible to detect similarities and differences between the strategy maps of the former, receiving a targeted physiotherapy service, and the latter,

undertaking assessment only (Figure 5.2, p. 134). These similarities and differences are reported in relation to each area of the strategy map (Chapters 6-10).

At this point in the research the nature of ‘cases’ changed again. As part of the research we were looking for examples of self-management strategies - specific, empirical units; empirical because the concept of self-management had been generated from the evidence during the research and specific because cases were being bounded in the course of the research (Table 1.1, Cell 1). Each casing in the research spiral had involved evidence being more structured by theory (Ragin 1992a) as the focus of the research sharpened.

1.6.4 Mapping strategies in practice (ENCOUNTER 3)

Self-management strategies were mapped at three monthly intervals for both the control and the active group in the randomised control trial over a twelve month period (5.4, p. 134). Strategy maps were developed collaboratively with participants and used to plan treatment in the active group. They were derived from the notes of individuals in the control (assessment only) group.

1.6.5 Tracking strategies (MAKING SENSE 3)

As Table 1.2 illustrates, involvement in CYCLE 3 was intense, with collaboration, involving different participants, at all stages of the research cycle. Figure 1.5 shows repeated movement between ENCOUNTER 3 and MAKING SENSE 3 as myself, as researcher, and Sheila Harrison, as practitioner-researcher, reflected together, went into the field separately and together, and made sense separately and together (Table 3.4, p. 81).

1.6.6 Linking backwards and forwards (COMMUNICATION 3)

COMMUNICATION 3 included taking the results of the research spiral back to the participants who contributed the first data three years earlier for verification (Table 3.4, p. 81). This phase also extended into BEING 4 with writing of the thesis, conference presentations (Appendix 1) and lectures to professional and lay audiences.

To summarise this section on the content of research spiral phases, Table 1.3 sets out the methodology, methods and analysis strategies related to PROJECT, ENCOUNTER and MAKING SENSE phases of the spiral, and indicates the chapter, section and page number within the thesis where presentation of the topic can be found.

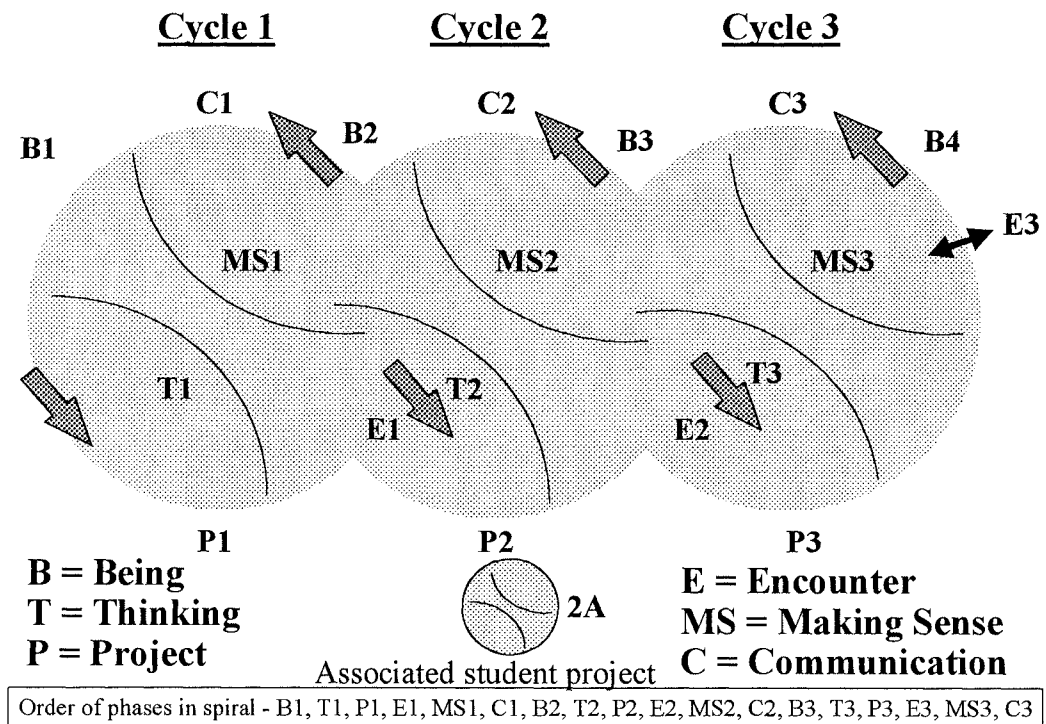
Table 1.3 Methodology, methods and analysis strategies used in research spiral

Research spiral phase	<u>Methodology, methods and analysis strategies</u>	Chapter, section and page number
<u>PROJECT 1</u>	<u>Group case study</u>	3.4, p. 67
ENCOUNTER 1	Group interview Brainstorming Informal conversations	4.2, p. 85
<i>MAKING SENSE 1</i>	<i>Thematic analysis</i> <i>QSR NUD*IST analysis</i>	4.3, p. 88
<u>PROJECT 2</u>	<u>Individual case study</u>	3.4, p. 67
ENCOUNTER 2	In-depth interview Self-assessment Parkinson's Disease Disability Scale Parkinson's Disease Questionnaire-39 and associated impairment scale 24 hour ambulatory monitoring Videotaping of functional activity with monitoring Activity and medication diary Ambulatory monitoring exit questionnaire	4.4 – 4.7, p. 96
<i>MAKING SENSE 2</i>	<i>Quantitative analysis of qualitative coding</i> <i>QSR NUD*IST analysis of interviews</i> <i>Scale analysis</i> <i>Ambulatory monitoring with video, diary and exit questionnaire analysis</i> <i>Integrated analysis with initial strategy mapping</i>	4.8, p. 108
<u>PROJECT 3</u>	<u>Action research</u>	3.5, p. 76
ENCOUNTER 3/ <i>MAKING SENSE 3</i>	Participants Strategy mapping Collaborative reflection Peer group consultation Feedback to and from participants, professional and lay groups	4.9, p. 121

1.7 Finding a way forward (BEING 4)

At the end of the three year research contract, having undertaken three research cycles (Figure 1.6) I returned to part-time clinical work in a care of the elderly setting and was retained part-time by the University. Physiotherapy has yet to formalise a research career structure. My research experience enabled me to facilitate the continuing professional development of my clinical work colleagues in a variety of ways, by providing links with University courses and personnel; feeding back on academic meetings; sharing literature and presentation skills; identifying potential research links; supporting research ideas; investigating the use of outcome measures; and contributing to a reflective practice culture. However, I was again made aware of the overwhelming pressure to ‘treat’ patients which, coupled with the difficulties experienced in relation to accessing information management resources, made practice development and research within the clinical workplace difficult (11.6, p. 281). I later wrote about the information needs of therapists with physiotherapy and information management colleagues (Ellis et al. 2000).

Figure 1.6 The spiral of research activity



At this time a change also occurred in my family life. My father-in-law had been diagnosed as having Parkinson's disease on his retirement twelve years previously. Increasingly physically disabled and cognitively impaired, he was becoming difficult for my mother-in-law to care for in the community in the south of England where they lived. A decision was made to move them to the north to enable us to help in his care. Sadly, shortly after their move north, my mother-in-law was diagnosed as having terminal cancer and died. My father-in-law moved into a nursing home. He died, seven months after his wife, of a urinary tract infection. Not only was I an 'insider' from the perspective of physiotherapy but I progressively became a stronger 'insider' from the perspective of the condition under study. I watched my parents-in-law's fifty-year marriage come under increasing stress as first physical disability and then cognitive decline forced changes to their lifestyle and relationship. I watched my family come to terms with progressive disability and death. The genetics of Parkinson's disease have personal significance for us.

As I complete this thesis I am working full-time in contract research in the area of physiotherapy practice. The work I am involved in has strong links to the current project and details of published work and conference presentations from this period are included in Appendix 1. A discussion of possible future work based on the outcomes of this project is contained in Chapter 11.

1.8 Chapter outlines

The final section of this chapter will detail the part each chapter of the thesis plays in telling the story of the outcomes of the study.

Chapter 1 A spiral of research activity

This chapter introduced the aims of the research and has used the research cycle model (Rowan 1981) to explore the relationship between the project and myself, the researcher. It has outlined how the study evolved into a spiral of research activity over three linked

cycles. The six phases of the research cycle – BEING, THINKING, PROJECT, ENCOUNTER, MAKING SENSE and COMMUNICATION – have been used to introduce the activity undertaken over the course of the research spiral.

Chapter 2 Paradigms, Parkinson’s disease and physiotherapy

Chapter 2 focuses on the concept of paradigms and their potential to influence both beliefs and associated actions. Paradigms underpinning the overall management of Parkinson’s disease will be explored, together with an investigation of paradigm influences over the knowledge base relating specifically to physiotherapy and Parkinson’s disease. This discussion forms the backdrop to the conceptual framework for the study and associated research questions.

Chapter 3 Methodology within the research spiral

Chapter 3 sets out the methodological strategies employed in the research spiral. The current status of ontological and epistemological thinking in physiotherapy research will be presented. This study is a mixed-methodology design with a combination of quantitative and qualitative paradigm influences at most methodological steps. This chapter aims to make clear the thinking behind the precise combinations employed.

Chapter 4 Methods within the research spiral

Details of the methods, associated data types and analytical strategies employed within each research cycle are set out in Chapter 4. The chapter contains early results pointing to the importance of self-management, which influenced the methodological thinking in relation to later cycles. Between them Chapters 3 and 4 present the conceptual genesis of strategy mapping, a framework for locating how individuals make decisions about and use their resources in response to the challenge of Parkinson’s disease.

Chapter 5 Strategy mapping: background and process

Chapter 5 gives details of the development of the concept of strategy and mapping strategies within the project. The categories and operational definitions for the four areas and associated sections of the map are presented, together with the overall aims of strategy mapping. The process of strategy mapping within the randomised control trial of a targeted physiotherapy service is described.

Chapter 6 Strategy mapping: SELF strategies

Chapter 6 focuses on the strategies individuals use to address particular challenges as a result of Parkinson's disease, drawing on their own physical, cognitive and emotional resources. The extent of 'disguise' and 'awareness' self-management work is uncovered, in addition to work to develop a personal approach to the condition. The implications of acknowledging this work for practice and research are explored.

Chapter 7 Strategy mapping: ROUTINES strategies

This chapter focuses on the regular patterns of behaviour individuals employ to try to ensure the maintenance of body functioning. A key theme running through the chapter is the difficulty of maintaining a routine. Fluctuations may be inherent within a medication routine, which can affect both dietary and exercise routines. Similarly fluctuations in dietary and exercise routines can feed back to affect medication uptake. It is the fact that individuals are engaged in self-management work that allows some form of routine to be experienced. The importance for physiotherapy practice and research of acknowledging these complex linkages is explored.

Chapter 8 Strategy mapping: SUPPORT strategies

The area of the strategy map reported in Chapter 8 relates to external support for the individual with Parkinson's disease from a range of individuals, including family and professionals; services, including statutory, non-statutory and business services; items of equipment, both ordinary and specialist; and environments. However accepting,

acknowledging, locating, using, timing and financing support can all be problematic. The area has highlighted lessons for practice and future directions for research.

Chapter 9 Strategy mapping: INVOLVEMENT strategies 1

The outer ring of the strategy map records strategies relating to the undertaking of everyday activities within the full range of social settings, encompassing the home and the wider community. It is concerned with identifying the complex inter-relationships between the performance of the activity itself, the context within which it is undertaken and the meaning that involvement in that activity has for individuals. Previous sections of an individual's strategy map provide key background information that coalesces in approaches to involvement. An involvement strategy model emerged involving a series of linked domains relating to continuation, modification, reduction, avoidance and stopping strategies in relation to activities, which is illustrated through the use of thick description (Creswell 1998). Sections focusing on personal, home and community activities are addressed.

Chapter 10 Strategy mapping: INVOLVEMENT strategies 2

The final section of the involvement area relating to mobility is explored separately in Chapter 10, using the same mode of description as the previous chapter. The chapter includes a discussion of the involvement strategy model, which suggests an overall trend towards sub-optimal performance and progressive withdrawal from involvement in all aspects of everyday life, despite major efforts by individuals to adjust performance from the early stages to maintain participation. A description of physiotherapy involvement in relation to mobility, sensitive to the model and focused on involvement strategy promotion, is presented.

Chapter 11 Strategy mapping and physiotherapy: a discussion

Four perspectives – the ontological, methodological, epistemological and practitioner/research perspectives - are examined in this final chapter, in relation to the aims of the research, to identify what the project has been able to contribute to the

knowledge base in relation to each area. The limitations of the study are examined. Future directions for practice and research are highlighted.

1.9 Summary

This first chapter set out to provide an overview of the research process undertaken in the course of the project to enable the relationship between the developing ideas, emerging evidence and final results to be introduced. Three cycles of research activity, forming a spiral, have been presented. Whilst the influence of research paradigms with their associated methods is discussed in relation to each cycle in Chapters 3 and 4 respectively, the following chapter will examine professional paradigms in relation to Parkinson's disease management which influenced the conceptual framework for the study.

2 Paradigms, Parkinson's disease and physiotherapy

2.1 Overview of chapter

This chapter comprises a discussion of the literature underpinning the ontological, methodological and epistemological perspectives in relation to physiotherapy and Parkinson's disease that are explored in this study. A recurring theme running through this thesis is the power of paradigms to influence beliefs and actions. A paradigm in a generic sense is "a basic set of beliefs that guides action, whether of the everyday garden variety or action taken in connection with a disciplined inquiry" (Guba 1990). This chapter will initially review the influence of a number of theoretical disease management paradigms in Parkinson's disease, each grounded on a different knowledge base. A brief account of the concept of paradigm formation in physiotherapy will be presented. Following a historical review of paradigm influences on physiotherapy in Parkinson's disease, their influence on the current evidence base related to the physiotherapy management of Parkinson's disease will be discussed. The importance of an understanding of self-management emerged over early research cycles and relevant literature is reviewed here. Finally the conceptual framework developed from the literature, which guided the detailed research questions addressed within the research spiral, will be articulated. Additional literature is included at relevant points later in the thesis, e.g. in relation to specific research methodologies (Chapter 3) and methods (Chapter 4). Literature in relation to specific results' areas is included in Chapters 6-8 and 10.

2.2 Paradigms and power

Paradigms provide a cultural framework within which there is a focus on specific problems, theories and actions. Control and power in health and social care is vested in those who are seen to hold the most highly prized knowledge base (Clarke 1999), and who are thereby enabled to shape the cultural framework. The power of a cultural framework stems from the fact that people working within it see the framework it imposes as self-evident (Kitwood 1995). A continuum of differential knowledge domains was proposed by Clarke (1999) for the study of dementia care. I have adapted this continuum to examine care in Parkinson's disease (Table 2.1). At one end of the continuum is the pathophysiological domain, comprising the highly prized biomedical knowledge base, which has had a major influence on the current dominant culture of care in Parkinson's disease (Stern 1990). At the other end of the continuum is the sociocritical domain, where power resides with the 'expert' or 'informed patient' (Illman 2000). Between the two can be sited the interactional domain, embodying the concept of multi-disciplinary team management and the involvement of individuals in decision-making (Oxtoby et al. 1988). Table 2.1 presents the *theoretical* implications for Parkinson's disease management if it were governed predominantly by each domain of knowledge.

Within the pathophysiological knowledge domain search for a cure with a focus on biology, classification, diagnosis and medical treatment takes precedence (Calne 1989; Jankovic 1995; Gelb et al. 1999; Hughes 1997). The aim of medical management is to minimise impairment and maximise function over the downward course of the illness (Hoehn and Yahr 1967), and the role of health care workers is the optimal management of decline. The role of the patient is to comply with pharmaceutical regimes (Evans et al. 2000). Carers are viewed as useful sources of information about the patient and co-workers in gaining compliance with regimes. Their role is perceived as onerous (Nanton 1985). Through education about the condition patients collaborate by complying with professional advice (PDS 1998; ABPI 1998).

Table 2.1 Differential knowledge domains related to Parkinson's disease management

<i>Implications</i>	Domain: Pathophysiological	Interactional	Sociocritical
Causality/ diagnosis	Degeneration within basal ganglia; guidelines for diagnosis	Stress the importance of the telling of diagnosis	Stress on exogenous as well as endogenous causal factors
Trajectory	Unremitting decline	Development of coping strategies	Personal work
Role of person with Parkinson's disease	Patient	Partner	In control
Role of carer	Semiprofessional, resource	Relationship central	Ongoing personal renegotiation
Role of health care professional	Management, education	Supportive strategies	Marginalised, to train 'trainers' who have condition
Degree of partnership	Compliance and collaboration	Consensus and partnership	Relationship negotiated

Based on Clarke (1999)

The interactional knowledge domain places importance on the telling of the diagnosis as this encounter sets the tone for future interaction with patients and carers (Oxtoby et al. 1988, Oxtoby 1999). Emphasis is placed not only on medical but also on welfare issues within the research agenda (PDS 1999). Even though the degenerative aspect of the condition is not denied, the emphasis is on finding optimal strategies to maintain a stable trajectory (Bodagh and Robertson 1994). The fact that there is currently no cure is acknowledged, optimal management is stressed and meaningful life with the condition is the goal (Clarke et al. 1995). Management is likely to be undertaken within a multidisciplinary team context (Mutch 1992). Patients are viewed as partners in management with their individual needs acknowledged (Williams 1988). Caring is seen as part of family relationships and supporting these relationships is seen as central to enhancing quality of life (Davies et al. 1999). Consensus is sought between professionals, patient and carer on management plans and collaboration is sought in carrying them out (MacMahon and Thomas 1998).

Within the sociocritical knowledge domain emphasis on causality is placed on both endogenous (intra-individual) and exogenous (environmental) causes of Parkinson's disease (Ben-Shlomo 1997). The work individuals themselves undertake to combat the effects of their condition is of central importance, with individuals taking control of their illness trajectory (Thompson 1999). The aim is for the continuance of individual growth despite the diagnosis of Parkinson's disease. The term carer becomes inappropriate as their role will be negotiated and renegotiated within the context of their relationship with their partner. Health care workers are seen as possessing a particular knowledge base that may or may not be useful. The preference is for individuals with the condition, who have been trained by health care workers and experts with the condition, to deliver self-management courses to others with the condition (Cooper 1999).

Whilst it must be acknowledged that in current everyday practice there is considerable exchange between particularly the pathophysiological and interactional knowledge domains, the exercise of critically assessing the assumptions of each domain and their implications can be a stimulus for grounded healthcare practice development and change (Jones et al. 1999d). Understanding the assumptions underpinning different management paradigms, and how they link to the experience of individuals with the condition and to the structure of the health and social care system, enables the activity of physiotherapists to be congruent with those assumptions or be equipped to challenge them. Of central importance for physiotherapy practice in Parkinson's disease is a clear understanding of how it contributes to the overall management paradigm.

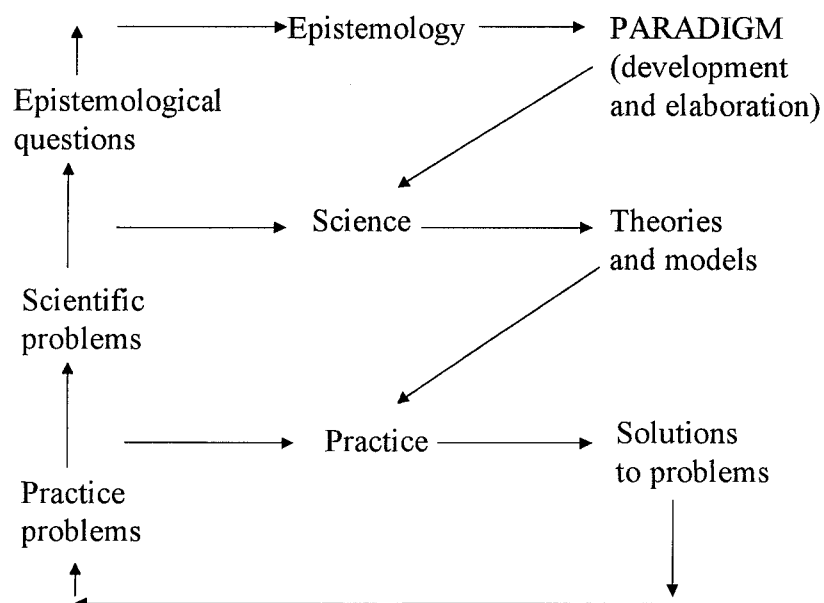
2.3 Paradigm development in physiotherapy

The increasing range of activities undertaken by physiotherapists has made it difficult to encapsulate the essence of physiotherapy's uniqueness, what it adds to healthcare practice and how it will develop in the future (Richardson 1993; Bassett 1995; Chartered Society of Physiotherapy 2000). Tyni-Lenne (1989) highlights the problem of defining physiotherapy and suggests that what is lacking is an overarching theory of physiotherapy. Theory formulation presupposes an ontological paradigm encompassing

beliefs about the nature of the world and knowledge generation (Tyni-Lenne 1991). Established practices in the field, including their underlying rationale and contribution to health care generally, need to be articulated to identify a physiotherapy practice paradigm on which a congruent research paradigm can be built (Tyni-Lenne 1989; Cott et al. 1995).

The genesis of a paradigm is illustrated in Figure 2.1 (Richardson 1993). Practice problems generate and develop scientific theory, which challenges epistemological thinking within a discipline. Durward and Baer (1995) identify the technique versus science imbalance for the lack of research-based evidence in neurological as well as other branches of physiotherapy. In other words, too much emphasis at the level of ‘Solutions to problems’ within Figure 2.1 to the detriment of activity at the ‘Theories and models’ level. Richardson (1993) suggests the development of a unifying theory of human movement from a physiotherapy perspective would unite the individual paradigms of practitioners in differing spheres of practice (Grant 1995). It would allow the testing of empirical knowledge, often embodied in the work of illustrious named therapists (Jackson 1994), and aid debate about the role of physiotherapy in relation to health care developments such as health promotion.

Figure 2.1 Issues involved in paradigm formation and their interaction



Van Gigh and Pipino 1986, in Richardson 1993
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Figure illustrates links between practice, scientific and epistemological problems, with practice problems developing scientific theory and challenging epistemological thinking

The following sections attempt to chart the extent to which physiotherapists have been reactive or proactive in relation to changes and challenges within developing Parkinson's disease management paradigms.

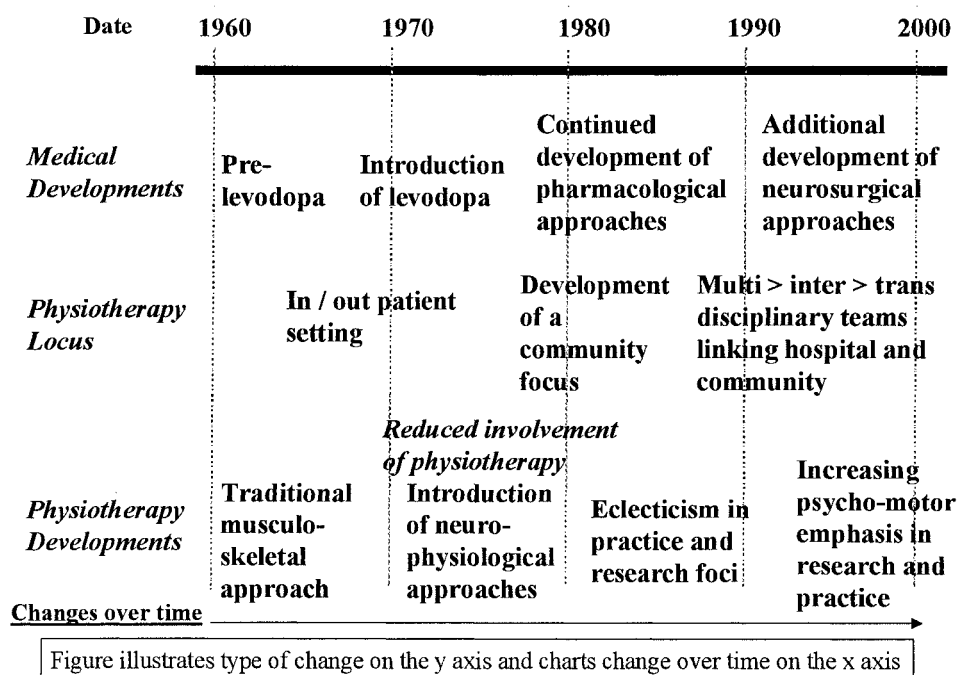
2.4 Physiotherapy and Parkinson's disease: a historical review

Roberts (1994) asserts that the need for medical patronage to establish the status of physiotherapy has led to the moulding of practice to meet the needs of the medical profession. The extent and level of physiotherapy involvement with people with Parkinson's disease have been closely related to management within the dominant pathophysiological paradigm (Table 2.1). Prior to the introduction of levodopa in the late 1960's physiotherapy played an important part in the management of Parkinson's disease, related primarily to the prevention and treatment of musculo-skeletal sequelae (Doshay 1962) (Figure 2.2). The 'lifelong' nature of a therapeutic exercise programme was stressed (Cailliet 1968), but combined medical and physiotherapeutic effect was minimal in the face of inevitable disability (Turnbull 1992). During the introduction of levodopa aggressive physiotherapy was employed to help individuals with established physical problems gain benefit from the new drug therapy (Stern et al. 1970). Although some therapists were hopeful that traditional and newer neurophysiological treatment techniques could be adjunctive to levodopa therapy (Irwin Carruthers 1971), the dominance of the pharmacological approach subsequently marginalised physiotherapy input. However there was renewed interest in the contribution of physiotherapy when the limitations and complications of long-term drug therapy were recognised (Franklyn et al. 1985).

In the area of physiotherapy and stroke there has been a proliferation of condition-specific approaches, often centred around named pioneering individuals, for example Rood, Bobath, Brunstrom, who based their work on observation, experience and current neurophysiological concepts (Ashburn 1995). By contrast historically approaches specific to Parkinson's disease have not been developed (Turnbull 1992), and the eclectic use of approaches developed largely in relation to other conditions has been a feature. Lack of

theoretical underpinning of physiotherapy approaches in Parkinson's disease had been observed as long ago as 1967 by Ball and again by Homberg (1993). The traditional musculoskeletal approach of the pre-levodopa period was augmented, at the same time as the introduction of levodopa in the early 1970's, by the use of approaches developed for other neurological conditions such as proprioceptive neuromuscular facilitation for lower motor neurone disease, the Bobath approach to stroke and conductive education for cerebral palsy (Yekutiel et al. 1991). This range of approaches together with an equally wide range of outcome measures has been incorporated into the relatively small number of research trials in the area of the physiotherapy management of the condition, making synthesis of results difficult (Jones 1997b; Deane et al. 2001a, 2001b; de Goede et al. 2001).

Figure 2.2 Medical and physiotherapy management time-line in Parkinson's disease



The realisation that Parkinson's disease symptomatology extended beyond the motor deficits to cognitive and emotional disturbance, to cause a range of functional and psychosocial problems led to the use of group therapy in an attempt to address a wider treatment agenda (Carlson Davis 1977; Szekely et al. 1982, Gauthier and Gauthier 1983;

Gauthier et al. 1987). In contrast increasing interest was being taken in more specific tools and techniques for assessment and treatment respectively, such as gait analysis (Flewitt et al. 1981) and visual and verbal cueing (Bagley et al. 1991; Weissenborn 1993). A note of caution was sounded by Handford (1986) who reminded the profession that little value was served in correcting one abnormality in order to treat a range of problems. However increasingly links are being made between the specific neurological deficits found in the condition and physiotherapy treatment approaches (Tables 2.4 and 2.6). Acknowledgement of the multifaceted needs of the client group has led to an emphasis on multidisciplinary team work working within a shared philosophy of care (Oxtoby et al. 1988; Morris and Ianssek 1997). Increasingly the role of the individual with the condition and their carer to educate the team is being acknowledged (Bilclough et al. 1999).

Despite developments in the knowledge base and changes in the structure of health service delivery over the last 20 years, referral rates to the paramedical therapies have changed little, with the exception of speech therapy (Table 2.2). The perceptions of therapists are that referrals occur in the later stages of the condition (Asbjornsen 1995; Chesson et al. 1996; Plant et al. 2000). Baker (1994) highlighted the threat to the purchase of physiotherapy in Parkinson's disease due to the lack of strength in the evidence base. The fact that widely differing treatment programmes produce favourable results has led to the observation that the specifics of physical therapy programmes might not be as important as the promotion of motivation (Weiner and Singer 1989), and that other more cost-effective programmes to improve patient performance might be developed, such as the mail-delivered patient education and health promotion programme of Montgomery et al. (1994). The following section will examine the evidence base of physiotherapy in Parkinson's disease in an attempt to identify why it may have failed to be persuasive in terms of effectiveness of interventions.

Table 2.2 Referral rates to paramedical therapies in Parkinson's disease

Study	Physiotherapy	Occupational therapy	Speech therapy
Oxtoby 1982 n=261	17%	13%	3%
Mutch et al. 1986 n=227	7%	25%	4%
Clarke et al. 1995 n=72	29%	18%	15%
Chesson et al. 1996 n=665	38%	24%	18%
Yarrow 1999 n=1693	27%	17%	20%

2.5 Paradigms and evidence in physiotherapy and Parkinson's disease

Minute percentages of the total annual publications relating to Parkinson's disease management address physical therapy approaches (Ward 1992; Chandler et al. 2001). The physiotherapy evidence base is generated from a range of methodologies, from personal literature reviews to randomised control trials (Guidelines Group 2001). Classical hierarchies of evidence (Gray 1997) rank evidence from at least one systematic review of multiple well-designed randomised control trials as the gold standard, category I type, evidence, attracting level A strength of recommendation in relation to practice (Eccles et al. 1996). Less robust research designs in terms of eliminating the likelihood of errors in conclusions come lower in the hierarchy, with the opinions of respected authorities at the base of the hierarchy. Evidence from patients is not included.

Evidence-based healthcare practice shifts the focus from knowledge based on clinical experience to knowledge based on rules of evidence applied to the interpretation of healthcare literature (Bithell 2000). The paradox is that evidence-based healthcare at one and the same time offers the potential for high quality care whilst also posing the threat of bypassing patients' opinions in the name of guidelines (Bensing 2000). The applicability of the disease-oriented randomised control trial as a gold standard for patient-oriented

therapy and rehabilitation research has been questioned (Parry 1991; Bithell 2000). Concerns centre on adopting a reductionist approach to the multitude of factors that influence the outcomes of physiotherapy, including the interaction between individual therapist and patient. Often the types of patient treated by physiotherapists are excluded from such trials, i.e. those whom are elderly with multiple pathology. Parry (1997) characterised the evidence-based practice of physiotherapy as a battle of agenda: the response of the condition to a specific treatment protocol versus the response of the person to individually-designed physiotherapy. It has been suggested that a bridge could be formed between the differing epistemological bases of evidence and patient based healthcare by addressing three dimensions in clinical decision-making instead of the normal two (Bensing 2000). The concept of patient significance, information that stems from the individual patient, should be added to that of statistical significance, information that stems from meta-analysis of randomised controlled trial results, and clinical significance, information that stems from the professionals' experience. Research and practice literature in relation to physiotherapy and Parkinson's disease will be reviewed under this framework - considering systematic reviews of randomised controlled trials; evidence from individual studies and from expert opinion; and evidence from the experience of individuals with Parkinson's disease.

2.6 Systematic reviews

Systematic reviews attempt to provide answers to questions about health care by identifying and appraising all available studies relating to a specific question and synthesising their results according to explicit methodologies. The process places emphasis on assessing and maximising the value of data. Two systematic reviews, which aimed to compare the efficacy and effectiveness of physiotherapy with placebo interventions and standard physiotherapy with novel physiotherapy in patients with Parkinson's disease, have recently been undertaken under the auspices of the Movement Disorders Group of the Cochrane Collaboration (Deane et al. 2001a, 2001b). In addition a research synthesis of studies evaluating the effects of physiotherapy on neurological signs, activities of daily living and walking ability has been completed by de Goede et al.

(2001). Only randomised or quasi-randomised controlled trials were included in the Cochrane study. Eleven trials comparing physiotherapy with placebo or no treatment in 280 patients and 7 trials comparing two forms of physiotherapy in 142 patients (Table 2.3) were identified. The main outcome measures monitored by reviewers were at the level of motor impairment, activities of daily living, handicap and quality of life scales and depression. The majority of outcomes measured were reported to have improved as a result of the primary therapy under study. However it was not deemed possible to summarise the results quantitatively by meta-analysis. Methodological weaknesses were compounded by low numbers in the trials, and the variety of outcomes measures, treatment techniques and time durations employed. The conclusion drawn was that there was insufficient overall evidence to affirm or deny the efficacy of physiotherapy in Parkinson's disease. It was stated that this did not imply a lack of effect, rather that further work using strict methodological guidelines (Begg et al. 1996) was required.

Table 2.3 Trials of physiotherapy interventions included in the Cochrane (Deane et al. 2001a, 2001b) and de Goede et al. (2001) reviews

Cochrane Physio vs Placebo	Cochrane Type A vs Type B	de Goede et al. in press
Gibberd et al. 1981		
Hurwitz 1989		
Cerri et al. 1994		
Comella et al. 1994		Comella et al. 1994
Forkink et al. 1996		
Katsikitis & Pilowsky 1996		
Patti et al. 1996		Patti et al. 1996
Thaut et al. 1996	Thaut et al. 1996	Thaut et al. 1996
Schenkman et al. 1998		Schenkman et al. 1998
Homann et al. 1998	Homann et al. 1998	
Chandler and Plant 1999		
	Palmer et al. 1986	Palmer et al. 1986
	Mohr et al. 1996	Mohr et al. 1996
	Hirsch 1996	
	Shiba et al. 1999	
	Marchese et al. 2000	
		Gauthier et al. 1987*
		Formisano et al. 1992
		Kamsma et al. 1995
		Dam et al. 1996
		Muller et al. 1997
		Nieuwboer 1999

*Included in Cochrane Occupational Therapy and Parkinson's Review (Deane et al. 2001c)

De Goede et al. (2001) included both true and quasi-experiments in their research synthesis (Table 2.3): a true experiment comprised a control condition and randomization, and a quasi-experiment did not include randomization procedures. When the estimated effect size and the summary effect size were calculated for each outcome measure there were significant results in relation to activities of daily living, walking speed and stride length but not in terms of neurological signs. The authors highlight the need to assess whether the statistically significant results were clinically significant (Bain and Dollaghan 1991). De Goede et al. (2001) also highlighted methodological weaknesses in the research base.

2.6.1 Systematic reviews: implications for physiotherapy

The literature contains challenges to trials included in the Cochrane review of physiotherapy and Parkinson's disease (Deane et al. 2001a, 2001b). Andrews (1981) questioned the methodology, outcome measures and treatment in the trial by Gibberd et al. (1981). He felt that the use of cross-over trials was inappropriate in rehabilitation research where a learning effect is sought; suggested that much larger numbers were needed given the large number of variables in the therapeutic relationship; questioned whether the five point scale used would detect small but important changes; and suggested that 'inactive' physiotherapy was in fact comparing one type of physiotherapy with another. MacKay Lyons and Turnbull (1995) questioned whether the type of physiotherapy employed in the Comella et al. (1994) study was optimal, based uncritically as it was on work emanating from the 1970's (Wroe and Greer 1973). They recommended an individually tailored and goal-directed programme of exercise and education, regularly reviewed and supported by video and/or written instructions. The trialists themselves highlight a range of issues emanating from their studies, including the sensitivity of classic outcome measures (Chandler and Plant 1999); the link between optimal physiotherapy and reduction in medication levels (Cerri et al. 1994); the optimisation of the carryover of treatment effect (Comella et al. 1994; Hirsch 1996); the location of therapy for maximum effect, hospital (Patti et al. 1996) or home (Gibberd et al. 1981); the timing of therapy in the disease course for best effect (Formisano et al. 1992; Schenkman et al. 1998); and distinguishing between the motor and motivational effects of exercise (Palmer et al. 1986).

Whilst it is disappointing to acknowledge that the quality of the evidence base is not robust enough to support systematic review with meta-analysis (Deane et al. 2001a, 2001b), it is important not to dismiss the whole evidence base as thereby not having anything to offer. It contains important clues as to why the evidence may not be robust and what needs to be done to redress the weaknesses. The following section looks at the evidence base in relation to individual studies with the aim of tracing links between the stated aims of treatment, types of intervention used and the outcomes employed to measure effect.

2.7 Evidence from individual studies of physiotherapy and Parkinson's disease

The main body of research in physiotherapy and Parkinson's disease takes the form of intervention studies using a range of research designs which aim to record changes in patient status associated with different types of physiotherapy (Jones 1997b). The knowledge base relating to intervention studies falls into two distinct parts (Jones and Plant, in press). The first is composed of those studies evaluating a physiotherapy intervention package - active exercises, passive mobilisation, relaxation, training e.g. of gait, cueing and sequencing, in addition to pain relief, advice and education. A second group of studies of physiotherapy in Parkinson's disease has addressed particular problem areas encountered by the client group using specific physiotherapy treatment techniques. Specific techniques include compensatory movement strategies, cueing, a targeted focus on trunk or balance work, and the use of treadmill training. Table 2.4 lists studies of physiotherapy intervention, undertaken between 1980 – 2001, which have employed a physiotherapy intervention package, and those that have used a specific treatment technique for a target problem, as the experimental or principal treatment approach within a study. Studies have been identified through regular searches of literature databases and immersion in the field of study over a period of seven years. All the studies included in Table 2.3, listing those studies involved in systematic reviews, are classified in Table 2.4 in terms of type of intervention employed.

Table 2.4 Studies using a physiotherapy intervention package and those using specific physiotherapy techniques

Packages of treatment techniques	Specific techniques
Gibberd et al. 1981	Banks and Caird 1989^
Palmer et al. 1986	Yekutieli et al. 1991~
Hurwitz 1989	Bagley et al. 1991#
Pederson et al. 1990	Weissenborn 1993#
Formisano et al. 1992	Chan et al. 1993^
Comella et al. 1994	Kamsma et al. 1995~
Cerri et al. 1994	Morris et al. 1996a#
Patti et al. 1996	Mohr et al. 1996#
Viliani et al. 1999	Dam et al. 1996#
Chandler and Plant 1999	Thaut et al. 1996#
	Forkink et al. 1996+
	Hirsch 1996+
	Nieuwboer et al. 1997#
	Bridgewater and Sharpe 1997^
	Shenkman et al. 1998^
	Moore and Robertson 1998#
	Homann et al. 1998^
	Nieuwboer 1999~#
	Shiba et al. 1999#
	Marchese et al. 2000#
	Miyai et al. 2000*

~ compensatory movement strategies; # cueing (verbal, visual, auditory); ^ trunk focus; + balance focus; * treadmill

A growth in the number of studies using a specific physiotherapy technique is illustrated. In common with the finding of the Cochrane systematic reviews (Deane et al. 2001a, 2001b) the majority of primary outcomes measured in the studies reported positive results. However this section does not seek to review results but rather to explore the congruence between stated aims of the studies and the chosen levels of measurement for the outcome of physiotherapy. Aims and outcomes have been related to the ICIDH-2 classification of impairment, activity and participation (WHO 1997), with the classification informed by discussion of neurological outcome measures in Wade (1992) and the conceptual framework for assessment in Shumway-Cook and Woollacott (1995):

IMPAIRMENT (body structure and function)

Motor – e.g. mobility of joints, muscle force, co-ordination

Other – e.g. memory, respiration

ACTIVITY (daily activities)

Ability (degree of difficulty, assistance, time taken) – e.g. personal care, mobility

Performance (how the activity was undertaken) – e.g. walking, chair and bed transfers

PARTICIPATION (involvement) - e.g. getting around in the home and wider community, communication using writing skills

For the purposes of this exercise temporal and spatial parameters of gait have been included in the Performance section of Activity outcomes as opposed to the Ability section (Shumway-Cook and Woollacott 1995) as a central concern of the studies has been to relate these outcomes to gait strategies. Studies using an intervention package and specific techniques respectively will be discussed in the two sections that follow.

2.7.1 Physiotherapy intervention packages

The conventional physiotherapy treatment approach is eclectic, combining techniques based on biomechanical, neurophysiological and motor learning principles (Plant et al. 2000). At its core are mobilising exercises designed to address movement, postural control, gait and balance (Dam et al. 1996). Table 2.5 presents the treatment techniques used in studies of a package of physiotherapy techniques, listed in Table 2.4, and classifies the stated aims of treatment and the outcome measures employed in relation to their principal focus, at the level of impairment, activity or participation.

Table 2.5 Range of techniques, aims of treatment and outcome measures used in studies of a physiotherapy intervention package in Parkinson's disease

TECHNIQUES	Active exercises: Gait, Throwing, Lower limb, Upper limb, Trunk, Balance, Stretching, Facial, Breathing, Dexterity, Speech Passive mobilisation Relaxation Specific training: Circuits, Fitness, Parallel bars, Gait Named approaches: PNF, Bobath, Peto Cueing and sequencing Advice and education Pain relief
AIMS	
Impairments/ Motor	Improve Strength, Co-ordination, Rotation, Balance, Range of movement, Postural control, Reduce festination, Prevent contractures, Reduce rigidity
Impairments/ Other	Improve voice projection, Increase lung capacity, Relieve pain
Activity/Ability	Mobility, Endurance, Dexterity
Activity/Performance	Improve motor performance, Make movement conscious
Participation	Empower
OUTCOMES	
Impairments	Long latency stretch responses, Machine measurements of motor signs, EMG, Torque, Grip strength, Lower limb strength Geriatric Depression Scale Grading: Speech, Gait, Posture and balance, Rigidity, Tremor
Impairments and Activity	Parkinson's Home Visiting Assessment Tool, Columbia University Rating Scale, UPDRS, Webster Disability Scale, Hoehn & Yahr
Activity/Ability	Timed tests: Stand/walk 6m/sit, 10 m walk, Transfers (sit to stand, roll etc), Single leg stand, Open/close fist, Finger taps, Peg board, Card in envelope, Cube test Northwestern University Disability Scale, Functional Independence Measure, Nottingham Extended ADL Index, Barthel Index, Schwab-England Grading: ADL
Activity/Performance	Gait: Velocity (distance per unit time), Stride length, Amplitude of step, Step number
Participation	Short Form 36 Health Survey Questionnaire, Parkinson's Disease Questionnaire-36, Satisfaction/exit questionnaire

Figure 2.3 illustrates the imperfect match between stated aims of treatment and levels of measured outcome. Aims were mainly articulated in relation to motor impairments, such as improvement of joint range, strength, lung capacity and the reduction of contractures.

However outcomes were largely measured at the level of activity, relating mainly to the ability to undertake daily activities. Extensive use was made of both focal (e.g. Nine Hole Peg Test) and global (e.g. Functional Independence Measure) disability scales, activity of daily living scales (e.g. Barthel Index), Parkinson's disease specific scales primarily designed to measure drug efficacy (e.g. Northwestern University Disability Scale) and timed tests (e.g. 10 m walk). Only one study included quality of life aims and outcomes (Chandler and Plant 1999). No study was located that measured the effect of a package of physiotherapy techniques in terms of achieving outcomes negotiated as goals with individuals. The poor linkage of aims and outcomes is likely to predispose to equivocal results (Ashburn et al. 1993).

Figure 2.3 Relationship between stated aims of treatment and levels of measured outcome in studies of a physiotherapy intervention package approach

Intervention package - active exercises, passive mobilisation, relaxation, specific training of gait, balance and transfers, advice, education, pain relief

AIMS		OUTCOMES
	IMPAIRMENT	
XXX	Motor	XX
XX	Other	X
	ACTIVITY	
XX	Ability (difficulty/timing)	XXX
X	Performance (how)	X
X	PARTICIPATION	X

Figure highlights links between stated level of aims and outcome measures.
 X=least represented in evidence base, XXX=most represented in evidence base.

2.7.2 Specific treatment techniques

A second group of studies of physiotherapy in Parkinson's disease has addressed problem areas encountered by the client group using specific physiotherapy treatment techniques.

Table 2.6 illustrates the range of techniques, aims of treatment and outcome measures used in trials of specific physiotherapy techniques listed in Table 2.4.

Table 2.6 Range of techniques, aims of treatment and outcome measures used in studies of specific physiotherapy techniques in Parkinson's disease

<i>Compensatory movement strategies:</i>	
TECHNIQUES	Individualised strategies for problematic activities (freezing, turning) Executing sequences of simple movement elements separately and consciously for chair, walking and bed related skills
AIMS	
Impairments/Motor	
Impairments/Other	
Activity/Ability	
Activity/Performance	Understand biomechanics, Free concept of task from restrictions of physical environment, Learn alternative movement strategies, Promote effective movement strategies, Apply strategies to real life and over time, Improve quality of movement
Participation	
OUTCOMES	
Impairments/Motor	
Impairments/Other	Mini-Mental State Examination
Impairments and Activity	UPDRS, Hoehn & Yahr
Activity/Ability	Timed tasks: Sit/walk/turn/walk/sit, Lie to stand, Floor to stand
Activity/Performance	Video analysis of skills areas: chair, walking, bed; Gait analysis: velocity, stride length, double support, stance, swing phases; Movement strategy assessment; Electronic Movement Analysis; Falls records; Parkinson's Disease Functional Activity Scale
Participation	Subjective Wellbeing of the Elderly, Satisfaction questionnaire
<i>Cueing:</i>	
TECHNIQUES	Gait – Verbal and visual to target above eye level, Customised visual cues on walkway, Attentional cue of appropriate stride size, Rhythmic auditory stimulation, External cues for gait blocks External cues and internal commands for motor behaviour Sensory reinforcement for tasks
AIMS	
Impairments/Motor	Trunk rotation, Posture
Impairments/Other	
Activity/Ability	
Activity/Performance	Enhance task performance, Arm swing, Broader base, Rhythm, Reduce freezing, Improve temporal and spatial gait parameters
Participation	
OUTCOMES	
Impairments/Motor	Motor Performance Test Series (computer assisted), EMG
Impairments/Other	Beck's Depression Inventory, Mini-Mental State Examination
Impairments and Activity	Hoehn & Yahr, UPDRS
Activity/Ability	Northwestern University Disability Scale, Schwab & England,
Activity/Performance	Gait: Walking speed, Stride length, Step length, Stride time, Velocity, Duration of single and double support phases, Cadence, Number of freezing episodes, Video analysis of motor skills, Electronic Movement Analysis, Parkinson's Disease Functional Activity Scale
Participation	Satisfaction questionnaire

Trunk focus:	
TECHNIQUES	Individualised active exercises, Passive stretches, Aerobic exercises, Trunk muscle strengthening, PNF, Bobath
AIMS	
Impairments/Motor	Improved Rotation, Extension, Flexibility, Co-ordination, Strength, Range of Movement
Impairments/Other	Improved cardiorespiratory function
Activity/Ability	Mobility, Reaching
Activity/Performance	Lower limb function, Gait
Participation	Wellbeing
OUTCOMES	
Impairments	Functional axial rotation Isostation B200 (trunk muscle performance measurements) Cardiorespiratory fitness assessment
Impairments and Activity	Hoehn & Yahr, Webster Rating Scale
Activity/Ability	Timed tasks: Walk 3m, Sit to lie, Sit to stand, Rolling, Lie to stand Functional reach Northwestern University Disability Scale, Human Activity Profile
Activity/Performance	Zebis 3D movement analysis test battery; Gait - Stride length, Stride frequency, Step length, Velocity, Cadence, Video observational analysis
Participation	Diary (ADL, fatigue, exercises)
Balance focus:	
TECHNIQUES	Balance exercises, Lower limb strength training
AIMS	
Impairments/Motor	Equilibrium, Strength
Impairments/Other	
Activity/Ability	ADL
Activity/Performance	Falls reduction
Participation	
OUTCOMES	
Impairments	Equitest computerized dynamic posturography Biodex b-2000 isokinetic dynamometer, Muscle strength test
Impairments and Activity	
Activity/Ability	
Activity/Performance	Falls record
Participation	Groningen Activity Restriction Scale
Treadmill:	
TECHNIQUES	Body-weight supported treadmill training
AIMS	
Impairments/Motor	
Impairments/Other	
Activity/Ability	
Activity/Performance	Improve functional outcome
Participation	
OUTCOMES	
Impairments	
Impairments and Activity	UPDRS
Activity/Ability	Number of steps for 10m walk, Ambulation endurance and speed
Activity/Performance	
Participation	

In those studies which sought to evaluate specific physiotherapy interventions there was a closer linking of treatment techniques and aims of intervention to the level at which the primary outcomes were being measured (Figure 2.4). Two principal categories emerged within specific intervention studies, one group of studies focusing at the level of impairment in an attempt to improve neuromusculoskeletal body functions (WHO 1997) affecting movement, and the other focusing at the level of activity to promote movement strategies that improve functional performance. In relation to trunk and balance work there was a focus on impairment level aims but, unlike the studies using a package of techniques, targeted techniques and primary outcomes related to impairments, such as dynamometry and computerised dynamic posturography, matched these aims. In studies investigating compensatory movement strategies there was clear articulation of the nature of the technique. The stated aim was to promote effective movement strategies, and the primary outcomes focused at the level of performance of movement strategies, with extensive use of observational, video and electronic movement analysis. A similar logical linkage was seen in relation to cueing techniques. Again, no study was located that measured the effect of physiotherapy in terms of achieving client-centred goals.

Figure 2.4 Relationship between stated aims of treatment and levels of measured outcome in studies of specific physiotherapy techniques

Compensatory movement strategies, Cueing, Trunk focus, Balance focus, Treadmill

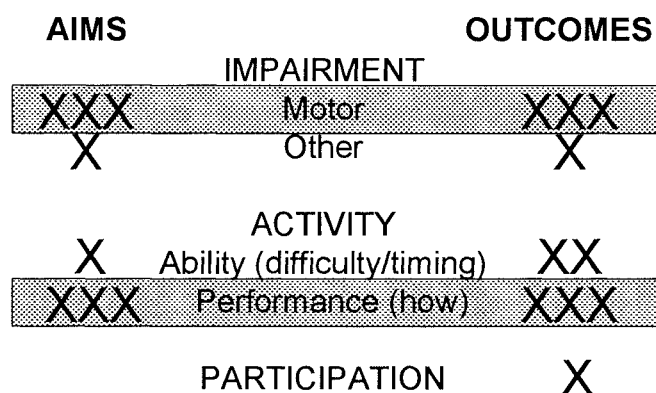


Figure highlights links between stated level of aims and outcome measures.
 X=least represented in evidence base, XXX=most represented in evidence base.

2.7.3 Individual studies: implications for physiotherapy

So far this overview of the evidence for physiotherapy and Parkinson's disease has highlighted a lack of robustness in the evidence base which may have been contributed to by a lack of congruence between the stated aims of intervention studies and measured outcomes. However a body of more recent work on specific physiotherapy techniques demonstrates greater congruence between aims and outcomes (Figure 2.4). It is still important to know the precise nature of physiotherapy in Parkinson's disease. A clear articulation of the nature of physiotherapy should ensure that the outcomes being measured in research will have implications for the everyday clinical practice of physiotherapists and, more importantly, for the everyday lives of individuals with Parkinson's disease.

2.8 Evidence from expert opinion

According to Richardson (1996), who investigated paradigms of practice in physiotherapy, "Paradigms incorporate a view of life, a value system and a particular orientation of attitudes and knowledge which are demonstrated through expressions of thought and behaviour". Expert opinion is likely to incorporate current practice paradigms, and despite being at the base of the evidence hierarchy (Gray 1997), can provide valuable insights into the professional value system and its influence on practice. The following sections will review expert opinion in relation to a study of best practice physiotherapy, in addition to evaluation, treatment and management models.

2.8.1 Best practice

Plant et al. (2000) undertook an investigation of physiotherapy in Parkinson's disease in the UK. The study was conducted under the auspices of the Parkinson's Disease Society, who were concerned about the threat to purchasing of a service they knew their members valued due to the perceived poverty of the evidence base. Using a Delphi consensus survey involving 49 specialist physiotherapists, and case studies of nine Trusts with proactive physiotherapy services for people with Parkinson's disease, they identified that

even within the practice of specialist physiotherapists provision was variable and early referral rare. On the basis of consensus the role of physiotherapy in Parkinson's disease was defined as the maximisation of functional ability and the minimisation of secondary complications through movement rehabilitation within the context of education and support for the whole person. A model of physiotherapy was articulated which linked the four core areas of practice to emerge from the study – gait, balance, posture (including range of movement) and transfers – to treatment and outcomes. There was a strong consensus that an eclectic approach to treatment (i.e. using techniques drawn selectively from a variety of approaches) had the best effect. Treatment was based on exercise regimes and movement strategies. Functional performance was specified as the principal level of outcome, with effect measured in relation to individually specified aims of treatment. A number of recommendations were made on the basis the evaluation, including work on developing assessment batteries and charting the natural history of aspects of functional performance, such as transfers, over the course of the condition. The work of the evaluation project has been taken forward into the development of guidelines on physiotherapy practice in Parkinson's disease (Guidelines Group 2001). This group has drawn on the whole depth and breadth of the evidence base to answer a series of practice based questions, relating to, for example referral, treatment and team work. Again, the work of the Guidelines Group will be taken forward in specific areas, for example in relation to the development of a minimum outcome data set for physiotherapy in Parkinson's disease.

2.8.2 Evaluation, treatment and management models

Evaluation and treatment models highlight where a profession proposes its impact should be directed in terms of treatment and measured in terms of outcome. Different models place differing stress on the centrality of assessment and treatment of impairment (Schenkman and Butler 1989a, 1989b; Schenkman et al. 1989), and disability (Handford 1993). This mirrors the dual focus found in the studies of specific treatment techniques (2.7.2), with a body of work centred on remediation of impairment and another on movement performance. Due to the lack of a clear articulation of a physiotherapy paradigm (2.3), measures of outcome specific to the foci of physiotherapy input are underdeveloped. Again this was found on investigation of outcome measures used in

intervention studies, with marked reliance on global as opposed to specific measures (Tables 2.5 and 2.6). Increasing numbers of qualitative and observational studies are illuminating the core areas of physiotherapy practice in Parkinson's disease, for example balance and falls (Ashburn et al. 1998; Stack and Ashburn 1999; Morris et al. 1999; Ashburn et al. 2001a) and turning in bed (Ashburn et al. 2001b). This body of work will inform future research and clinical evaluation instruments.

Comprehensive management models require links to be made from body systems, through physiotherapy techniques to patient outcomes. Morris and Iansek (1997) led an all-encompassing movement disorders programme which included outpatient clinic, ward facilities, research unit and community programmes. The work within the programme was developed within a unifying paradigm based on current concepts of basal ganglia function. A set of guidelines was developed from the underlying knowledge base, which guided the work of all disciplines working in the programme and the education of patients (Morris et al. 1995). The basic premise was that normal movement was possible in Parkinson's disease and that what was required was appropriate activation. Complex movements were broken down into smaller components to avoid sequences breaking down. This approach also had the advantage of increased amplitude at the beginning of each movement sequence. As conscious attention appeared to bypass the basal ganglia and restore movement towards normal, each component of a task needed to be performed at a conscious level. External visual, auditory or proprioceptive cues, which appeared to activate attentional motor control mechanisms, might be used to initiate and maintain movement and cognitive processes. Simultaneous motor or cognitive tasks were avoided because only the task demanding attention was satisfactorily completed and the more automatic task was not executed properly. Articulating how and why particular techniques are used helps make clear the processes of clinical reasoning, decision-making and evaluation (De Souza 1998). It allows others to replicate treatment based on stated criteria (Partridge and Edwards 1996). A substantial body of knowledge has been amassed based on theoretical propositions developed from the guidelines (Morris et al. 1994a; Morris et al. 1996b), including a task-specific approach to physiotherapy training (Morris 2000) and articulation of the contribution of physiotherapy to the evaluation of motor fluctuations (Morris et al 1998).

There are other examples of multidisciplinary teams who have developed a shared philosophy about the management of Parkinson's disease and based their working practice on shared values. Team working and early referral is embodied in the philosophy of the Romford Neurocare Team (Oxtoby et al. 1988; Oxtoby 1999). The physiotherapist involved in the pilot of the team found the need for medium to high levels of involvement with the majority of people assessed immediately post-diagnosis (Oxtoby et al. 1988). A multidisciplinary pathway of care and a care programme approach co-ordinated by a key worker is being evaluated in North Tyneside (Bilclough et al. 1999). User involvement at all stages of development, education and evaluation has been espoused.

The current Parkinson's disease physical therapy paradigm (Turnbull 1992) (Figure 10.1, p. 250), characterised by lack of referral to physiotherapy until drug effect is waning and disability increasing (Wiener and Singer 1989), means that the potential to utilise a range of educational and therapeutic strategies to avoid potentially preventable complications is lost. Lack of change over the last 20 years in the referral rate to physiotherapy (Yarrow 1999) illustrates the lack of success of the profession in terms of developing an evidence base which would allow it to move towards the proposed and preferred progressive physical therapy paradigm (Turnbull 1992) in Parkinson's disease management. This is based on careful monitoring from diagnosis to underpin a preventive treatment strategy with a strong educational element to enhance patient self-efficacy.

2.8.2.1 Evidence from expert opinion: implications for physiotherapy

The models and frameworks reviewed in this section have all arisen from the 'Solutions to problems' area of Figure 2.1. Because they all offer the potential to articulate hypotheses on the basis of relationships between the parts of the frameworks, which would allow for their systematic investigation, they qualify for sitting at the level of elementary 'Theories and models' within Figure 2.1. Equally the models and frameworks reviewed here have the potential to influence the epistemology of practice by challenging the dominant practice paradigm. For example, management models highlight the potential for prevention of disability with early access to physiotherapy. Continuing low levels of referral at later stages in the condition suggest that a challenge to current referral practice is necessary. The best practice study has articulated a model of physiotherapy in

Parkinson's disease (Plant et al 2000). Use of this model as a basis for future evaluations should help promote a move from a disparate to a coherent knowledge base and address many of the issues raised by researchers seeking to determine effectiveness of physiotherapy intervention (Deane et al. 2001a, 2001b). However this work all needs to be placed within the context of the challenges to movement in the everyday lives of people with Parkinson's disease.

2.9 Evidence from perspectives of individuals with Parkinson's disease

One approach to identifying where physiotherapy may be expected to impact on individuals' lives is to look at the levels of reported problems in relation to movement and functional activities. A major survey of the members of the Parkinson's Disease Society undertaken by Oxtoby (1982) has recently been updated by Yarrow (1999). Yarrow (1999) highlights the extent to which functional and additional problems faced by people with Parkinson's disease and their carers fall within the remit of physiotherapy practice. As in the earlier survey most respondents were experiencing multiple problems associated with Parkinson's disease. In relation to walking 62% reported difficulty even during their best performance time. Respondents reported difficulties at their worst time in relation to turning over in bed (63%); getting in and out of a chair (57%); gait initiation (50%); freezing (46%); climbing steps or stairs (46%); negotiating doorways or walking in confined spaces (40%); and getting to the toilet (28%). Parkinson's disease was often complicated by co-existing morbidity such as anxiety (48%); arthritis (43%); depression (37%); memory problems (35%); and chest problems (14%). For the majority of respondents their carer was their spouse or partner. Turning over in bed was a task needing help from 38% of carers, and getting a good night's sleep was rated as very important by 69% of carers. Carers themselves experienced multiple pathology with high levels of arthritis (48%), anxiety (33%) and depression (27%). An increase in parkinsonian symptoms has been documented in the spouses of individuals with Parkinson's disease (Kirolos et al. 1993), and Weller et al. (1992) reported reduced axial rotation in this group compared to controls.

User perceptions of therapy were evaluated as part of a study of the availability of, access routes to, and delivery of, therapy services in Scotland in the 1990s (Chesson et al. 1996). Sixty-two percent of questionnaire respondents with Parkinson's disease (n=665) reported problems with daily activity, 60% with mobility and 43% with walking. Thirty-eight percent had received physiotherapy. The reasons given for this were to improve mobility and walking, to have exercise and to reduce pain. Only a third reported that their expectations of physiotherapy had been met, however this did not stop a quarter of this group expressing possible future needs for physiotherapy. The highest fulfilment of expectations for physiotherapy at 40% related to improved mobility and walking, but this percentage was much lower than for core activities related to occupational therapy and speech and language therapy. It is not possible to know how expectations in relation to physiotherapy were engendered. However late referrals were the norm when disabilities were likely to be established. A quarter of respondents cited improvement in mobility as the single thing that would most improve their quality of life. Many carers cited improvement in therapy provision as something that would improve their quality of life as well as that of those they cared for.

Perceptions of quality of life and congruence with therapists' perceptions were the subject of a second study by Chesson et al. (1997). Overall more congruence than non-congruence of view was detected. However tremor, the cause of the greatest distress for clients, was mentioned by only a quarter of the therapists. Getting about, enjoying life, being able to do what they did before and being independent were key aspects identified by individuals in relation to quality of life. Most therapists were concerned with physical aspects of the disease and felt that improving these aspects would improve quality of life. Therapy was a source of support and social interaction. Most patients perceived benefit from the intervention compared to half the therapists. Interestingly therapists perceived psychological benefits but these were not considered as worthwhile as functional gains. Chesson et al. (1997) suggest that one way forward may be greater emphasis on psychological aspects of disability, information and advice and a focus on patients' self-management strategies.

2.9.1 Perspectives of individuals: implications for physiotherapy

The core areas of physiotherapy identified in the study of best practice (Plant et al. 2000) are related to areas where individuals and carers experience high levels of difficulty. Key issues for physiotherapy at the level of the perspectives of individuals are the gaining of understanding about the impact of movement difficulties in everyday life, and the involvement of individuals in decision making about the goals of physiotherapy. Individuals' aspirations are articulated at the level of integrated activities, for example being independent, which allow them to maintain the maximum participation possible in all aspects of everyday life. Therapists are directing their input within the impairment and activity dimensions of the ICDH-2 continuum (WHO 1997) in the belief that this will promote participation, involvement and quality of life. However aims and outcome measures at the level of participation are lacking in intervention studies (2.7). A major lack in the evidence base currently is a theoretical understanding of the meaning of movement in everyday life and of quality indicators of meaningful movement for individuals. As movement is central to daily activity, one way of gaining insight into meaningful movement may be to focus on individuals' self-management strategies to maintain involvement in everyday activity. This became a strong theme within the current study as successive research cycles were completed (Chapter 5).

2.10 Self-management in Parkinson's disease

There is a similarity between the increased work that remaining neurones undertake in the basal ganglia in the face of cell degeneration, with the resultant loss of normal levels of neurotransmitters (Agid 1991), and the work that individuals with Parkinson's disease undertake in an attempt to maintain normal activities in the face of the symptoms of their condition. Supporting self-management was suggested as one way to align professional input to individuals' aspirations in Parkinson's disease (Chesson et al. 1997). A current (February 2001) search of the MEDLINE (United States National Library of Medicine 2001) bibliographic database (1993-present) on the word 'self-management' and asthma, diabetes and Parkinson's disease respectively produced total journal output as follows: 210 (asthma), 116 (diabetes) and 0 (Parkinson's disease). The self-management of

Parkinson's disease would appear not to have been explored in the literature, despite sharing many of the features of the other two long-term and highly medication-dependent and fluctuating conditions.

Within the trajectory framework (Strauss and Corbin 1988; Corbin and Strauss 1992), a non-discipline specific general theory about chronic illness, work is undertaken by individuals in three main areas: managing illness work (regimes); biographical work (coming to terms); and everyday life work (limitations management). However the work that individuals do to manage their chronic illness is largely "devalued, invisible and unacknowledged by society" (Lubkin 1995). The three identified areas of work can be seen as attempting to normalise activity, one of the key concepts in the chronic illness literature. In a phenomenological study of living with Parkinson's disease the overriding theme to emerge was the effort involved in every aspect of life to maintain normal activities (Marr 1991). Pinder (1988) highlights the strategies of acquiescence, avoidance, covering, combating and accommodation needed over time to preserve some normality in Parkinson's disease. These strategies are congruent with the normalising strategies identified in relation to coping with the uncertainty of rheumatoid arthritis (covering-up, keeping-up, pacing and adjusting to reduced activities) (Wiener 1975). Stenstrom et al. (1993) suggest that physiotherapists might acknowledge the range of psychosocial coping strategies used by individuals with rheumatoid arthritis and include them in assessment and evaluation.

Robinson (1993) stresses the need for professional intervention to be congruent with existing trajectory work and values. Assessment should include questions which illuminate the personal story that often begins "our life is normal, we just have a few problems". Likewise Reif (1973) suggests that nurses would be better placed to support individuals to manage ulcerative colitis if they acknowledged the range of "pollution-control tactics" individuals employed, involving preventive, protective and corrective strategies, and the strategies they devised for managing time, including conserving and scheduling. Haberman (1996) undertook an interpretive study of life with Parkinson's disease in which the day-to-day demands of the condition were examined. Demands directly related to the condition included dealing with a changing body and with unpredictability, and gaining knowledge. Demands were also created in relation to roles,

identity and relationships. She suggests that acknowledging such embodied experiences offers the potential for enhanced professional management.

2.10.1 Strategies, coping or style?

Strategies form the basis of individuals' trajectory work. For Locker (1983) resources and strategies are viewed as variables which intervene between disability and handicap. Resources encompass physical, cognitive, material, social resources in addition to medical and social services. Strategies are viewed as coping mechanisms drawing on knowledge, time, personal help and material effects. The more extensive and varied the resources, the more successful individuals are likely to be at managing problems because they are able to select from a range of available strategies (Locker 1989).

The word coping is used regularly by health care professionals (Kelleher 1988) who aim to find coping strategies to teach to people who they perceive have not developed them (Burckhardt 1987). In a study of coping, social support and depressive symptoms in Parkinson's disease, Ehmann et al. (1990) suggest that active (cognitive and behavioural) coping strategies are superior to avoidance strategies in managing affective distress. For Kelleher (1988) however, coping refers to the behaviour and meaning people construct around their experience of having a long-term health condition. If the experience of living with a long-term condition is to be at the centre of management, rather than stage theories, he suggests that careful attention needs to be given to understanding an individual's construction of coping.

Bury (1991) calls for greater clarity in the use of the terms 'coping', 'strategy' and 'style' in the chronic illness literature. He suggests that coping should be restricted to the cognitive processes whereby the individual learns how to tolerate the effects of the illness, for example maintaining a feeling of self worth. 'Strategy' should refer to what people do in the face of illness; how they mobilise resources to maximise favourable outcomes. Use of the term 'style' is appropriate when the way people respond to illness is being discussed. It is embedded in discourses about the body and self.

2.10.2 Compliance or self-management?

More recent professional conceptualisations of the disablement process such as the model proposed by Verbrugge and Jette (1994) and ICDH-2 (WHO 1997) have moved away from the linear pathology – handicap continuum (WHO 1980) to a feedback model which incorporates personal and environmental contextual factors. Personal factors can include an individual's spirituality and feelings of control, whilst environmental factors can include the attitudes of other individuals as well as the physical environment. In both models medical and rehabilitation services comprise an environmental contextual factor. Professional management can be viewed as the treatment, prescriptions or advice that doctors, nurses, therapists and other professionals give to individuals, and with which individuals are expected to comply. For some in the disability lobby, this multi-professional management, founded on the ideology of normality and focused at the level of change in the individual, is viewed as a series of "intrusions into disabled peoples' lives on the basis of discreet and limited knowledge and skills" (Oliver 1996). Professional management is just one part of the social environment that the social model of disability challenges.

Self-management refers to an individual's management of her/his condition in order to minimise symptoms and maximise participation in everyday life (Bartholomew et al. 1991). It has been suggested that effective professional approaches designed to facilitate the development of self-management in individuals with long term illness and their carers may improve quality of life and reduce dependency (Clark and Nothwehr 1997; Fries et al. 1998; Ghosh et al. 1998). These professional approaches often aim at empowerment, preparing individuals to take informed decisions about their own care (Anderson et al. 1991). However, for some groups this remains paternalistic and illustrates a continued imbalance in relation to the value placed on professional and personal knowledge bases about long term illness (Cooper 1999). Empowerment of individuals is only needed because professionals have sought to take power for themselves.

2.10.3 Self-management in Parkinson's disease: implications for physiotherapy

The outputs of professional management are accepted and incorporated, or not, into everyday life through decisions taken by individuals themselves. Often referred to as compliance or carryover of treatment, this was highlighted as an area of concern in a number of research studies of physiotherapy and Parkinson's disease (2.6.1). In the context of self-management professionals should perhaps be thinking more of concepts such as 'incorporation' rather than carryover. The success of professional management could relate to its congruence with the lived reality of the individual; at its most effective it would be absorbed into the self-management of everyday life. Focusing on the incorporation of strategies into personal trajectory work and acknowledging that the individual with Parkinson's disease was in control of that trajectory would site professional management towards the sociocritical end of the knowledge domain continuum (Table 2.1). Chapters 6-10 of this thesis present the results of focusing on self-management in physiotherapy intervention in Parkinson's disease, and on the implications for practice and research.

2.11 Philosophical questions and physiotherapy

The literature reviewed for this study has highlighted that the ontology, methodology and epistemology of practice – the nature of reality, how it can be measured, and practice relationships – are major issues in Parkinson's disease management generally and physiotherapy management specifically. For physiotherapy in Parkinson's disease there are implications in relation to, for example:

- Evidence – should the emphasis be on realist outcomes or interpretivist perceptions?
- Relationships – can there be a move from professional dominance to equality in partnership?
- Intervention – in a long-term condition what is the balance between conventional treatment and supporting self-management?
- Evaluation – should there be a professional focus or an individual goal orientation?

- Education – what should the balance be between biomedical knowledge and the lived experience?

As in nursing (Richardson 1993), not all physiotherapists feel that it is necessary for the profession to have discussions at the level of philosophy or paradigms (Figure 2.1). Parry (1997) asserts that the questions that have dominated Western philosophy for centuries about the character of our knowledge and the kinds of things there are in the world are equally important for physiotherapy today. They underpin the undertaking of empirical inquiry: “every research tool or procedure is embedded in commitment to particular versions of the world and to knowing the world” (Parry 1997). Higgs and Titchen (1995, 1998) assert that the body of knowledge and its generation defines a profession, underlining that the study of knowledge, or epistemology, is of major importance to a profession. Robertson (1996) on the other hand asserts that a focus on epistemology and individual knowledge bases is unlikely to contribute to the growth of a knowledge base for physiotherapy. According to Robertson (1996) scientists contribute to the body of knowledge without attending to issues of the relationship between the knower and the known. She suggests that physiotherapists should do likewise, working within a practitioner-scientist model to develop practice-related knowledge. This requires facilitation of research in a practice setting and engagement with published work. She is dismissive of therapists using the concept of paradigm to explore developments within the profession, accusing them of shallow understanding of the concept (Robertson 1996).

The idea of paradigm and its associated epistemology as a lens through which both individuals and professionals are selectively attentive to problems and issues based on their experiences and interests (Richardson 1993) is taken up by Robertson (1996):

“To claim that to generate knowledge in physiotherapy, physiotherapists should know about a range of the different ideas of knowledge proposed by epistemologists, is analogous to claiming that a spectacle wearer should know about the laws of optics to be able to benefit from spectacles”.

I challenged Robertson's stance in a published letter in *Physiotherapy* (Jones 1997a) (Appendix 2). In her reply Robertson (1997) restated her position that epistemology was not a useful concept in physiotherapy:

“Optics, like epistemology, is at a different level of analysis from seeing a view changed by different lenses or implementing a clinical outcomes study”.

Unconvinced by her argument, I would maintain that you could only choose your outcomes if you understood the level at which you were measuring, the epistemological relationship between the measurer and the measured.

2.12 Conceptual framework for research

The conceptual framework developed for this study centres on the notion of lenses and the development of alternative ways of seeing and knowing, and ultimately doing. The traditional way of seeing Parkinson's disease for healthcare professionals is from a biomedical perspective born out of technical knowledge about the condition, its cause, the symptoms it manifests and ways of countering them from a professional perspective. This has led to a dominant epistemology of practice in physiotherapy based on the model of technical rationality (Schon 1983), where professional activity consists of instrumental problem solving made rigorous by the application of scientific theory and technique (Tables 2.5 and 2.6). In an attempt to explore a different epistemology this project moved towards a person-centred focus and located its activity in the mid-range of the research continuum from pure to applied, which involves building bridges between researcher and researched (Robson 1993). This research approach acknowledges a concern for the locus of power in research on disability (Chambers 1986; French 1992; Coleridge 1993), with an emphasis on building partnerships. Also of concern in this research approach is the physical locus in which the research is conducted. The ecological critique (Heuer 1988) has highlighted the need for awareness of the relationships between people and their environments. There are difficulties associated with the generalization of results from laboratory-based experiments on simple movements to the complex everyday life motor

skills used in the real world. This project has placed an emphasis on obtaining knowledge about what people actually do in a context where the activity is usually performed (Mulder and Geurts 1991; Geurts et al. 1991).

In effect the project chose to move from the technically interesting “high, hard ground” (1.3, p. 4) to the “swampy lowground” (1.4.3, p. 10) where the personally challenging problems are to be found (Schon 1983). The project qualifies as practitioner research (Reed and Procter 1995) because of the insider knowledge brought to the research activity (1.4.1, p. 6). It is also reflective research (Schon 1983) where research is seen as an activity of practitioners. Schon (1983) identifies four types of reflective research which can be undertaken outside the context of practice in order to enhance a practitioners capacity for reflection-in-action, when practitioners make sense of a situation by reflecting on understandings implicit in the action by surfacing, critiquing, and restructuring them into further action. This schema forms the basis of the conceptual framework within which the project can be examined. Table 2.7 highlights the types of reflective research identified by Schon (1983), describes their domain, relates them to the research questions which emerged during the course of the study, and links them to the research spiral detailed in Chapter 1.

Table 2.7 Conceptual framework based on reflective research typology

Type	Descriptor	Research Questions	Relationship to Research Cycles
Frame analysis	Dominant cultures provide professions with ways of framing and approaching problems. Frame analysis helps practitioners become aware of their tacit frames. This fosters awareness of the possibility of alternative ways of framing the reality of practice.	How is the everyday experience of living with Parkinson's disease articulated in a group context? What do physiotherapists feel they can contribute? How can the everyday experience of Parkinson's disease be captured?	Cycle 1 <i>Cycle 2A</i> & Cycle 3 Cycle 2
Repertoire-building	When practice situations do not fit available theories, models or techniques they are still seen as familiar situations, cases or precedents. Repertoire-building research accumulates and describes examples that are useful for reflection.	How do individuals approach and manage life with Parkinson's disease?	Cycle 2
Fundamental methods of inquiry and overarching theories	Theory and method are used to restructure a situation that is then tested by practitioners using themes derived from action science.	What effect does a focus on individuals' strategies have on physiotherapy intervention in Parkinson's disease?	Cycle 3
Process of reflection-in-action	Study of feelings about task, performance and practitioner-researcher relationship.	What challenges does a focus on individuals' strategies pose for the traditional practitioner-patient relationship?	Cycle 3

Notes - Table lists types of reflective research (Schon 1983) in left hand column, defines each type, relates each to the project's research questions, and links them to the research spiral.

2.13 Summary

Paradigms are underpinned by knowledge bases. Those with the most highly valued knowledge base hold power. The value placed on types of evidence within the dominant paradigm will influence other knowledge bases. Understanding the nature of paradigms will enable the physiotherapy profession to take control of its knowledge base to help shape as opposed to react to paradigm shift. A key feature of paradigms is a distinctive epistemological relationship between the would-be knower and what can be known. This study aims to explore how changing the epistemological relationship between a physiotherapist and individuals with Parkinson's disease can change both ways of knowing (methodology) and knowledge (ontology) about the condition. The following two chapters will detail the methodology (Chapter 3) and associated methods (Chapter 4) chosen to address the research questions detailed in Table 2.7.

3 Methodology within the research spiral

3.1 Overview of chapter

This chapter will commence with a review of the current status of the debate concerning the ontological and epistemological assumptions underpinning physiotherapy research with the aim of contextualising the present study within this body of knowledge. The combination of qualitative and quantitative research methodologies employed over the three cycles of the research spiral outlined in Chapter 1 will be presented. (Chapter 4 will review associated research methods.) The quantitative/qualitative inquiry paradigm debate in relation to this study will be discussed. The similarities in the tasks of researchers working in both qualitative and quantitative paradigms will be reviewed as a basis for identifying their differing approaches to those tasks. Thereafter the background to and development of my own thinking in relation to those tasks, using constructivist and critical theory perspectives, will be explored. The specific research approaches of case study and action research adopted within the project will be explored. Case study research will be examined, with a focus on mechanisms to ensure quality; the relationship of the inquiry paradigm to the research process; and the central issue of triangulation. The project's use of action research will be explored. Cross-references to both earlier and later parts of the text will enable the reader to make links if required. Table 3.1 sets out the methodological strategy of this study to be explicated in this and the following chapter.

Table 3.1 Methodological strategy of this study

Research process	Methodological strategy	Thesis section
Inquiry paradigm	Qualitative	3.3
Research perspectives	Constructivism and critical theory	3.3
Research approaches	Case study and action research	3.4 and 3.5
Research methods	Multiple	3.4 and Chapter 4
Data	Qualitative and quantitative	
Analyses	Content/case, Integrated, Statistical	

Based on Patton (1990)

3.2 The qualitative/quantitative debate within physiotherapy research

According to Ekdahl and Nilstun (1998) physiotherapists are eclectic in their approach to research, combining elements from different paradigms, with no single scientific ideal that could be called “the paradigm of physiotherapy research”. Sixty-eight doctoral dissertations written in Sweden between 1977 and 1997 were examined. Paradigm dimensions were transformed into a graded ordinal 3 point scale against seven dimensions of a classification scheme, with 1 implying agreement with the nomothetic tradition (preactive, experimental design; testing hypotheses; generalising; no focus on meaning; quantitative data and analysis); 3 the idiographic tradition (interactive, naturalistic design; generating hypotheses; non-generalising; focus on meaning; qualitative data and data analysis); and 2 containing important elements from both. Most studies used a preactive, experimental design to test hypotheses. The authors suggest that this was probably influenced by supervisors from a medical background. There was evidence of therapists striving for naturalistic elements in design, the generation of hypotheses and a focus on meaning. The fact that few studies avoided statistical methods was again seen as a function of supervisor background and fear of not getting work published. This classification scheme will be applied to the current study at end of the current chapter to synthesise the methodological issues discussed (Table 3.5).

Combining research traditions forms a strong theme in the physiotherapy literature, largely because it is congruent with practice. Schmoll (1987) and Shepard (1987) introduce the ‘physiotherapy as science and art’ debate into the discussion of research paradigms. Schmoll (1987) suggests that “the practice of physiotherapy involves a fluid mix of behaviors that are both objective and subjective; scientific and intuitive”. They are both concerned to develop research methodologies suited to investigation within the practice setting and favour eclecticism rather than a single paradigm. Shepard (1987) proposes, on familiarity with both main paradigms, moving

“back and forth mixing many different research methods to frame and answer clinical questions. The combined use of qualitative and quantitative research strategies may be the single most important breakthrough in defining a body of knowledge that is unique to the practice of physical therapy”.

Likewise Noronen and Wikstron-Grotell (1999), who stress the need for heightened ontological awareness in the profession, highlight the possibilities for extending the physiotherapy knowledge base through the complementary use of positivism, with its focus on verification through observation; hermeneutics, with its focus on understanding; and pragmatism, with an action focus. Parry (1991) also points to the multi-paradigmatic nature of physiotherapy, combining positivist/empirico-analytical, interpretivist, and critical/empowerment traditions. She suggests that triangulation could be used to combine research paradigms. This concept assumes that all methodologies and methods have strengths and weaknesses, which can be compensated for by counterbalancing against other methodologies and methods with different strengths and weaknesses to produce more meaningful results. This chapter contains a full discussion of this concept (3.4.3). In her opinion the future of physiotherapy research lies in combining different paradigms to enable more complete answers to practice questions (Parry 1997), with questions being the determining factor in research design rather than tradition (Carpenter 1997; Partridge 1999). The ontological and epistemological bases of the paradigms employed in the current study will be reviewed in the following section.

3.3 Quantitative/qualitative inquiry paradigm debate within this study

There are marked similarities in the work of quantitative and qualitative researchers (Glesne and Peshkin 1992; Creswell 1994). Each will state a purpose, identify a question, use the literature, define a population to study, choose methods to collect and analyse data and present outcomes. Each will also be guided by theory and concerned with rigour. However these activities are approached differently depending on the basic set of beliefs the researcher brings to the tasks. The research cycle model introduced in Chapter 1 can

be equally applied to the work of quantitative and qualitative researchers (Rowan 1981). A period of THINKING is followed by the development of a PROJECT. An ENCOUNTER is required to collect data, which require to be turned into results during a period of MAKING SENSE. Subsequently there is COMMUNICATION of findings. However the characteristics of a quantitative design have the potential to predispose the cycle to being a low-energy, linear experience, merely passing through the various stages, as opposed to a high-energy, possibly cyclical experience leading to the potential for change in the researcher (Rowan 1981).

Inquiry paradigms are characterised by their stance on ontological, epistemological and methodological issues (Guba 1990; Cresswell 1994). Quantitative design is congruent with the positivist paradigm. Stated in simplified form, its aim is explanation, with the nature of knowledge established via hypothesis testing. Knowledge accumulates by generalisations of cause and effect. Internal and external validity, reliability and objectivity form the quality criteria, and ostensibly the influence of personal values is excluded. The voice is claimed to be that of the disinterested scientist. The training is largely technical in nature. Control is in the hands of the researcher. The basis of my worldview was examined earlier at BEING 1 (1.4.1, p. 6). Its effect on my thinking was explored at THINKING 1 in relation to cases (1.4.2, p. 8). I was predisposed to seeing reality as socially constructed, to giving primacy to the participants in the research, and to acknowledging a complex set of variables and relationships. I was interested in context, which meant studying my participants in their home setting, and interpretation, which meant listening intently to their own words. I acknowledged I myself was an instrument affecting the research process, involved and partial. I was prepared to use an inductive approach to allow a story to emerge from the data. I looked for patterns and complex linkages which I was prepared to take back to informants for verification or disaffirmation. My predisposition in relation to assumptions, purpose, approach and role was therefore congruent with a qualitative inquiry paradigm.

However there are not only distinctions to be made between quantitative and qualitative inquiry paradigms. Guba (1990) identifies four distinct traditions within the qualitative paradigm - positivism, postpositivism, critical theory and constructivism - which can be identified with reference to ontological, epistemological and methodological positions

(Guba and Lincoln 1994). Positivism and postpositivism share many of the assumptions of the quantitative paradigm. Cycles 1 and 2 of this study can be sited within the qualitative paradigm of constructivism, and more specifically within the perspective of social constructionism. This relativist philosophical perspective focuses on the ways in which individuals singly and collectively interpret the social and psychological world, actively constructing meaning within everyday life (Schwandt 1997). The aim of Cycles 1 and 2 was to better understand the experience of living with Parkinson's disease (Table 2.7, p. 60). The nature of knowledge was established in part through group and individual mental reconstructions, socially and experientially based, which coalesced around themes. Knowledge accumulated via increasingly focused reconstructions. A social constructivist view of Parkinson's disease would hold that the condition is more than the sum of objectively and subjectively identified signs and symptoms. Each individual's experience of Parkinson's disease reflects their unique response to those signs and symptoms, but much will also be held in common. Science aims to build universal understanding and the aim of the constructivist perspective is to distil a consensus construction that is more informed and sophisticated than competing constructions, which in turn become better understood through their juxtaposition with the emerging construction (Guba and Lincoln 1994). Trustworthiness and authenticity were pursued via a range of interlocking measures discussed in section 3.4.1.

In contrast research Cycle 3 was sited within the critical theory qualitative paradigm (Thompson 1995). There was an explicit focus on the critiquing of existing practice and transformation of practice on the basis of new knowledge from previous cycles. Critical theory aims to integrate theory and practice by challenging belief systems and social relations, which are traditionally based on technical reasoning. It is oriented toward individual and social transformation, based on self-knowledge born of reflexivity and social action respectively (Schwandt 1997). The aim of Cycle 3 was to develop a theoretical framework, centred on an understanding of self-management, which would inform physiotherapy practice in Parkinson's disease. The changed relationship to the concept of the case under study is discussed at PROJECT 3 (1.6.3, p. 17). Knowledge accumulation took the form of generalisation through the identification of patterns of client strategies, and reflexivity about the application of client-centred physiotherapy practice (Table 3.4). Quality criteria in critical theory relate to the clarification of the

issue under study and the ability to mount on-going action (Guba and Lincoln 1994). In the current study the quality of client-professional interaction which ensued from the new knowledge and associated action was under scrutiny. The voice of the researchers was that of activist for recognition of needs and advocate for changed practice (11.5, p. 278). Partnership was sought and valued at all points in the research cycle (Table 1.2, p. 11).

Some research approaches are more congruent with the philosophical assumptions of the different schools of thought within qualitative inquiry than others (Noronen and Wikstrom-Grotell 1999). A case study approach was chosen for use in Cycles 1 and 2. This was designed to explore the social construction of Parkinson's disease. Some authors restrict case study to one paradigm, for example Merriam's (1988) qualitative case study research in education. However others argue that both qualitative and quantitative components can be incorporated within case study research as long as the embedded sub-units are analysed in accordance with their tradition (Yin 1994). The latter has been the stance taken within the current project because of the congruence with the qualitative and quantitative aspects of physiotherapy practice (3.2). Cycle 3 then took a new practice framework, developed from across-case analysis in the case study phase, out in to professional practice by means of action research methodology.

3.4 Case study approach

The case study approach suffers from the fact that it has become an umbrella term: used for studies that are not clearly experimental, survey, or historical; used interchangeably with fieldwork, ethnography, participant observation, exploratory research, and naturalistic inquiry; and confused with other approaches with 'case' in their title, such as single case experimental design (Merriam 1988). The concept of a 'case' and 'casing' was introduced in Chapter 1 (1.4.2, p. 8), and displayed in matrix form in Table 1.1 (p. 9). Case study can be conceptualised as a strategy for undertaking an empirical inquiry in which the case is at the centre of the study as opposed to variables. It is the preferred research strategy when:

- How and why questions predominate
 - The case is a contemporary phenomenon
 - The setting is the real life context
 - The phenomenon and context have complex inter-linkages
 - In-depth knowledge of the particular is desired
 - The researcher has little control over events
 - Multiple sources of evidence are desirable
 - Data collection over time is helpful
 - Analytical as opposed to statistical generalisation is sought
- (Yin 1994; Stake 1995; Schwandt 1997)

The following section will relate each of the above points to the current study.

1. How and why questions

Table 2.7 (p. 60) sets out the research questions addressed by the study in the context of the reflective research typology (Schon 1983). Frame analysis, which enables practitioners to become aware of, and in this case challenge, their tacit frames of reference, was addressed in Cycle 1 by investigating **how** groups of individuals with Parkinson's disease articulated the experience of living with Parkinson's disease; and in Cycle 2 by investigating **how** the everyday experience of Parkinson's disease can be explored and **why** some tools are more successful than others in capturing that experience. In relation to repertoire-building, Cycle 2 also explored **how** individuals with Parkinson's disease approach and manage everyday life.

2. Contemporary phenomenon

The overarching purpose of the current study was to inform physiotherapy management of Parkinson's disease through an investigation of aspects of life with the condition. The contemporary phenomenon forming the case in Cycle 1 was life with Parkinson's disease from a group perspective. The unit of analysis was at the level of the group. This narrowed in Cycle 2 to become a focus on the experience of living with the condition from the perspective of individuals. The unit of analysis was at the level of the individual.

3. Real life context

Unlike experimental or survey research strategies, which also focus on contemporary phenomenon, case study strategy aims not to disturb ordinary activity. It permits the grounding of observations and concepts about social action and structures in natural settings studied at close hand (Feagin et al 1991). Everyday life with Parkinson's disease was studied in the context of home and community. This aimed to maximise ecological validity from the perspective of the environment and social validity due to the influence of usual social relationships.

4. Inter-linkage between phenomenon and context

In an experimental situation it would have been possible to separate the phenomenon under study from the context. For example, a number of individuals could be studied performing sit to stand strategies within the laboratory setting at prescribed times using standardised procedures and equipment (1.3, p. 4). The holistic emphasis in case study research is based upon a contention that social actions can only be adequately understood in relation to the context in which they are embedded (Snow and Anderson 1991). Research can elicit perspectives of action in response to researcher questioning, but the more interested researchers are in lived experience and everyday routines the more their focus becomes perspectives in action, identifying feelings that are linked to action sequences (Snow and Anderson 1991). Within the current case study the opportunity was taken to examine everyday life within the normal environment and subject to variations in performance as a result of physical, social or psychological factors. Perspectives in action were identified through the linkage of research methods (Chapter 4).

5. Knowledge of the particular

At the start of analysis in variable as opposed to case study, cases are reduced to the variables through which the dialogue between ideas and evidence will occur (Ragin 1992a). Small-n case study research allows for a fluidity of casing which enhances theoretical development and innovation. Casing changed from Cycle 1 to 2 to allow a progressive focusing (Stake 1995) to occur from group strategies to individual strategies to approaching life with Parkinson's disease (Table 1.1, p. 9). Through excursions into the field, recording and analysing, observations are redirected to refine meaning. With each casing ideas and evidence interact, with the empirical world becoming more structured by

theoretical ideas (Ragin 1992a). The study of the issue takes over from the study of the case. This is possible because in case study the course of the study is not charted in advance. Its open ended, emergent design allows a dynamic and recursive process which facilitates discovery (Snow and Anderson 1991).

6. Lack of researcher control

Instead of adopting a set of standardised questions and categories with which to characterise, or construct, a simplified social world from a researcher perspective, the researcher using a case study strategy assumes complexity and plurality (Feagin et al 1991). It has been suggested that the role of the physiotherapist should be less directive and more collaborative, with the emphasis placed on individuals being active participants in maintaining their own health (Noronen and Wikstrom-Grotell 1999). This is particularly important in relation to long term chronic conditions. Case study offered the opportunity to study everyday life with Parkinson's disease in all its complexity in order to improve understanding of the context into which physiotherapy intervention could seek to be integrated rather than imposed.

7. Multiple sources of evidence

Case studies classically involve a range of methods. However Stake (1994) highlights the difference in choice of methods between cases chosen for intrinsic interest, a focus on the case itself, and for instrumental interest, where the focus is more likely to be answering a researcher generated question. In the latter critical issues are more likely to be known in advance and previously validated instruments and scales are more likely to be incorporated (Stake 1994). This study can be classified as a collective case study of instrumental cases. The choice of methods used in the current project was designed to map on to the information that is classically sought during subjective and objective assessment in clinical practice within group and individual treatment sessions. The range includes elements of all ICDH-2 (WHO 1997) domains of impairment, activity and participation. Cycle 1, which focused on group perspectives of life with Parkinson's disease, employed group discussion, brainstorming and informal conversations as research methods. Cycle 2, involving individual case studies, used in-depth interviews, 24 hour ambulatory monitoring with medication and activity diary, and impairment,

disability and quality of life scales. Chapter 4 presents a discussion of each of these methods.

Because case study has a bottom up not a top down research orientation it provides a strategy to give a voice to individuals who may not normally have a mechanism to make their views known (Feagin et al 1991). Individuals with Parkinson's disease have many barriers to communication – their speech may be affected, writing is difficult, filling in questionnaires may need to be done by a carer, scoring systems in relation to answers often do not reflect the fluctuations in their condition. The multiple methods within case study research give an opportunity to tap a range of mechanisms to aid a voice to be heard, congruent with an empowerment focus research strategy (Thomas and Parry 1996).

Case study data analysis takes place within and across cases with an emphasis on pattern matching of themes. This study employed qualitative data analysis software to develop and match themes and also to identify tensions within the qualitative and quantitative data sets (4.3.2.1, p. 90, 4.8.2, p. 110 and 4.8.6, p. 118). Both deductive and inductive frameworks were used to explore the data (Jones et al. 1996b).

8. Data collection over time

Whilst some case study participants were visited over a short duration allowing cross-sectional data collection only, others were followed up for a maximum of 2 years, which enabled patterns of thinking, behaviour and activity to be explored longitudinally (4.4.2, p. 98). Taken together with the multiple levels of data from a range of sources, the extended time period permitted a more holistic study of both continuity and change in complexes of social action and meanings (Feagin et al 1991).

9. Analytical generalisation

Cases are not sampling units and neither are they studied primarily to understand other cases. However within collective case study cases are chosen to maximise what can be learnt to aid understanding, and potentially theorising, about an even larger collection of cases (Stake 1994). Even within a few cases, studied in depth and at length, particular activities, problems or responses will recur. An example of such petite generalisations (Stake 1995) from the current project would be individuals' conceptualisations of their

Parkinson's disease symptomatology in relation to normal ageing or personality (4.8.2, p. 110) (Jones et al 1996a). Grand generalisations (Stake 1995) can also be modified by case study. The management of disease in the dominant paradigm is conceived to be a largely professional activity mediated through medical and paramedical interventions. This study has illuminated the work that individuals undertake to manage their disease trajectory (Jones et al 1998a), offering an opportunity to reassess the grand generalisation. Here the method of generalisation is 'analytic generalisation', with a previously developed theory being used as a template to enable comparison with case study results (Yin 1994).

3.4.1 Ensuring quality in case study research

Because case study research can combine elements of different inquiry paradigms the criteria to establish its quality are problematic. Goodness criteria such as reliability and validity, which are related to realist ontology, may not be applicable within a paradigm that is underpinned by a relativist ontology (Guba 1990), which emphasises context (Snow and Anderson 1991) and which would view such concepts as socially constructed (Marshall 1990). Robson (1993) suggests that the reliability of case study research relies on the trustworthiness of the human instrument i.e. the researcher rather than the data collection techniques themselves. A pragmatic approach for justifying and judging the quality of case study research has been suggested. Merriam (1988) proposes that case study can be advocated on the grounds that it is more useful, appropriate or workable than other research designs for a given situation. Knowledge produced by case study would be judged by how understandable and applicable it was. Yin (1994) sets out the classic tests of social science methods and suggests how they may be used in case study. Table 3.2 illustrates how these tests have been addressed within the current study. For Najman et al (1992) however, it will only be through the creative use of methods to address these criteria, whatever paradigm is overarching, that the quality of contributions to knowledge will be improved.

Table 3.2 Addressing design tests in case study phase (Cycles 1 and 2)

Tests	Case study tactic	Thesis section
Construct validity <i>establishing operational measures for concepts being studied</i>	<ul style="list-style-type: none"> - use of multiple methods and triangulation of results - maintenance of chain of evidence from research questions, through raw data to conclusions - involvement of participants - taking results back to case study participants 	<p>E.g. 4.8.6, p. 118</p> <p>Table 2.7, p. 60</p> <p>E.g. Table 4.5, p.99</p> <p>Ch 11</p> <p>Table 1.2, p. 11</p> <p>Table 3.4. p. 81</p>
External validity <i>establishing the domain to which findings can be generalised</i>	<ul style="list-style-type: none"> - use of replication logic guided by theoretical needs in collective case studies - focus on saturation in relation to categories or themes - use of detailed description 	<p>4.4.1, p. 96</p> <p>4.8.1 & 4.8.2, p. 108</p> <p>E.g. Ch 9 and 10</p>
Reliability <i>demonstrating repeatability of study</i>	<ul style="list-style-type: none"> - clear statement of researcher values and paradigm assumptions - use of case study protocol – sampling, tools etc - development of case study database 	<p>Ch 1</p> <p>Table 4.4, p. 98</p> <p>Table 4.1, p. 84</p>

Based on Yin (1994)

3.4.2 Relationship of inquiry paradigm to research process

Case study research is inherently multi-method but it remains important to address the philosophical basis of the precise combination of methods within each case study. Design and instrumentation of quantitative methods seek to show how bias and error are eliminated in the pursuit of objective facts. The multiple realities captured by qualitative methods seek to persuade through thick description developed in context (Firestone 1987). Creswell (1994) identifies three schools of thought about mixing methods - the ‘purists’ who assert that paradigms and methods should not be mixed; the ‘situationalists’ who think that certain methods are appropriate in particular situations; and the ‘pragmatists’ who feel researchers should make the most effective use of both paradigms. Glesne and Peshkin (1992) are pragmatists, asserting that although the different paradigms rest on different assumptions and require different instruments to find the desired type of data, it does not mean that a researcher in one paradigm cannot use the methods of another in a supplementary rather than dominant way. Patton (1990) is

likewise a pragmatist, advocating a “paradigm of choices” in which “methodological orthodoxy” is replaced by “methodological appropriateness”. A pragmatic position has been taken in this study, which Chapter 4 will seek to explain.

It is not just at the level of methods that differences in paradigm occur. Different paradigms make different requirements on researchers at every stage of the research process from question formation to reporting (Brannen 1992). Researchers manipulating multiple methods have to confront the tensions between different theoretical perspectives and the relationships between the data sets produced by the different methods. Patton (1990) links the concept of mixing methodological strategies to triangulation (3.4.3) and suggests that a variety of mix is possible at the levels of design, measurement and analysis (Table 3.1). The overall research design of the current study has been congruent with the ontological and epistemological tenets of qualitative inquiry. However both words and numbers have been collected, separately or together, at different stages in the research, and words and numbers have been analysed separately and brought together in analysis (Chapter 4). Appendix 3 explores the technological support that facilitated the process. This has had the effect of deepening understanding through triangulation; adding scope and breadth to the study; and most importantly of providing new insights which would not have been possible with a single focus approach (Greene et al. 1989). However the integrative strategies for mixed-method data analysis need to be carefully explicated, to clarify whether data is, for example, being transformed or merged (Caracelli and Greene 1993).

The current study fulfils Creswell’s (1994) criteria for a mixed-methodology design, with a mix of quantitative and qualitative paradigms at most methodological steps in the research process (Tables 3.1 and 3.5) in an attempt to gain maximum insights from exploring their strengths and weaknesses. Creswell (1994) acknowledges that this design probably follows the actual research process, which involves moving between inductive and deductive modes of thinking. He also acknowledges the danger of working in a way that may be unacceptable to some and unfamiliar to most.

3.4.3 Triangulation

Given the nature of case study research, with its emphasis on holism, context and multiple perspectives, triangulation must comprise a key case study strategy (Snow and Anderson 1991). However it is a term fraught with difficulties in relation to precisely what its meaning is in research. The term itself originated in navigation, surveying and civil engineering where it is “a technique for precise determination of distances and angles for location of a ship’s or aircraft’s position, and in such endeavours as road building, tunnel alignment and other construction” (Gummesson 1991). In the late 1950’s psychologists employed more than one method of psychological testing to check that variation was in the trait and not the method (Stake 1995). By the late 1970’s Denzin was applying the term triangulation to the use of other data sources, methods, investigators and theories in order to overcome the problems of using a single data set, method, investigator or theory (Blaikie 1991; Flick 1992). However in later work he acknowledges triangulation is more an attempt at deep understanding rather than a capturing of objective reality (Denzin and Lincoln 1994). Questions such as whether qualitative and quantitative research is tapping the same things; which paradigm should be considered more trustworthy if discrepancies occur; and what a conflict of results of triangulation comprises have been raised (Bryman 1992). The positivist rationale behind the original use of the concept in the social sciences was that if all approaches pointed to the same results it would increase the likelihood that the ‘facts’ were ‘true’. Morse (1991) asserts that if contradictory results occur when triangulating qualitative and quantitative methods then it implies one set of results, and the study, is invalid. Bryman (1988) however asserts that it is in the spirit of triangulation that different results may emerge, leading to further questions and new areas of inquiry. For Mathison (1988) a triangulation strategy means that the researcher will need to assess the extent of convergence of the data but also of inconsistent and contradictory results. This conception shifts the focus away from ensuring validity to constructing plausible explanations.

For Stake (1995) triangulation is problematic within a constructivist epistemology which acknowledges multiple perspectives. For him, working in the case study tradition, the need is “to establish meaning rather than location, but the approach is the same. We assume the meaning of an observation is one thing, but additional observations give us grounds for revising our interpretation” (Stake 1995). Triangulation also clarifies

meaning by identifying different ways a phenomenon can be seen (Stake 1994). This idea is behind the concept of 'embedding' (Hamilton-Smith 1996), the notion that each approach to a topic gives a different view, some individualistic and some contextual, from which to better comprehend what went before and the impact of what follows. It is the concept of triangulation as 'embedding' in the sense of enlarging insight, rather than pinpointing or narrowing focus, that best describes why mixed methodology was employed in this study.

The strategy mapping framework developed during the case study phase of the project was born out of triangulating data. Appendix 4 summarises the qualitative-qualitative linkages (Miles and Huberman 1994) and the triangulation strategies related to methods, data type and analysis employed in Cycles 1 and 2, which will be explained in Chapter 4. The second research approach, employed in Cycle 3 of the research spiral to develop and use strategy mapping, was action research.

3.5 Action research approach

Gummesson (1991) classifies action research as an extreme method of case study research. The term action research suffers from a similar multiplicity of definitions and interpretations to those previously discussed in relation to case study research and to the concept of triangulation. The term action science has been proposed to distinguish it from methods such as consultancy which do not fulfil the traditions of systematic inquiry made public that marks out scientific research (Gummesson 1991). Action research or science is characterised by:

1. the pursuit of two goals - to solve a problem and contribute to science
2. mutual learning and development of competence for participants
3. development of an holistic understanding
4. co-operation, feedback and continuous adjustment to new information and events between participants
5. primary focus on the understanding and planning of change in social systems
6. a shared ethical framework
7. prior understanding of the area in which action science is being applied
8. primacy of meaning

(based on Gummesson 1991)

These characteristics mean that action research is a useful methodology within which to attempt to transfer knowledge into the clinical practice setting whilst making that change the subject of systematic inquiry. The case study phase of the current project had initiated the development of a framework to map client self-management strategies in Parkinson's disease (Chapter 5). This framework required further development in the context of professional intervention in disease management. This established the dual purpose of characteristic 1 above. Strategy mapping was designed to enhance knowledge of overall disease management at research, practitioner and client levels (characteristics 2 and 3). The framework moved forward with the adding of increasing numbers of strategies, which were fitted to areas of the developing map, accompanied by continuing reflection on how acknowledging strategies affected practice from professional and client perspectives (characteristics 4 and 5). A conceptual framework, including ethical considerations, articulated the way in which practice was to be explored (characteristic 6), and was based on research, professional and personal knowledge of the area (characteristic 7). The importance of strategy mapping lies in its ability to convey the meaning of life with Parkinson's disease to health and social care professionals and the meaning of professional advice to people with the condition (characteristic 8).

Hart and Bond (1995) have developed the general characteristics of action research into a typology on a consensus/conflict continuum. The four types identified are experimental, organisational, professionalising and empowering. Cycle 3 is an example of a combined professionalising/empowering action research type at the conflict end of the continuum.

This form of research is practitioner/client focused with its educative aim to raise the consciousness of both parties. This study aimed to highlight and value the work individuals with Parkinson's disease and their supporters were already undertaking to adapt to changes as a result of the condition through the use of strategy mapping. Physiotherapy would then be targeted at supporting, modifying or extending existing client work. Within the professionalising/empowering action research type the balance of power in the practitioner/client relationship is addressed. The research was designed to enable clients to play a more equal part in the professional/client relationship and to enable practitioners to acknowledge client expertise in chronic illness. To achieve this end Cycle 3 was theoretically informed by generating and testing a set of explanatory principles designed to move towards client-centred practice (Titchen 1993; Titchen and Binnie 1993a, 1994). Data from previous phases of the research project, the literature and the joint personal and professional experience of the collaborating researchers combined to generate a theorised account of the situation we were trying to change:

- a high percentage of client expectations of physiotherapy intervention in Parkinson's disease are not met (Chesson et al. 1996)
- a low level of involvement at a late stage of the disease contributes to lack of perceived success of physiotherapy amongst therapists
- physiotherapists focus principally on increasing personal capability which may be inappropriate in a deteriorating condition
- much work is done by individuals themselves to reduce the demand of tasks.

Tentative explanatory principles for action were developed followed by the generation of action hypotheses designed to test and refine the principles. Table 3.3 illustrates the nature of the explanatory principles and action hypotheses formulated (Clarke 1998).

Table 3.3 Explanatory principles and action hypotheses in Cycle 3

This table illustrates tentative explanatory principles [EP] and action hypotheses [AH] stated as follows – in situation *type X*, strategies type Y, will achieve goals type Z – which were designed to test and refine principles

<p>EP When there is an attempt by a physiotherapist (X) to change the power relationship between themselves and clients (by moving from a position of professional superiority to a partnership relationship), firstly, roles must be clarified and negotiated, and secondly, the physiotherapist must explicitly validate lay knowledge.</p> <p>AH <i>When there is an attempt by a physiotherapist to change the power relationship between themselves and clients (by moving from a position of professional superiority to a partnership relationship):</i></p> <ol style="list-style-type: none"> 1. <u>If expectations of physiotherapy intervention are elicited at the first visit, and X explains her role and the nature of her intervention, any gap between expectations and the service offered will be evident and able to be worked on.</u> 2. <u>If clients and supporters are to take on a partnership way of working, X needs to work with them to acknowledge their knowledge base and the work they have done to construct it.</u>
<p>EP When there is a gap between client expectations and the service on offer (e.g. client expecting to work within traditional cure paradigm as opposed to progressive Parkinson’s disease paradigm), the nature of targeted physiotherapy in the context of ongoing advice and support must be explained and demonstrated.</p> <p>AH <i>When there is a gap between client expectations and the service on offer (e.g. client expecting to work within traditional cure paradigm as opposed to progressive Parkinson’s disease paradigm):</i></p> <p><u>If clients are to take on responsibility for incorporating physiotherapy principles into their daily lives, X will need to set up an example of such an activity and monitor its performance early in the intervention.</u></p>
<p>EP When there is a gap between the individual’s physical capability to perform an action or activity and the demand of the action or activity (i.e. disability), individuals will accommodate firstly from their own physical resources, then by changing the environment of the task or use of an aid, and use the resources of another person as a last resort.</p> <p>AH <i>When there is a gap between the individual’s physical capability to perform an action or activity and the demand of the action or activity (i.e. disability):</i></p> <p><u>If each activity accommodation is to be of optimal use at maintaining independence at each level, X will need to be aware of how disability is being accommodated for and prepare for the next stage when its usefulness is waning.</u></p>

(Based on Titchen 1993; Titchen and Binnie 1993a, 1994)

In this study the change intervention, central to all action research, was professionally led and designed to facilitate both professional learning and client understanding. Improvement as a result of the intervention was jointly assessed by practitioner and client. All action research is a cyclical process of planning, acting and observing and reflecting (Waterman 1995). Data collected during the action component was reformatted to take back to clients to influence intervention. The data content and the context in which it was employed, together with the perceived fit of tentative explanatory principles and action hypotheses, were reflected on by researcher practitioner (the author, DJ) and practitioner researcher (Sheila Harrison, SH, 4.9, p. 121) collaborators (Reason 1988; Titchen and Binnie 1993b; Moore 1997). Additionally both researchers reflected together on the process with a number of the clients involved. The fit between actions and observations underpins face validity in action research, and reliability is approached through collaborative agreement between researcher and participants (Webb 1989). Because of its context-specific and problem-solving nature generalisability can be questioned (Hart 1995) but is countered by rich descriptions to enable readers to relate findings to their own situation (Titchen 1995). The current project's collection of strategies across encounters (Chapters 6-10) strengthens the applicability of strategy mapping. Table 3.4 maps the detail of collaborative and recursive effort within the action research phase onto the research cycle model for Cycle 3, which in itself serves validation purposes.

Table 3.4 Collaborative and recursive effort in action research (Cycle 3)

Columns along the top of this table indicate whether action research activity was being undertaken singly or jointly by DJ and SH. The table is divided into research Cycle 3 phases, with those which were undertaken on a recursive or repeated basis highlighted.

Diana Jones (DJ)	Sheila Harrison (SH)	BOTH
BEING 3		
Practice experience (community multiple sclerosis), and academic experience (OU, research), personal exposure (supporter of father-in-law)	Practice experience (mental health, elderly care, community)	
THINKING 3 recursive		
		Sharing backgrounds through taped conversations with feedback of themes. Sharing literature; research findings; resources; targeted physiotherapy project planning. Networking with clinical colleagues (visit to centres of expertise; Forum Group of peers to explore goal setting), and academic colleagues.
PROJECT 3 recursive		
		Development of conceptual framework of tentative explanatory principles and action hypotheses in an attempt to move towards a client-centred model of physiotherapy practice in Parkinson's disease through the use of strategy mapping
ENCOUNTER 3 recursive		
Reworking of strategy mapping framework	Collecting and using strategy mapping in practice	Videotaping/audiotaping collection and feedback of strategies Taking the concept of strategy mapping back to clients and reflecting on its use with them

DJ	SH	BOTH
MAKING SENSE 3 recursive		
Working on final operational definitions of map areas Evaluation of map to establish reliability Development of NUD*IST database for analysis	Continued collection and use of strategies	Reflective conversations face to face/telephone – taped/notes Preparing to communicate work
COMMUNICATION 3		
Undergraduate teaching – physical management of Parkinson’s disease Peer group teaching – in service training in local Trusts x 4 Association of Chartered Physiotherapists Interested in Neurology - 2 AGM addresses, one with taped feedback on strategy mapping Client group – talks to local PDS Groups x 3, one with taped feedback on strategy mapping Multi-professional groups - Rehabilitation researchers Practice development group Conference presentations – British Geriatric Society PD Interest Group x 2 Towards 2000 Practice Development Conference European Federation for Research in Rehabilitation 1 st National Therapy Weekly Rehabilitation Conference Dutch Physiotherapy in Geriatrics Conference (for details see dissemination schedule Appendix 1)		
BEING 4		
Part time practice in day hospital setting and part time research and academic work, to full time research and academic work	Practice in elderly care in day hospital setting, to rapid response community team for the elderly	Reflection on challenges and conflicts in moves back to clinical work without a research focus (e.g. time constraints, access to evidence)

3.6 Summary

This chapter has addressed the ontological, epistemological and methodological implications of the inquiry paradigm and associated research perspectives and approaches that have been employed in this study. In common with the main body of physiotherapy research, elements from different paradigms have been combined in an attempt to explore the issue of physiotherapy intervention in Parkinson’s disease. Table 3.5 uses the Ekdahl and Nilstrun (1998) classification to place the current study in relation to the nomothetic (quantitative), idiographic (qualitative) and combined traditions (3.2). The study emerges as predominantly combined and qualitative. The following chapter, which discusses the range of methods employed for sampling, data collection and analysis, will enable further illustration of the combined and qualitative elements of the study.

Table 3.5 Classification of current study in relation to nomothetic (1), combined (2) or idiographic (3) traditions

Nomothetic tradition	1	2	3	Idiographic tradition
Preactive design			X	Interactive design
Experimental design			X	Naturalistic design
Testing hypothesis		X		Generating hypothesis
Generalising		X		Non-generalising
No focus on meaning			X	Focus on meaning
Quantitative data		X		Qualitative data
Qualitative data		X		Qualitative analysis

Notes – main features of contrasting research traditions listed on left and right of table; grading of agreement with features of traditions as follows nomothetic (quantitative) 1, combined traditions 2, idiographic (qualitative) 3; X marks classification of current project in relation to features

Based on Ekdahl and Nilstrun (1998)

4 Methods within the research spiral

4.1 Overview of chapter

This chapter will present details of the methods, associated data types and analysis strategies employed within each of the research cycles of the study. Because the three research cycles linked to form a spiral of research activity, this chapter will include examples of the results that played a part in shaping the methodology and methods of later cycles. Table 4.1 sets out methods and analyses related to ENCOUNTER and MAKING SENSE research spiral phases (Figure 1.6, p.20), and indicates the chapter sections within which they are presented. Given the iterative nature of the research process at a number of points in the spiral, cross referencing will be made to enable the reader to move backwards and forwards in the text if need be.

Table 4.1 Methods within the research spiral and associated chapter sections

Research spiral phase	Methods and <i>analysis strategies</i>	Thesis section
ENCOUNTER 1	Group interview Brainstorming Informal conversations	4.2
<i>MAKING SENSE 1</i>	<i>Thematic analysis</i> <i>QSR NUD*IST analysis</i>	4.3
ENCOUNTER 2	In-depth interview Self-assessment Parkinson's Disease Disability Scale PDQ-39 and associated impairment scale 24 hour ambulatory monitoring Videotaping of functional activity with monitoring Activity and medication diary Ambulatory monitoring exit questionnaire	4.4 – 4.7

Research spiral phase	Methods and <i>analysis strategies</i>	Thesis section
<i>MAKING SENSE 2</i>	<i>Quantitative analysis of qualitative coding</i> <i>QSR NUD*IST analysis of interviews</i> <i>Scale analysis</i> <i>Ambulatory monitoring with video, diary and exit questionnaire analysis</i> <i>Integrated analysis with initial strategy mapping</i>	4.8
RESEARCH CYCLE 3	Participants Strategy mapping Collaborative reflection Peer group consultation Feedback to and from participants, professional and lay groups	4.9

4.2 ENCOUNTER 1

The aim of PROJECT 1 was to investigate how the everyday experience of living with Parkinson's disease was articulated in a group context (Table 2.7, p. 60). Results of this cycle would be used to inform further development of the project.

4.2.1 Sampling

The branch structure of the Parkinson's Disease Society (PDS) offered the potential to meet with groups of information-rich informants. An approach was made to the Northern Regional Organiser of the PDS who provided contact details for two northern branches of the Society, in addition to a Young Alert Parkinson's Patients and Relatives (YAPP&Rs) group. Data collection was desirable as early in the project as possible. As timetables for speakers at branch meetings were arranged well in advance, it was agreed that I would join the next monthly meeting of each branch and the YAPP&Rs group and talk to members in the most appropriate way. This required maximum flexibility of approach and in the end three different methods were used to maximise data collection – group interview, brainstorming and informal conversations. Arranging a separate meeting for data collection would have been problematic given the transport difficulties of the client group. Only one branch arranged transport to enable members to attend meetings. Table

4.2 provides information on the sample populations for the data collection episodes. Informed consent was obtained to use the data collected.

Table 4.2 Details of sample for case study ENCOUNTER 1 data collection

Method	People with Parkinson's disease				Carers		
	Male	Female	Total mean age	Total mean disease duration	Male	Female	Total mean age
Group interview (Total n=20)	6	6	66 yrs	9 yrs	3	5	64 yrs
Informal conversations (Total n=12)	3	3	58 yrs	9 yrs	3	3	59 yrs
Brainstorming (Total n=22)	16		67 yrs		6		
Total sample n=54							

4.2.2 Data collection

The first branch meeting was attended by approximately 26 people in total, comprising people with Parkinson's disease, their carers and friends. The majority of attendees were married couples, mostly with husbands with Parkinson's disease. There were no young people. People had to make their own transport arrangements by private car or taxi. Only one person with Parkinson's disease was in a wheelchair, and she also used a Memowriter communication aid due to speech difficulties. Other people were mobile on their own, with or without walking aid, or with carer support. Prior to the meeting, which was addressed by the District Information Officer of the Benefits Agency, I was able to talk to some members individually. After the planned talk I was able to conduct an audiotaped group interview (n=20) in the form of a facilitated discussion on the theme of difficulties encountered in everyday life and ways to ameliorate them. Initially this was analysed through focused listening to develop a framework of thematic categories (4.3.1), but later

a verbatim transcript was prepared for computer aided qualitative data analysis using QSR NUD*IST software (QSR 1994) (4.3.2.1).

The second branch meeting was attended by approximately 70 people in total, again people with Parkinson's disease, their carers and friends. There were a high percentage of married couples in attendance and younger people with Parkinson's disease were well represented. Transport was arranged if necessary by the branch. Two people with Parkinson's disease were in wheelchairs. Other people were mobile on their own, with or without walking aid, or walked with carer support. One member had no audible speech but did not use a communication aid. A representative of British Telecom who focussed on services for disabled people addressed the meeting. During the tea break I outlined the proposed study and moved around the room asking a number of people with Parkinson's disease and carers (n=22) to give me the first two difficulties in everyday life that came to mind as a result of Parkinson's disease. Everyday difficulties were analysed thematically (4.3.1) and later introduced on-line into NUD*IST software to enable comparison with other ENCOUNTER 1 data sources (4.3.2.1).

The YAPP&Rs group I joined met one Saturday a month for a pub lunch. Attendance was down due to holidays and one member had had a fall. Twenty people were in attendance, again comprising people with Parkinson's disease, carers and friends. The majority were couples, and aged 50 years and above. Transport was not arranged for this meeting. No one used a wheelchair to access the session, although one member in attendance had been in her wheelchair at the main branch meeting. Two members needed carer support for mobility; no walking aids were observed. This was a very informal gathering, apart from the giving out of notices when everyone had gathered. The notices themselves underlined how active the group was, with trips to Scotland to meet another YAPP&Rs group and a visit to Holland planned to meet their counterparts there. National conferences run by the PDS were attended by members. It was not appropriate to run a group interview. Instead I mingled with the attendees over a buffet lunch. Field notes were made of my impressions and the content of my conversations (n=12) on the theme of everyday difficulties and how they were approached. These were introduced into NUD*IST for comparison with data from other ENCOUNTER 1 sources (4.3.2.1). It was mentioned that a nurse had attended the group some time ago to gather information for a project but had not fed back

on the outcome of the study. It was apparent that this would be important for me to do as a matter of courtesy as well as to address the validity of research findings. An opportunity arose unexpectedly to do this when I was asked to address the branch meeting on an occasion when a planned consultant speaker was unable to do so because of an emergency.

There were marked differences between the two main PDS branches visited. The first meeting attended was a much more intimate affair, held in a social club as opposed to a rehabilitation gymnasium. The population served was a rural/urban mix rather than the predominantly urban population served by the second branch. The membership of the first branch was largely elderly, with no YAPP&Rs group, and it was not in a position to offer transport for meetings. Similarities included the small number of individuals attending in wheelchairs and a similar small number experiencing severe speech deficits. It has been estimated that membership of the PDS accounts for about one fifth of the total diagnosed with the condition in the UK (Yarrow 1999). Members are likely to be better informed than non-members, and therefore the extent of difficulties being encountered in everyday life can be viewed as a measure of residual problems after presumed optimal pharmacological management.

4.3 MAKING SENSE 1

4.3.1 Thematic analysis

Focused listening to group interview data produced three groups of categories and associated subcategories of everyday difficulties which mapped on to a biomedical understanding of Parkinson's disease, with a fourth related to dissatisfaction with biomedical management. The three biomedical categories related to: (1) motor symptoms such as slowness of movement; (2) functional difficulties such as bed mobility; and (3) other physical problems such as pain. The fourth category related to management and included difficulties with iatrogenically induced movement disorder and access to the multidisciplinary team. Analysis indicated that problems resulted from Parkinson's

disease itself but also from its management. This was born out in the brainstorming data, which developed an understanding of carer issues such as lack of support, and again within the informal conversation data, which highlighted the theme of complexity within drug management, accomplishing everyday activities, liaison with official agencies, and social relationships. It was in order to attempt to approach this complexity that computer aided qualitative data analysis software was employed.

4.3.2 QSR NUD*IST

Handwritten field notes, typed transcripts, marked up photocopies, filing cards with cut, sorted and pasted text related to themes, shuffled cards and typed analyses have been the stuff of qualitative analysis. This group of activities was seen to allow researchers to become close to and immersed in their data, adding to the trustworthiness of emerging outputs. Word processors were accepted for their ability to produce better transcripts. However placing a qualitative data analysis computer software program between text and researcher has been regarded with suspicion by some (Dey 1993). Seeing a small fraction of total text in a box on a computer screen is a very different experience to physically handling filing boxes of data on cards. However the challenges of qualitative analysis – keeping track of the data, coding and managing categories, recording thinking, cutting up the data to look at it in different ways, developing and testing ideas, and communicating your activities (Tagg 1996) – are all suited to computer use. According to Weitzman and Miles (1995) it is people that analyse data not computers, although computers have the potential to help them in their task. However the level of ease of computer use is an important factor in the decision to use qualitative analysis software.

The drivers to use a software program within the current project were my desire: (1) to make use of a structured yet flexible approach to data management and analysis; and (2) as a new researcher to learn the use of developing tools. Research for suitable programs was approached through reading about alternative software, such as Ethnograph and Atlas, in addition to personal and e-mail discussion list (QUALRS-L 1996) contact with other researchers using a range of software. Introductory courses on NUD*IST, the chosen program, were attended. NUD*IST was selected because it best supported my developing concept of the tasks involved in qualitative analysis. It was piloted in depth

with data from the project (4.8.1). Use of computer-aided qualitative data analysis software did not mean that scissors and sort techniques were redundant. The complex range of technical support for analysis within the project is presented in Appendix 3. The major problem with software usage was the length of the learning curve in the absence of technical support. Early advice on the setting up of documents, choosing the optimum size of the text unit (the smallest amount of text that can be coded), structuring the index system, writing command files and using search procedures to allow optimum interrogation of the data would have been invaluable. Notwithstanding these difficulties, the software has provided an aid to project management and communication of process and outputs. Sections of this chapter illustrating use of NUD*IST will discuss the structure of the index system for the specific phase of the project, and give examples of how the index system was investigated to develop propositions and test them within the data set.

4.3.2.1 QSR NUD*IST within MAKING SENSE 1

NUD*IST exploits the theory of hierarchical categories as an organising principle (Richards and Richards 1995). This supports the development of a taxonomy of indexing categories (nodes) and sub-categories, each containing material bounded by a common definition. The verbatim transcript of the audio-taped group interview, summary of issues from the brainstorming session and notes of informal conversations were introduced on-line into the program. NUD*IST makes use of two main types of category structure which allow analysis of coding using powerful operators. Factual categories code attributes of text (for example, whether contributed by someone with Parkinson's disease or a carer), and referential categories code what the text is about (for example, changes individuals make in their lifestyle to accommodate Parkinson's disease). Five main root (or level 1) referential categories were derived from ENCOUNTER 1 data. Four main category structures were derived inductively from the data:

Experiencing Health Changes illustrated the range of physical and cognitive symptoms encountered;

Medical Management Issues focused on interaction with and access to professionals and services;

Psychosocial Consequences highlighted key stressors, feelings and social relationships; and

Self-management Strategies demonstrated the work individuals undertook to accommodate to changes imposed by Parkinson’s disease.

A fifth main root category was deductive. A category structure representing the three main performance areas of the **Occupational Performance Model** (Law et al 1990) - self-care, productivity and leisure, and their sub-divisions - was constructed in order to test the hypothesis that Parkinson’s disease would affect all aspects of everyday life.

Figure 4.1 displays the hierarchical structure of the first main category - Experiencing Health Changes.

Figure 4.1 Experiencing Health Changes: NUD*IST node tree

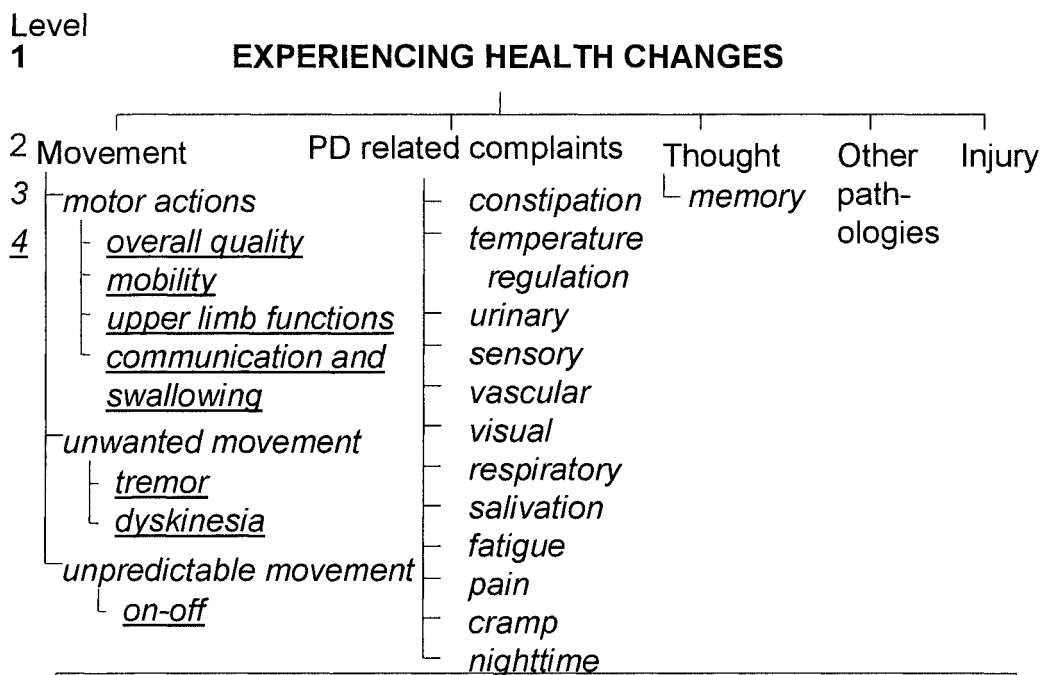


Figure illustrates NUD*IST node tree with levels of coding indicated down left hand side

Whilst Parkinson's disease is classified as a movement disorder, and the complex hierarchy of level 3 and 4 categories below the level 2 category of Movement underlines its importance, the taxonomy illuminates the wide range of other symptoms which may be experienced. Categories extending from this root or level 1 category relate in complex ways to one another as well as to other areas of the taxonomy. For example, someone who is exhibiting a flexed posture, reduced facial expression and changes in the quality of the voice who is also deaf is likely to experience severe disadvantage in relation to social interaction. A urinary problem in an individual with poor mobility at night is likely to put considerable stress on a carer.

NUD*IST exploits this taxonomic structure to enable complex questions to be asked of qualitative data. Figure 4.2 illustrates the hierarchy developed from the level 1 categories of Medical Management Issues and Psychosocial Consequences. To find out, for example, about stress on carers as a result of nighttime disruption, a search would be undertaken to collect data relating to Physical and Emotional Stress and intersect it with data from the Nighttime category of Figure 4.1 and data in the category containing all that was contributed by carers. An example of text retrieved from this search is:

“Well, he can't turn over on his own ... I've got to be there. I've got to get out of bed and I've got to put him back in again, you know ... Last night I think it was about six times.”

To give a further illustration, to explore what participants did not like about current review procedures, an intersect search would be performed to find all the data that is indexed both at Review and Feelings/Negative. Here is an example of text located as part of that search:

“They don't bother with you ... he says, “You've got Parkinson's disease. That's the trouble with you. Can't do nothing for it”.

A service planner could use this information to inform in-service training programmes with staff.

Figure 4.2 Medical Management and Psychosocial Consequences of Parkinson's disease: NUD*IST node tree

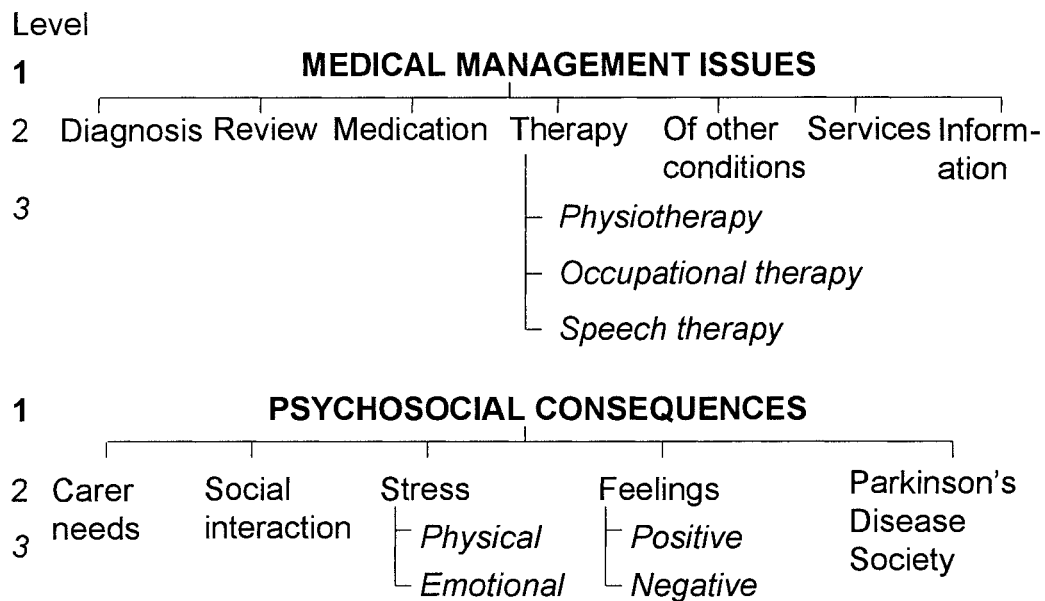


Figure illustrates NUD*IST node trees with levels of coding indicated down left hand side

Another feature of analysis using the category structure is the ability to look at the relative weight of each in terms of text coded to categories (Morgan 1993). NUD*IST software enables a report to be made on a category which calculates the percentage of total text units coded to it. These weightings must be considered carefully for validity; for example, in the discussion group one individual was using a communication aid and her contribution was only occasionally relayed by a carer. Figure 4.3 illustrates the main areas of the occupational performance model, a theory-driven set of categories. The 'strongest' category in terms of coded text was Functional mobility, relating to moving around the environment, turning in bed etc (Chapter 10). The relative 'strength' of Socialization (writing letters, talking on the telephone) and Community management (signing cheques, shopping) was influenced by the amount of text relating to difficulties with writing and speech (Chapter 9).

Figure 4.3 Exploring occupational performance using NUD*IST

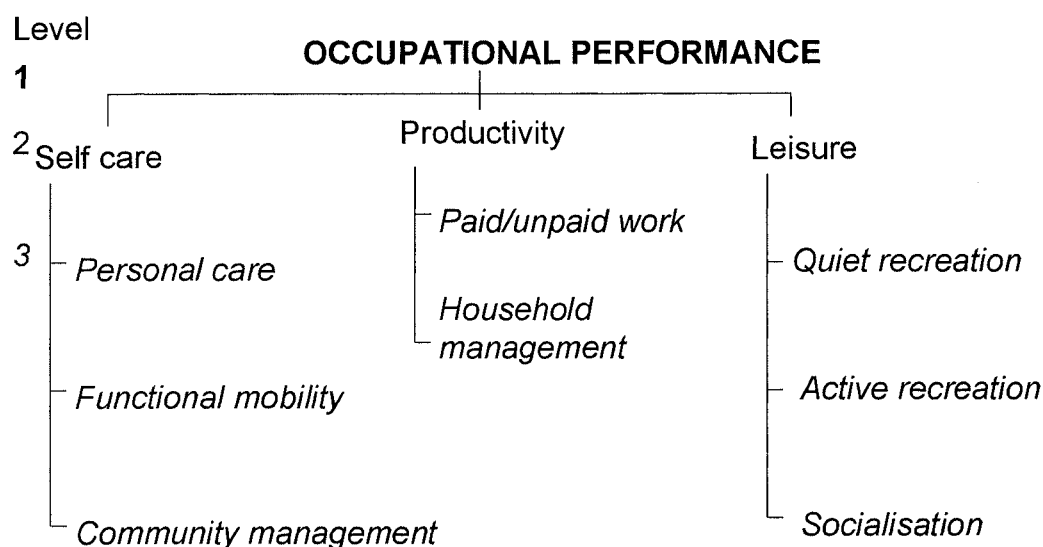


Figure illustrates NUD*IST node tree with levels of coding indicated down left hand side

From the first thematic analysis of ENCOUNTER 1 data the strength of the issue of self-management in Parkinson’s disease was beginning to emerge. Individuals and carers employ a range of strategies as they adapt to living with Parkinson’s disease. These are largely initiated independently of professionals given the limited time at medical review and low referral rates to multi-disciplinary team members (Table 2.2, p. 34). Even in the case of medication individuals were often tailoring their own dosages. The **Self-management Strategies** category structure (Figure 4.4) formed the basis of the concept of strategy mapping (Chapter 5), which developed throughout Cycle 2 and was the central focus of Cycle 3.

Figure 4.4 Self-management strategies: NUD*IST node tree



Figure illustrates NUD*IST node tree with levels of coding indicated down left hand side

The use of NUD*IST's taxonomic structure in relation to Encounter 1 data enabled the breadth of symptomatology that may be experienced in Parkinson's disease; the implications of the condition for everyday life; the perceptions of health and social care management; and the work undertaken by individuals and their carers to accommodate for the changes being experienced to be portrayed. Furthermore by relating categories to one another using NUD*IST's operators individuals' and carers' perceptions of their situation and current disease management could be explored (Jones et al. 1996b). Re-analysis of ENCOUNTER 1 data was undertaken in parallel with analysis of ENCOUNTER 2 data. The emerging focus on self-management guided Cycle 3 development.

4.4 ENCOUNTER 2

The main aims of Cycle 2 were to investigate how individuals approach and manage life with Parkinson's disease, and how the everyday experience of the condition could be captured (Table 2.7, p. 60). Results would be used to inform physiotherapy management. A mix of methods that mapped on to those which might be used clinically within physiotherapy assessment, relating to both subjective and objective domains at a range of levels from impairment to participation, was employed (Guidelines Group 2001). For example, rigidity, gait parameters and lifestyle are examples of impairment, activity and participation foci respectively that could be expected to be found within a physiotherapy assessment. Amongst other issues, within ENCOUNTER 2 self-rating of rigidity was obtained, gait was examined in the context of 24 hour activity monitoring, and lifestyle explored in the context of interview data and quality of life scale responses.

4.4.1 Sampling

In discussion with the collaborating consultant neurologist, a purposive, heterogeneous sampling frame was formulated. The inclusion criterion was a diagnosis of idiopathic Parkinson's disease and exclusion criteria were substantial cognitive impairment and additional pathology involving movement disorder e.g. a stroke. A range of ages, drug regimes and levels of disability was sought and achieved. Ethical permission had been granted for the study and informed consent was obtained from the 8 case study participants who were identified from patients attending a regional neurological out-patient department (Table 4.3). Five men and three women took part, with ages ranging from 43-76. The mean age for the total sample was 63 years, with the mean age of male participants 59 years, and of female participants 70 years. Participants had been diagnosed between 2-14 years, with the youngest participant diagnosed for the longest time. Mean years diagnosed for the total sample was 7.3 years, with the mean years diagnosed for male participants 6.4 years, and for female participants 8.6 years. Symptoms possibly attributable to Parkinson's disease had been experienced for between 2.5 and 16 years, longer than range of years diagnosed. Seven participants were married,

one being a carer of an 80 year old husband who had had a stroke. He was admitted to long term nursing home care during data collection for the project.

Table 4.3 Details of sample for case study ENCOUNTER 2

P	S	Age	Diag	Yrs diag	LH	Sym onset	Sym yrs	MS	Carer sex	Carer age
1	M	70	1993	2	2	1992	2.5	M	F	72
2	M	65	1987	7	3	1986	8	M	F	61
3	F	64	1987	7	3	1985	9	M	M	67
4	F	70	1984	10	4	1984	10	M	M	50
5	M	68	1989	6	3	1987	8	M	F	71
6	M	49	1993	3	2	1992	4	M	F	49
7*	F	76	1986	9	3	1985	10	M		
8	M	43	1982	14	4	1980	16	Sep		

Notes: Abbreviations P – participant; S – sex; Diag – year diagnosed; Yrs diag – number of years diagnosed; LH – Langton-Hewer Stage 1 (diag <2 years), Stage 2 (diag 2-4 years), Stage 3 (diag 5-9 yrs), Stage 4 (diag >10 yrs) (PDS 1994; Chandler and Plant 1999); Sym onset – year of symptom onset; Sym yrs – number of years with symptoms; MS – marital status

* carer for husband who had had a stroke

Details of the protocol followed for the completion of each case study are given in Table 4.4.

Table 4.4 Case study protocol: Cycle 2

Stage	Action
1	Referral from consultant
2	Telephone contact with participant to introduce self and explain project.
3	Home visit. Information sheet (Appendix 5) explained and written informed consent (Appendix 6) obtained. Interview with participant and carer, if appropriate, audio-taped, together with completion of Self-Assessment Parkinson's Disease Disability Scale (SAPDDS) (Gotham et al. 1986) (Appendix 7), and Parkinson's Disease Questionnaire 39 (PDQ-39) with impairment scale (Peto et al. 1995) (Appendix 8) when introduced. Explanation of ambulatory monitoring procedure, including diary keeping.
4	Interview transcribed and post-contact notes recorded.
5	Home visit approximately one week later. Ambulatory monitoring equipment fitted and information sheet (Appendix 9) and diary (Appendix 10) left. Opportunity for continued discussion of points raised by participant, carer or researcher.
6	Home visit 24 hours later. Researcher completes final section of diary (exit questionnaire) with participant.
7	Letter to GP giving background to research project
8	Analysis of ambulatory monitoring and video recording.
9	Return home visit arranged to repeat video recording and monitoring in the event of initial technical problems. Feedback of initial analysis of interview data to participants for comment.
10	Potential for continued data collection in relation of individual areas of problem-solving.
11	Recording of telephone updates and related correspondence.
12	Updating of participants in relation to project progress.

4.4.2 Data collection

Data collection for the individual case study phase spanned two years and an individual data collection calendar was kept for each participant. Table 4.5 sets out the data sources for all participants that were available for analysis. Numbers of audio-taped interviews with any one individual ranged from none to five. One participant had such marked speech difficulty that recording was not appropriate so post-contact notes were used as the primary data source. Two participants declined to use the ambulatory monitoring equipment (4.7.4). The PDQ-39 with impairment rating was not introduced into data collection until later in the case study phase so data was not collected during initial interviews with early participants.

Table 4.5 Individual case study data collection schedule: Cycle 2

P no	Inter-views	Post con note	SAP DDS	PD Q -39	Imp	NUM diary	NUM anal-ysis	vid per	vid sp	Tel note	Cor	Ind tools
1	abcde	ac	acde	cde	cde	ade	abde	abde	abde	Yes	Yes	Yes
2	abcde	adf	ade	de	de	acf	acf	abf	abf	Yes	Yes	Yes
3	a	a	a	-	-	-	-	-	-	-	-	-
4	a	a	a	-	-	a	a	a	a	-	-	-
5	abcd	abcd	abc	bc	bc	ac	ac	ac	ac	Yes	Yes	Yes
6	acde	abcde	acd	bcd	bcd	cde	cde	bcde	bcde	Yes	Yes	Yes
7	abc	abc	abc	abc	abc	-	-	-	-	Yes	-	Yes
8	-	abcd	cd	cd	cd	bcd	bcd	bcd	bcd	Yes	Yes	Yes

Notes: P no – participant number; Post con note – post-contact notes; SAPDDS – Self-Assessment Parkinson’s Disease Disability Scale; PDQ-39 – quality of life scale; Imp – impairment rating; NUM diary – NUMACT diary; NUM analysis - NUMACT analysis; vid per – video recording with NUMACT; vid sp – video speech included in analysis; Tel note – telephone note; Cor – correspondence; Ind tools – development of individual problem-solving recording tools; abc etc chronology of data collection episodes

4.5 In-depth interview

A similar development occurred in the planning of the interview for ENCOUNTER 2 to that which took place in relation to data analysis techniques within MAKING SENSE 1 (1.4.5, p. 11). As I moved further away from practice the biomedical influence waned and the social constructionist perspective developed. An unstructured interview was always envisaged, as opposed to a structured or semi-structured survey-type interview.

Standardised scales calling for a restricted range of answers were already included in the methods to be used. The focus of the originally planned interview centred on symptomatology, function and handicap. However following piloting and increasing awareness of Cycle 1 results, a change was made to a focus on the history of the disease trajectory and the meaning of significant events along each individual’s trajectory. These could include the impact of diagnosis, changes in role and problems with drug management. Thus the methodology moved towards a life-history approach where the focus is on an individual’s subjective definition and experience of life (Schwandt 1997).

Interviews were conducted in the individual's home. As most participants were older people and married there was the possibility of including the spouse in the interview. It was necessary to be sensitive to the relationship of the participant and their spouse to assess how they may wish to proceed. Some spouses made it clear that they did not want to be involved; others were present on the periphery, perhaps bringing coffee, staying to input into the discussion, and leaving; yet others were keen to be present throughout. On several occasions husbands and wives took advantage of the absence of their spouse to offer information they were obviously uncomfortable about divulging in their presence. In the case of both participants and spouses the nature of such private disclosures related primarily to anxiety about the future which they were avoiding confronting together for fear of distress. On one occasion disclosure centred on a suicide attempt in a house where to my knowledge there was a supply of unused medication which would enable this to occur again. I was able to negotiate the return of the unwanted medication to the local pharmacy on my way home. My post-contact notes offered an opportunity to reflect on the tensions in the data as a result of conjoint interviewing. Occasionally this kind of selective disclosure was captured during the videoing of functional activities with NUMACT recording.

When contacting individuals about participation in the study I introduced myself as a research physiotherapist with an interest in the experience of Parkinson's disease in order to inform practice. Because I was a health professional and one of the themes in the data was often lack of time for questioning during medical follow-up, my opinion was regularly sought on approaches to symptoms and drug management. I always suggested reference back to either the GP, consultant or specialist nurse. However as an acknowledgement of the fact that individuals were prepared to share information with me, I felt able to direct people to information that was in general circulation e.g. PDS literature if appropriate.

Interviews were tape recorded and transcribed verbatim. A range of transcription symbols were used to identify approximate lengths of pauses, overlapped speech, stressed words etc. (Silverman 1993). Although time consuming, this information was particularly valuable when completion of scales was audiotaped. It enabled the degree of difficulty fitting a standardised response to a range of activities in a condition that can fluctuate within the space of an hour and over the course of the day to be assessed.

4.6 Impairment, Disability and Quality of Life Scales

Wade (1992) recommends measurement in Parkinson's disease should take place at the levels of impairment, disability/activity and handicap/participation. Self-report of the individual is the only way information can be obtained about the degree to which Parkinson's disease interferes with everyday life. Three disease-specific self-report scales were included in ENCOUNTER 2 data collection that corresponded to each level of measurement.

4.6.1 Self-Assessment Parkinson's Disease Disability Scale (SAPDDS)

The SAPDDS was developed by Gotham et al. (1986) for use in a study that aimed to study the nature of the depressive changes found in Parkinson's disease as compared with normal elderly subjects and patients with arthritis. Relationships between the scores of three self-report scales relating to depression and anxiety and the SAPDDS were explored, and revealed significant correlations between self-ratings of depression and functional disability. The original 24 item self-rated scale (to which an extra item relating to turning over in bed was later added) (Appendix 7) was assembled from a number in general clinical use, and was designed to cover a variety of aspects of everyday life likely to be affected by chronic illness such as arthritis or Parkinson's disease. Items cover activities ranging from manipulative skill e.g. dressing, to mobility e.g. walking to the local shops. Respondents are asked to rate their ability to perform each activity on a 5 point scale ranging from 1 - 'Able to do alone without difficulty' to 5 - 'Unable to do at all'. To make allowance for fluctuations in ability, respondents are invited to indicate how well they would perform the activity at the time they would usually undertake it. If an aid is employed they are asked to respond in relation to how well they would manage without the aid.

A total score is calculated, with a range from 25 - 125. The higher the score, the greater the disability. Two subscores can be calculated for subscales derived from a principal components analysis (Brown et al. 1988). The two factors derived relate to mobility and gross movement, such as walking up stairs and getting out of bed (range 12 - 60), and fine co-ordination, such as cutting food and writing a letter (range 13 - 65). Brown et al.

(1988) reported that together these factors accounted for 67% of the variance in total ADL scores.

Brown et al. (1989) tested the validity of the SAPDDS in a study designed to assess the accuracy of self-reported disability in individuals with parkinsonism, given that depression and cognitive impairment, both found in the client group, may influence scoring. The study showed high levels of agreement in all three ratings of disability - by the individual, a relative, and an independent observer - for total disability score, subscales and individual items. Depression had little impact on the accuracy of self-reported disability, whilst the presence of cognitive impairment tended towards a slight underestimate of disability. They found a small margin of disagreement between the ratings of the individual and relative for specific items, especially in cases of mild impairment. However, they concluded that the best single index of disability was the individual's own judgement of it.

A recent study of the SAPDDS reports high internal consistency and validity, a hierarchical structure to the scale and strong relationships between the scale, the Hoehn and Yahr rating scale, Sickness Impact Profile and observed performance (Biemans et al. 2001). Good validity and reliability has been reported for a new self-report ADL scale specifically designed for individuals with Parkinson's disease, the Parkinson's Disease Activities of Daily Living Scale (PADLS) (Hobson et al. 2001). The scale provides a single global rating rather than rating of individual tasks.

4.6.2 Parkinson's Disease Questionnaire-39 (PDQ-39) and associated impairment scale

A disease-specific Parkinson's disease quality of life scale – PDQ-39 (Peto et al. 1995) - became available during the life of the project and was included in ENCOUNTER 2 data collection (Appendix 8). Generic quality of life instruments such as the Nottingham Health Profile and the Short Form – 36 (SF-36) do not address important issues in the experience of patients with Parkinson's disease such as communication difficulties and social embarrassment. The Parkinson's Disease Questionnaire - 39 (PDQ-39) - is a health status questionnaire that was developed from interviews with people with the condition to

ensure content validity. The 39 items in the scale cover eight dimensions: mobility, emotional well-being, stigma, social support, cognitions, communication and bodily discomfort (Peto et al. 1995; Peto et al. 1998). Respondents are asked how often during the last month they have experienced a range of difficulties due to Parkinson's disease. They have the opportunity to rate Never, Occasionally, Sometimes, Often or Always/Cannot do at all. The scores for each dimension are computed into a 0-100 scale (0 - no problem at all, 100 - maximum level of problem). Work is on-going on other Parkinson's disease specific quality of life scales (Hobson et al. 1999) and on assessing generic quality of life measures for use in Parkinson's disease (Schrag et al. 2000).

The self-report of impairment has been investigated by those involved in studying the epidemiology of Parkinson's disease where large-scale mailings of self-report questionnaires may be employed (Golbe and Pae 1988). A simple scale with stringent validity testing is advised. The PDQ-39 research team rating of impairment in relation to tremor, stiffness, slowness, freezing and jerking within a quality of life research project (Peto, undated) was included in later ENCOUNTER 2 data collection. The rating followed the PDQ-39 5 option format of Never to Always with an additional rating of how bad each symptom was from No problem to Very severe.

4.7 Ambulatory monitoring and associated tools

Most measurement techniques in rehabilitation focus on what an individual *can* do (capability) over short time scales. Ambulatory monitoring offers the possibility of studying what an individual *does* do over a longer term period in their own environment in relation to the quantity (when, how long, how often) and the quality (how performed) of a number of mobility activities (Bussman et al. 1998). These include stationary activities such as standing, sitting and lying and movement-related activities such as walking and climbing stairs. Various types of activity monitoring devices have been used with patients with Parkinson's disease. These include wrist-worn activity monitors, which have been used to investigate sleep patterns (Van Hilten et al. 1994), therapeutic response fluctuations (van Hilten et al. 1993a) and fatigue (van Hilten et al. 1993b). Patients with Parkinson's disease were included in the work of Diggory et al. (1994) to test a device

consisting of a mercury tilt switch attached to an electronic counter designed to measure time spent upright within a hospital setting.

4.7.1 NUMACT ambulatory monitor

The NUMACT ambulatory monitor (Walker et al. 1997) was employed in this project. The activity monitoring recorder consists of position and movement sensors attached to the individual's body which are connected via an interface module to a Psion Series 3 pocket microcomputer carried in a belt pouch (Figure 4.5 and Appendix 9). A patient input module allows subjective assessment of symptoms on a 10-point scale, for example related to 'on/off' periods in Parkinson's disease. The NUMACT activity monitor can record for prolonged periods of time, up to 72 hours, but 24 hours is the normal monitoring period. The position of the individual is detected by two sealed mercury switches, which close a circuit if they are within 45° of the vertical position. Switches are encapsulated in silicone rubber and attached to the skin using an adhesive film. One switch is attached over the sternum and the other to the lateral aspect of the lower thigh. In the case of individuals with Parkinson's disease the lower limb least subject to tremor or dyskinesia was chosen. Overall position is detected by the state of the switches: standing (chest and thigh vertical); sitting (chest vertical and thigh horizontal) and lying (chest and thigh horizontal). An accelerometer, sensitive to vertical motion and mounted in the chest sensor, allows periods of standing, walking and individual steps to be identified and gives an indication of walking vigour, recorded as step amplitude related to the impact of heel strike. The system is lightweight, does not restrict activity apart from bathing/showering and is well tolerated by wearers.

Figure 4.5 NUMACT ambulatory monitoring equipment



Raw data is stored in real time on solid state disks and downloaded to a personal computer for analysis. A variety of displays are available with data visualised over 24 hours, 5 hours, 15 minutes or 50 seconds. Position is represented by a line against either stand, sit or lie and steps are represented by dots plotted as amplitude against time. An acceleration trace is shown on the 50 second display. Summary tables and histograms of step number against amplitude are available. Results of data analysis are summarised as:

- total time spent standing, sitting and lying
- total number of steps. A step is a peak on the acceleration trace exceeding the threshold when the trace then returns below the threshold; there has got to be a gap of greater than 0.3 seconds between two peaks to be detected as two discrete steps, although this can be varied.
- average amplitude (vigour of step). Amplitude refers to the height of a peak above threshold (maximum is 255, base line 136); measure of change in vertical acceleration of the body.
- energy (number x amplitude of step)
- step interval (measure of how fast). Step interval is the time between two adjacent steps in a period of walking (left heel strike to right heel strike); there has to be at least two steps occurring within 5 seconds, if greater than 5 seconds it is discarded (stopped and stood still).
- step interval number (number of steps attributable to walking)

- average amplitude of occasional steps (<20 consecutive steps), short walks (>20<100 consecutive steps) or periods of continuous walking (>100 consecutive steps).

An information sheet about the activity recorder was left with each participant (Appendix 9).

4.7.2 Videoing of functional activity with monitoring

Videotaping has an established role in Parkinson's disease assessment. Classically it is used to discern the presence or absence of abnormalities of movement, including dyskinesia, or posture (Stern et al. 1983; Lang 1990; Marsden and Schachter 1981). It allows the gathering of more useful information in relation to quality of movement than purely timed tasks. The Motor Examination of the UPDRS, with the exception of rigidity, can be incorporated into a standardised video format taking 3-5 minutes to complete. Kinsman (1986) developed a video assessment recording answers to questioning about medication, demonstration of tremor, and performance of writing, ADL, gait and posture tests. Assessment of video recordings of patients undertaking routine activities in their own home was investigated by Bannister et al. (1996). Members of the multidisciplinary team valued the additional information available from the home context, which was unobtainable within the clinic setting. Similarly Awenat (1999) utilised video recording in the ward and home setting to improve team assessment and evaluation of response to drug therapy and rehabilitation.

Within the current project concurrent videotaping with ambulatory monitoring allowed a validity check to be made against the monitored output (4.8.4.2) and often provided spoken data from the individual being monitored or their carer in relation to the task being undertaken (4.8.6 and Appendix 14, Figure 3).

4.7.3 Activity and medication diary and exit questionnaire

As with videotaping, diaries play an important role in Parkinson's disease assessment. These often take the form of monitoring symptoms and reporting on-off motor fluctuations or dyskinesias in an attempt to optimise drug therapy (Montgomery and

Reynolds 1990). Yekutieli (1993) used a falls diary with two individuals involved in a trial of physiotherapy in Parkinson's disease whose main problem was falling but who never fell in the laboratory setting. The individuals recorded the time and location of every fall that occurred before and during the trial on maps of their apartments. The diaries provided insight into the nature of the problems and how to address them, and also documented decreased falling during therapy.

For the purposes of this project a simple diary was kept by participants during 24 hour monitoring. It involved recording the type, amount and timing of medication and a brief description of the main activities carried out in each of four time periods - before breakfast, before lunch, before dinner and before bed (Appendix 10). If individuals experienced problems with writing the diary was completed by a carer or the researcher on removal of the monitor the following day. In addition an exit sheet was completed recording factors that may have influenced monitoring, e.g. day of the week, season of the year, weather conditions, mood, and events that may have increased or decreased activity. A number of case study participants completed individualised diaries to capture the extent of current problems in relation to motor fluctuations (7.2, p. 166), breathlessness (7.4, p. 173) and dietary/drug interaction.

Within the current project ambulatory monitoring offered the opportunity to maximise the ecological validity of objective activity data, being gathered during normal activity in the home environment. In combination with videotaping of functional activity, which generated additional subjective data, and records of activity, medication and wellbeing, it allowed insight to be gained into the complex relationship between an individual's drug regime, emotional status and activity level (Figure 7.4, p. 169).

4.7.4 NUMACT sample

Two case study participants declined to be monitored and both were female (Participants 3 and 7 – Tables 4.3 and 4.5), meaning that only one of the six individuals monitored was female. One woman declined fearing the equipment would exacerbate problems with hiatus hernia and diverticular disease, and the other was visiting her husband newly admitted to a nursing home following stroke. She was already aware of people looking at

her due to dyskinesia and freezing in doorways and lifts, and did not wish to draw attention to herself should the monitoring equipment be conspicuous. Individuals monitored ranged in age from 43 to 70, and in duration of diagnosis from 2 - 10 years. A range of Parkinson's disease medication regimes were represented. Monitoring was longitudinal (varying from 6 to 23 months) in 5 out of the 6 case studies, and in 4 participants spanned periods of modification of medication regimes (Table 4.6).

Table 4.6 Medication details for case study participants using NUMACT

P*	Medication 1	Medication 2	Medication 3
1	Eldepryl 1x5mg	Eldepryl 2x5mg	Madopar 2x62.5 mg
2	Eldepryl 1x5mg Celance 2x1mg, 1x.75mg Sinemet-Plus x7 Sinemet CR x1	Eldepryl 1x5mg Celance 2x1mg, 1x500 micrograms Sinemet-Plus x7 Sinemet CR x2	Eldepryl 1x5mg Celance 4x1mg, 1x.25mg Sinemet-Plus x7 Sinemet CR x4
4	Artane 4x2mg, Symmetrel x2		
5	Eldepryl 2x5mg Madopar 4x62.5mg Artane 4x2mg	Eldepryl 2x5mg Madopar 4x62.5mg Artane 4x2mg	
6	Madopar 5x125mg Madopar CR x2	Madopar 5x125mg Madopar CR x2	Madopar 6x125mg Madopar CR x3
8	Sinemet 110 x6 Sinemet CR x3 Eldepryl 2x5mg	Sinemet 110 x5 Sinemet CR x3 Eldepryl 1x5mg	Sinemet 110 x2.5 Sinemet CR x3 Eldepryl 2x5mg

Notes - * See Table 4.3 for details of participants; columns indicate medication regimes reported during monitored period, with P5 experiencing no change

4.8 MAKING SENSE 2

4.8.1 Quantitative analysis of qualitative coding

Analysis of the first two ENCOUNTER 2 interviews plus post-contact notes were undertaken using a QSR NUD*IST type indexing system offline as a pilot prior to a decision to purchase the software. Reading of the transcripts suggested thematic categories and sub-

categories, which were arranged into hierarchical trees of nodes. Each node was given a title and number. Text (transcript page and line numbers) was assigned to a relevant node. Participant number, page and line number and numerical node address were recorded on a coding sheet and entered into EXCEL spreadsheet software (Appendix 3). Memos were written about possible links between categories or uncertainties about coding. A sort was performed to identify all the occurrences of a particular node address. Relevant text for each node was cut and pasted into a document file. In addition to grouping the data, this system allowed the strength of a particular category within each interview and across the interviews to be assessed (Morgan 1993).

Results of this analysis, which were to be important to subsequent activity within the research spiral, included the amount of coding at the node relating to the social consequences of Parkinson's disease. A management model with an emphasis on pathology and impairment was failing to address the psychosocial aspects of the condition. The amount of coding relating to the social consequences of a diagnosis of Parkinson's disease for the partner of the individual highlighted the need to examine the support given to this group. In addition to patterns emerging in the quantitative analysis of coding, the indexing tree facilitated the tracking of emergent qualitative themes, which influenced the aims of strategy mapping (5.3, p. 130). These themes included the concept of life transitions (Moos and Schaefer 1986) and adaptive tasks encountered in managing them; the concept of a chronic illness trajectory (Strauss et al. 1984) and the notion of balancing options for management (Fagerhaugh and Strauss 1977); and the concept of normalisation (Robinson 1993) and its relationship to informal and formal management.

Qualitative analysis using the NUD*IST method off-line illustrated the potential of a conceptually ordered taxonomy to elucidate patterns in interview data. Of necessity a 'fixed' indexing tree was employed. The advantage of using the software package is the opportunity it affords to constantly challenge the indexing tree as new data is added. Restructuring is positively encouraged on the basis of new insights. Quantitative data about manual coding was possible by entry of data into a spreadsheet. NUD*IST software provides statistics about coding to a node each time it is investigated. Following purchase of the software, ENCOUNTER 1 data was reanalysed (4.3.2.1) and results of both off- and on-line analyses used to inform further individual case study analysis.

4.8.2 QSR NUD*IST analysis of Encounter 2 interviews

ENCOUNTER 2 interview data was explored both inductively and deductively as familiarity with the software developed. Within a tree of nodes dominated by life history categories related to symptoms, management and psychosocial consequences, refining those illustrated in Figures 4.1 and 4.2, the theme of uncertainty, common in the chronic illness literature (White and Lubkin 1995), began to emerge strongly from inductive analysis. The node to capture this was entitled 'But is it due to Parkinson's disease?' (Jones et al. 1996a), reflecting the difficulty individuals had in separating out what was due to the condition and what arose from other facets of their lives. This finding was particularly important given the phrasing of the question in the PDQ-39 which asks, "Due to having Parkinson's disease, how often have you experienced the following [difficulties] in the past month?" (Appendix 8). Individuals wondered if some of their symptoms were merely the effects of normal ageing, for example, slowing down mentally and physically, increasing stiffness and aching, deterioration of recent memory. Others had concurrent pathology whose symptoms bore a similarity to Parkinson's disease, such as stiffness and pain due to osteoarthritis. Difficulty sleeping or general slowness were often attributed to long-held traits; for example, "I never was a good sleeper", and "I never was quick silver". So-called Parkinson's disease symptoms such as poor memory, posture and balance and falling asleep during the day were described in spouses and friends. This had the effect of minimising their importance, "We all have that trouble". The interaction of symptoms with lifestyle was noted. One individual wondered whether her symptoms were actually worse when she retired or whether it was because she had lost the "regimentation" of employment. Another queried why she was "virtually normal" when visiting her daughter in America and the Far East. The data indicate how individuals' perceptions of their condition and its complex interplay with other factors over time shape their response to their illness. Listening to how individuals couch their description of their symptoms can sensitise health care professionals to existing belief systems that need to be respected during intervention (6.4, p. 145).

Deductive manipulation of ENCOUNTER 2 data involved the construction of an indexing tree designed to explore the concept of trajectories, or movement over time, relating to the person themselves, the disease itself, other conditions, health and social care management, social life and the carer. The theme of self-management emerged

strongly both from deductive analysis, where it featured within each trajectory, and inductive analysis. This finding built on initial MAKING SENSE 1 and 2 analyses. A return was made to ‘scissors and sort’ when a print out was made of all nodes relating to strategies from different analysis stages and the resulting category structure within this domain was subsequently used to guide reanalysis of ENCOUNTER 1 data (Figure 4.4).

NUD*IST was used again during MAKING SENSE 2 to enable an integrated analysis of all data sources (4.8.6) (Appendix 3).

4.8.3 Scale analysis

4.8.3.1 Self-Assessment Parkinson’s Disease Disability Scale

During piloting, use and analysis of the scale within Cycle 2 a number of areas of concern emerged which had major implications for the development of Cycle 3. The first centred on the aim of the scale. It was intended to be a brief, global rating of self-assessed disability for research purposes (Brown et al. 1989). I contacted Richard Brown to ascertain the reason for requesting that respondents complete the form in relation to how well they would manage without an aid. The research team had evidently wanted an index of “disease state”. They also wanted to exclude differential access to services and advice, e.g. one person might have had a wheelchair provided, another not (Brown 1994). What the SAPDDS scale set out to measure was ‘intrinsic disability’ (difficulty performing an activity without the help of another person or the use of equipment), as opposed to ‘actual disability’ (difficulty with personal or equipment assistance) (Verbrugge and Jette 1994). Much work is undertaken by individuals with chronic illness to overcome intrinsic disability by purchasing labour-saving devices available for the ‘normal’ population as well as mobilising the support of others (Chapter 9). Measuring intrinsic disability is likely to be the focus of professionals working within the medical model of disability, whilst actual disability is likely to be of interest to professionals espousing a social model of disability.

Subsequently Richard Brown (1996, cited with permission) agreed that the term ‘disability’ in the title was probably inaccurate, and pointed to the option of asking

individuals to rate the same item with and without an aid. A copy of all my correspondence with Richard Brown had been sent to Dr Derick Wade for his information. Dr Wade had included the SAPDDS in his book 'Measurement in Neurological Rehabilitation' (1992), with the comment that it needed further evaluation. He replied on the issue of level of measurement as follows (1996, reproduced with permission):

“As a general principle disability scales should ask about how individuals manage in their own environment using any aids that they may have available and that they may use. If one is interested in whether an impairment has been affected by a particular intervention then one should measure the impairment. Disability measures must focus on actual performance”.

Problems also arose in relation to the wording of items due to the lack of operational instructions. For example, 'Brush your teeth' was not perceived to include denture care; 'Pick up an object from the floor' left people uncertain about whether they answered from sitting or standing; 'Dial a telephone' was associated with using a phone with a dial whereas touch pads are the norm. In addition no allowance was made in the scoring for non-performance of items. Individuals may not do the activities included in the scale, or do them in the way the item is worded. For example, they may not travel by public transport if a car is available, and may therefore be unrealistic about how well they might manage on a bus or train. For people who take showers, getting into and out of a bath is irrelevant. Individuals reported alternative strategies for many of the activities in the scale, e.g. purchasing items such as electric toothbrushes to avoid difficult repetitive movements with the toothbrush (8.4.2, p. 190). Richard Brown (1996, cited with permission) agreed that changing the wording of some items was likely to make them more valid. In addition, giving instructions about scoring the item in relation to how well an individual would be able to perform an activity as stated if required, e.g. rating how well they could bath or brush their teeth, even if they normally showered or wore dentures, might be helpful. The author stated that the scale would then measure capability rather than actual functioning. At that time he was not aware of anybody working on improving the scale's psychometric properties. He felt that the scale's popularity - it was being used in a study of Parkinson's disease nurse specialists (Jarman 1998) and had been

used to validate a tremor rating scale (Bain et al. 1993) - was largely due to lack of an alternative.

Some quantitative manipulation was undertaken with SAPDDS data from early case study participants. Differences between disability factors within the scale (gross mobility and fine co-ordination), stage of disease and levels of independence (Langton-Hewer Stage 1 and 2 were classed as independent and Stage 3 and 4 were classed as dependent) were examined using a two tailed Fishers' Exact Test to take account of the small numbers and ordinal nature of the data. Results were not significant. In addition total disability factor scores were plotted against Langton-Hewer stages to explore relationships between the scores. Stages 1, 2 and 3 were independent (defined as scoring <24 for gross mobility, <26 for fine co-ordination and <50 for overall independence) whilst Stage 4 was dependent with scores >24, >26 and >50 for the respective domains. At Stage 2 scores for gross mobility, fine co-ordination and total score occurred at the same point. Gross mobility and fine co-ordination scores became increasingly spread in relation to total score as Stage advanced. Initially fine co-ordination was most problematic but later gross mobility caused most difficulty. Small sample size (n=5), the validity and sensitivity of the SAPDDS to detect change, the allocation of scores to independent and independent categories and the applicability of the years-diagnosed basis of the Langton Hewer staging all compromise statistical manipulation of the data. However the use of this quantitative instrument in a qualitative way to enable tensions between data sets to be explored proved invaluable. The richness of strategies for managing everyday life captured during interviewing were irreducible to a number between 1 and 5 relating to difficulty of the task without describing the use of creative strategies. Use has also been made of SAPDDS scores in the analysis of ambulatory monitoring data (4.8.5).

4.8.3.2 PDQ-39

As with the SAPDDS, use of the PDQ-39 proved problematic. Difficulties related to:

- Distinguishing the effect of Parkinson's disease from normal ageing which they and their peer group were also undergoing (4.8.2). For example, some degree of memory

difficulty is common (question 32), in addition to muscular aches and pains (question 38).

- Not routinely doing activities being rated, for example carrying bags of shopping (question 3).
- Visualising distances in terms of miles or yards. For example question 4 asks about problems walking half a mile, and question 5 about problems walking 100 yards.
- Making a distinction between difficulty dressing (question 12) and problems with buttons and shoe laces (question 13) when the latter is subsumed within the former and may be the only dressing problem.
- Inclusion of questions about interpersonal relationships when the form may need to be completed by a carer due to writing difficulties. Questions in the emotional well being and social support domains are particularly sensitive and the trustworthiness of answers is likely to be threatened if not completed independently. The fact that the scale was validated by postal questionnaire (Peto et al. 1995), with completion by a carer likely, constitutes a threat to validity.
- Distinguishing normal personality traits i.e. being sentimental, from Parkinson's disease symptoms, such as being weepy and tearful (question 19).
- The desire to distinguish between problems with short-term memory (question 32) and memory for events which happened a long time ago, which was often intact.
- Knowing whether feeling unpleasantly hot or cold included hypersensitivity to heat and cold in addition to flushing or shivering episodes (question 39).

Given the marked fluctuations possible it was difficult to find a middle ground that represented the norm. The scale was too long to consider completing for best and worst times. Once again, completion of the questionnaire gave an opportunity to record the ways in which potential problem areas had been addressed by a range of strategies.

4.8.3.3 Impairment rating

There were major problems with the understanding of terms used to describe impairment categories. Individuals were more likely to refer to the hand being less agile than to stiffness itself. Stiffness and slowness were often seen as part of growing older or general demeanour. Freezing was a symptom unknown to many participants. They were confused by the term and when it was explained they asked if that was something they would

experience. Thus administering an impairment scale to individuals not experiencing that particular impairment engendered anxiety about problems they may encounter in the future. Jerking was the supposed lay term used to cover dyskinesia but was sometimes not recognised by individuals with dyskinesia to apply to them. Individuals with late onset disease are not so prone to dyskinesia and the common response was, “I don’t know what you mean by that”.

4.8.4 Ambulatory monitoring with video, diary and questionnaire analysis

Ambulatory monitoring and associated tools were analysed at three levels – at a macro and micro level of activity (Chandler et al. 1996) and in relation to scales (Chandler and Jones 1998). Both within- and across-case analyses were undertaken. Ambulatory monitoring results are included as supportive material in relation to strategy mapping (e.g. Figures 7.4, p. 169, and 7.5, p. 174, and in Appendices 14 and 15).

4.8.4.1 Macro level of analysis

At the macro level of analysis gross patterns of activity over each 24 hour period a participant was monitored were identified. Details of medication regime were recorded during monitoring. Participants were also asked to describe their mood on the monitored day (on a spectrum from depressed to euphoric) and how they were feeling given the ways they were affected by Parkinson’s disease (from very poor to very good). Mean step amplitude was related to diary records of the timing of medication, type of activity being undertaken and subjective rating of well-being (Figure 7.4, p. 169). At a macro level it was also possible to examine 5 hourly time periods against diary records and interview insights.

Longitudinal data collection also allowed comparison of 24 hour activity patterns over time for participants in relation to type of steps taken (short walks, occasional steps and continuous walking were shown as red, green and black areas respectively on data display) (Appendix 14, Figure 1), and the amount of time spent in lying, sitting and standing (Appendix 14, Figure 2). Running NUMACT in a Parkinson’s disease clinic

setting enables the effect of medication change on activity levels to be recorded (Jones et al. 1998b).

4.8.4.2 Micro level of analysis

At the micro level of analysis the fine detail of the accelerometer recording can be examined. For example, accelerometer tracings were related to video recording of concurrent functional activities, such as moving about the home (Appendix 15, Figure 1). Once familiar with the pattern of traces corresponding to parts of the home from video footage, for example stairs and corridors with turns, it is possible to identify participants' movements about their home and garden from 50 second traces. On one occasion ambulatory monitoring coupled with video and accompanying speech provided both objective and subjective evidence of changes in gait (Appendix 14, Figure 3).

4.8.5 NUMACT and scale analysis

The combined use and analysis of activity monitoring and self-assessment scales afforded the opportunity to comprehend more fully the experience of living with Parkinson's disease from the individual's perspective and the self-management strategies that were developed to accommodate to physical and psychological challenges (Chandler and Jones 1998).

For example, when activity in relation to the step amplitude of short walks was compared to data from the PDQ-39, a significant negative correlation was seen with the bodily discomfort domain (Spearman's rank correlation $r=-0.84$, $p<0.05$) (Figure 4.6). This would indicate less vigorous walking as discomfort increased. Questions relating to discomfort include recording the experience of muscle cramps or spasms, and aches and pains in the last month.

Figure 4.6 Relationship of PDQ-39 Bodily Discomfort to mean amplitude of short walks

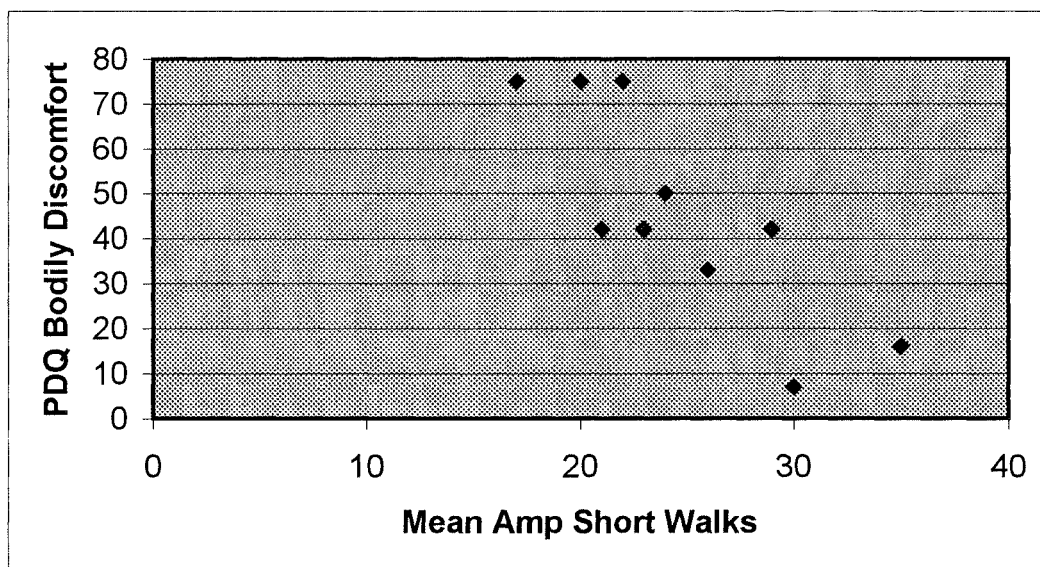


Figure shows mean amplitude of steps for short walks (>20<100 steps) on the x axis and scores in the bodily discomfort domain of the PDQ-39 on the y axis (n=6 participants)

Ambulatory monitoring also provided a tool for individualised assessment. One participant who was experiencing marked on-off fluctuations recorded the level of self-assessed fluctuations during 24 hour monitoring using a visual analogue scale where 1 equated to being fully 'on' and 10 to being fully 'off' (Figure 4.7). Activity diary records were also available. The lower the step amplitude, the greater the level of 'off', and the less the individual was able to accomplish in terms of everyday activity.

Following presentation of this pilot work using NUMACT to monitor activity in Parkinson's disease, Roche Pharmaceuticals funded a computer to enable a database of Parkinson's disease patients to be compiled within a local NHS Trust to allow tracking of a range of outcome measures including NUMACT over time. NUMACT is currently being used in clinical practice, alongside a range of other measures, to monitor effects of initiating and changing drug therapy, assessing the stability of drug management and as an aid to diagnosis by providing evidence of response to levodopa (Jones et al. 1998b).

Figure 4.7 Relationship of mean amplitude of step to visual analogue rating of 'on-off'

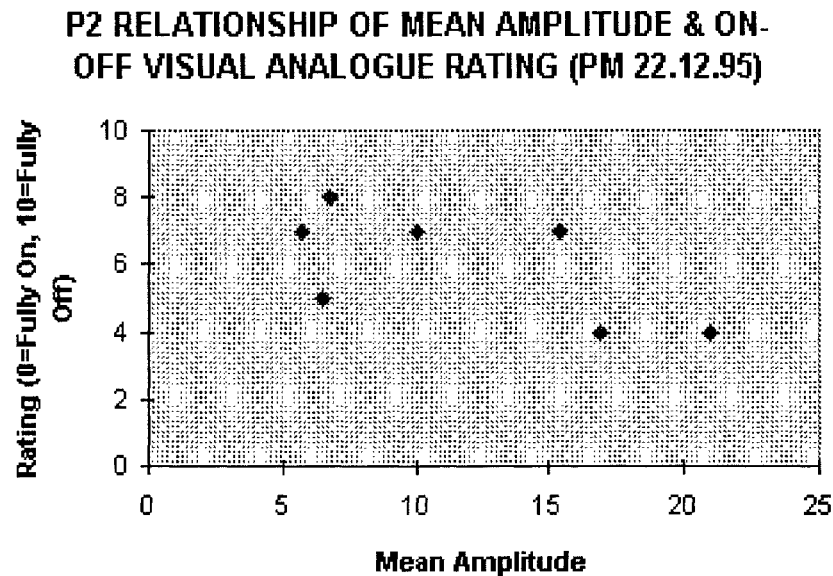


Figure shows mean amplitude of step on the x axis and rating of 'on-off' on the y axis. Monitoring undertaken over an afternoon/evening period

New versions of NUMACT are currently being developed. A monitor the size of a hospital bleep with a belt clip and 2 leads has been developed. This includes a patient input module, which is capable of recording ratings of parameters such as pain or on-off phenomena throughout the day. It is also capable of accepting 3 additional inputs, e.g. 3 lead ECG, airflow nose clip. European Union funding has been gained to further develop the equipment to site it within a chest harness, with a garter incorporating the thigh sensor with no wire attached, and a wrist watch for patient input. This work is being taken forward by a consortia of academic, health and manufacturing partners.

4.8.6 Integrated analysis

In order to move towards an integrated analysis of individual case study data sources a synthesis format was devised using the structure of the SAPDDS and PDQ-39 and performed in relation to two participants. A document format was designed which was amenable to indexing, searching and theorising within NUD*IST (Appendices 3 and 4). Each question in each scale was recorded together with the self-assessed score assigned to

it and my researcher-assessed score if appropriate. All the data sources were given a code relating to their data type and when collected (Table 4.5). For example, material from first interviews were coded Note 1, post-contact notes Note 2, with abc etc corresponding to data collection episodes in Table 4.5. Relevant insights from different data sources were recorded against each scale question as appropriate. Whilst preparing integrated analysis documentation, self-management strategies recorded within the various data sources in relation to emerging categories (Figure 4.4) were noted on a separate form. This comprised the first attempt to formally map strategies, the technique that will be the subject of Chapter 5.

The integrated analysis documentation was introduced into NUD*IST. An indexing tree was constructed and documents and insights into each question assigned to appropriate nodes using command files (automated search instructions). Use was then made of NUD*IST's searching and theorising capacities to interrogate the data. An example of a MATRIX INTERSECT search will be presented. This was used to qualitatively cross-tabulate each question within the PDQ-39, together with insights from other data sources, by values assigned to self-assessed frequency of experienced difficulty due to Parkinson's disease in relation to each question, for each completion of the scale. The aim was to examine data that may confirm or conflict with or illuminate that self-assessment.

Question 2 of the PDQ-39 relates to having difficulty looking after your home, e.g. DIY, housework, cooking, in the last month. Participant 1 recorded **Never** having difficulty in this respect on first administration of the scale. However the integrated analysis format allowed his answer to Question 9 to be identified as an illuminating data source. Whilst answering in relation to fear of falling over in public he had recounted an incident within the past month in relation to difficulty with DIY:

“You know the big tree outside ... I put the lights around for Christmas ... And I had to stand on the tall steps and I had to stand right on the top step and you ... I was just a little bit worried, but er ... More so because you realise you're getting older and you know that if you had a fall it could be nasty”.

Throughout all the interviews with Participant 1 there was a strong tendency to normalise his difficulties in relation to those expected within his age group. On second administration of the PDQ-39 with Participant 1 he recorded **Never** for Question 7 relating to difficulty getting around in public. A similar response had been recorded on first administration, although he confessed to backache walking in the local shopping mall. At that time his wife minimised his difficulty by saying friends felt the same, his grandfather had been stooped and, “It’s really nothing, nothing to do with this [Parkinson’s disease], is it?” Integrated analysis allowed speech recorded during the videoing of functional activity with NUMACT recording to illuminate his answer on second administration. Participant 1 said I was getting the wrong impression videoing in the morning. If I had seen him in the afternoon walking around the Metro Centre he would have been walking like an old man, tired, with back ache, and needing to straighten up.

Investigating the tension within the data sets in relation to assignment of scores allowed the identification of strategies in relation to difficulties with activities such as mobility, eating, dressing, writing and being with other people. This focus on the client centred problem solving, and the implications it could have for physiotherapy intervention, was taken forward into Cycle 3.

Miles and Huberman (1994) identify three levels of qualitative-quantitative linkage, each of which has been employed in this study (Appendices 3 and 4). The first is “quantizing” where qualitative information can be counted directly or converted into scales. The use of a spreadsheet to perform a sort on a qualitative coding frame (4.8.1) provides an example of “quantizing”. This is a way to collect quantitative data in terms of categories which are not imposed initially by the researcher but created inductively via analysis (Bryman 1988). Their second level of linkage is between distinct data types. Here qualitative information is compared to numerical data. Examples of this linkage with the current study are the comparison of disability and quality of life scales responses with textual data in the same domains from in-depth interview (current section). Another example would be the mapping of feelings about wellbeing onto amplitude of step from ambulatory monitoring (4.8.4.1). The third level of linkage involves multi-approaches. In

this study a framework for mapping strategies developed within a case study approach was subsequently tested in practice using an action research approach.

4.9 RESEARCH CYCLE 3

The aims of Cycle 3 were to investigate the effect on physiotherapy intervention in Parkinson's disease of a focus on client strategies, and the challenges that focus would pose for the traditional practitioner-patient relationship (Table 2.7, p. 60). A professionalising/empowering action research approach was utilised (3.5, p. 76). Because of the recursive nature of action research the principal methods employed within each phase of Cycle 3 were introduced with the methodological discussion and detailed in Table 3.4, p. 81. Unlike other sections within this chapter which have presented results which have influenced subsequent methods, the results of research Cycle 3 - the development, insights and implications of strategy mapping for physiotherapy practice and research - form the subject of the remaining chapters of this thesis. Therefore this section will review the participants in the action research process and review the methods used to undertake the process (Table 4.1).

4.9.1 Participants

There were three types of participants in the action research cycle: researcher practitioner (myself); practitioner researcher Sheila Harrison (undertaking a randomised control trial of a targeted physiotherapy service); and the sample population involved in the trial. The author's background was detailed in Chapter 1. The collaborating practitioner researcher had been qualified as a physiotherapist for twenty years. Her practice had been centred in the areas of mental health, care of the elderly and community delivered care. She was undertaking a study of the role of physiotherapy in the management of all stages of Parkinson's disease (Chandler and Plant 1999) (Figure 1.2, p. 5). Study subjects were recruited from a regional movement disorders clinic and an associated outpatient clinic in a neighbouring Trust. Table 4.7 details base characteristics of the population from which strategy maps were collected.

Table 4.7 Details of sample population for strategy mapping in Cycle 3

	Control Group	Active Group
Numbers of patients	35	32
Sex – female	12	14
male	23	18
Mean age – female	63 years	67 years
male	66 years	65 years
total	65 years	66 years
Langton-Hewer Stage		
Stage 1 diagnosed <2 yrs	10	11
Stage 2 diagnosed 2-4 yrs	5	6
Stage 3 diagnosed 5-9 yrs	8	6
Stage 4 diagnosed >10 yrs	12	9

(Chandler and Plant 1999)

4.9.2 Strategy mapping

Patients were randomised into control or active groups following initial assessment (Figure 5.2, p. 134). Strategy maps were constructed for both active and control groups at three monthly intervals over the course of the one year study from initial to 12 month assessment, giving a potential maximum of five maps per patient (potential total n=335). However a number of patients withdrew from the trial for a variety of reasons, including concurrent ill-health, the ill-health of a spouse or moving away from the area. Table 4.8 details the numbers of strategy maps prepared in each of the Langton-Hewer stages for control and active groups.

Table 4.8 Numbers of strategy maps prepared in each Langton-Hewer stage for control and active groups

Langton-Hewer Stage	Control	Active
Stage 1 diagnosed < 2 yrs	47	52
Stage 2 diagnosed 2-4 yrs	15	26
Stage 3 diagnosed 5-9 yrs	38	29
Stage 4 diagnosed >10 yrs	48	38
Total	148	145
Total number of strategy maps		293

4.9.3 Collaborative reflection

Regular reflection, in the form of joint conversations face to face or on the telephone, or in written notes to one another, was the principal method employed between research practitioner and practitioner researcher throughout the action research process. The themes covered related to the phase of the research cycle. For example in THINKING 3 the focus was on sharing the backgrounds we brought to the current project. In PROJECT 3 we shared our knowledge bases in relation to the management of chronic illness in order to formulate the tentative explanatory principles we would explore in ENCOUNTER 3 (Table 3.3, p. 79). This was a stage of reflection on action as we reflected on how strategies were being gathered from the practice situation and how they might be incorporated into intervention. Reflection here was an opportunity to explore the tensions of being a practitioner researcher within a randomised control trial. For example, the inability to intervene with control group patients experiencing problems that were not being acknowledged by the professionals involved in their care was particularly difficult. At MAKING SENSE 3 we shared our interpretation of the domains within the strategy map. COMMUNICATION 3 required reflection on how best to communicate the process we were undertaking. At BEING 4 it was important for us to reflect on the tensions as we both moved from research to clinical work.

4.9.4 Peer group consultation

Visits were arranged jointly and singly to clinical colleagues practising in the area of chronic neurological disease management. In addition a forum group of senior physiotherapists was convened to discuss approaches to goal setting. Colleagues (n=7) from clerical and professional backgrounds in health and education, who were unfamiliar with Parkinson's disease and the research project, were invited to categorise 34 strategies collected during the early stages of strategy mapping into areas of the strategy map and to comment on the framework. Operational definitions were supplied. As some strategies were composite and fitted a number of areas, up to three areas could be used for any one strategy. Respondents' overall totals for correct placement occurring within the three options ranged from 25-32 out of 34 (74-94% - mean 82%). The map and operational definitions were subsequently developed further to enhance reliability.

4.9.5 Feedback to and from participants, professionals and lay groups

A number of individuals were visited jointly by the researcher practitioner and practitioner researcher to enable the process of strategy identification within a therapeutic encounter to be investigated. Both audio and videotaping of therapist/patient encounters were made and subsequently evaluated. Towards the end of the project a number of individuals were visited again by both researcher practitioner and practitioner researcher to assess the impact of strategy mapping on intervention.

Permission was gained to use an address to a professional group, the Association of Physiotherapists Interested in Neurology, as a feedback session on the outputs of the project. Likewise an address to one of the branches of the PDS involved in ENCOUNTER 1 allowed feedback of results.

A range of other feedback opportunities were taken (Table 3.4, p. 81) which included joint teaching of undergraduate physiotherapists using data from the project; presentation of methodological development within a health practice development seminar series (Clarke 1998); in service physiotherapy training sessions in local Trusts; talks to local PDS groups; and poster and oral conference presentations (Appendix 1).

4.10 Summary

This chapter has presented the range of research methods, associated data types and analysis strategies employed over the course of the three research cycles making up the project. Key results that have had impact on the development of later cycles have been reported. The theme of linking qualitative and quantitative elements at most methodological steps, introduced in Chapter 3, has been developed. In addition the movement backwards and forwards between data sets as analysis strategies and theoretical understanding developed has been charted. Chapters 3 and 4 have set out the conceptual genesis of strategy mapping. The remaining chapters of the thesis will examine strategy mapping as a process; what has been learnt about life with Parkinson's

disease from mapping strategies; the implications of using strategy mapping within physiotherapy practice; and the implications for future research.

5 Strategy mapping: background and process

5.1 Overview of chapter

Early results of Cycles 1 and 2 of the research spiral indicated the emerging importance to optimum physiotherapy practice of understanding the work individuals do themselves to manage Parkinson's disease. The concept developed within this project to capture self-management undertaken by individuals was strategy mapping. This chapter describes how the concept of strategy arose within this project, outlines how categories for mapping came to be structured within the final map and sets out their operational definitions. The aims of strategy mapping will be examined. The process of strategy mapping in clinical practice will be presented. Chapters 6 –10 will go on to explore and discuss each area of the strategy map in turn.

5.2 Developing a concept of strategy and strategy mapping

Examination of the literature in relation to physiotherapy practice in Parkinson's disease (Chapter 2) revealed a fault line in part of the evidence base, which resulted in a mismatch of levels at which aims of intervention studies were articulated and outcomes were measured. A similar potential mismatch was identified in relation to practice, with therapists directing attention to remediation of isolated actions and activities whilst individuals sought integrated solutions. A focus on self-management, minimising symptoms and maximising participation, was proposed as a way of understanding the pursuit of integrated solutions in individual's lives. It was proposed that the success of professional management might be judged by the extent to which it was absorbed into self-management strategies.

Chambers Concise Dictionary (1991) defines strategy as “generalship, or the art of conducting a campaign and manoeuvring an army”. In the Concise Oxford Dictionary

(1982) a strategy is an “instance of, or plan formed according to [mounting a military campaign]”. Other terms for strategy in Roget’s Thesaurus (1982) are ‘tactics’, ‘plan of campaign/attack’ and ‘procedure’. All definitions and terms imply a mustering of resources and applying them to best effect. It has been suggested that ‘strategy’ should refer to how people with health conditions mobilise resources to maximise favourable outcomes (Bury 1991). The nature of coding to self-management nodes within the NUD*IST taxonomic structure (Figure 4.4, p. 95) was in accord with this. The concept of strategy within this project took shape over time, and the following definition was articulated:

Strategies are the current end-point of a dynamic decision-making process about the deployment of a wide range of resources – including physical, cognitive, social and medical resources – in response to the challenge of life with Parkinson’s disease.

Having identified the centrality of self-management strategies in the lives of individuals with Parkinson’s disease and defined the concept of strategy, the next stage was to investigate the implications of this understanding for physiotherapy practice. A mechanism to capture understandings about self-management was developed through the identification, or mapping, of individuals’ self-management strategies. A definition of the concept of strategy mapping was developed:

Strategy mapping is a framework for locating how individuals use the resources available to them to approach issues that may arise in everyday life as a result of Parkinson’s disease, and for recording the meanings they attach to decision-making about their deployment.

A strategy map (Figure 5.1) was devised based on NUD*IST categories and sub-categories and developed as data was collected and analysed during Cycle 3 (Table 3.4, p. 81 and 4.9, p. 121). Operational definitions for each main area and its related sections were constructed to guide the incorporation of data. Interestingly the final configuration of the strategy map changed even during the writing of the thesis. Most significantly the **MOBILITY** section, which had been included in the **ROUTINES** area,

was moved to the **INVOLVEMENT** area as a greater understanding of the need to consider the context and the meaning of mobility strategies became apparent (Chapter 10).

Figure 5.1 Strategy Map

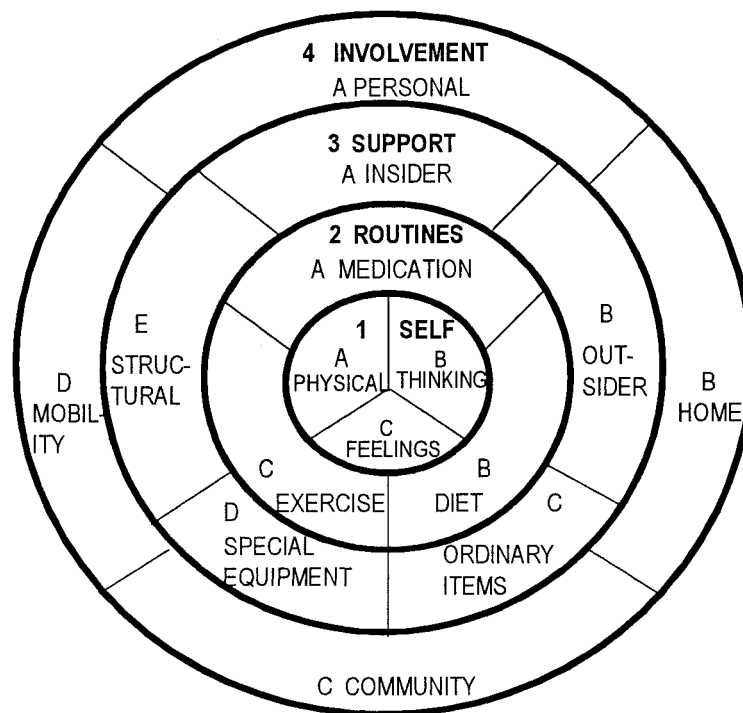


Figure illustrates the four areas of the strategy map, each divided into a number of sections

The operational definitions for each area and section of the map are as follows:

The **SELF** area (1) of the map records strategies that draw upon the physical and cognitive resources of the individual themselves to counteract specific symptoms and to approach life with Parkinson’s disease. The **PHYSICAL** section (1A) records strategies that reduce the effect of specific symptoms through the use of another part of the body, for example, *clamps hands between legs to reduce tremor*. The **THINKING** section (1B) records strategies that reduce the effect of specific symptoms through conscious thought for example, *says “ready, steady, go” in head to overcome freezing episodes*. The **FEELINGS** section (1C) of the map records strategies that make sense of, and develop an approach to, living with Parkinson’s disease (which may be explicit or inferred), for example, *feels he has to do something worthwhile every day otherwise life is not worth living*.

The **ROUTINES** area (2) forms the second ring of the strategy map and records regular patterns of behaviour in relation to activity concerned with maintenance of body functioning. The three areas to emerge as important in relation to **ROUTINES** were **MEDICATION**, **DIET** and **EXERCISE**. The **MEDICATION** section (2A) of the map records strategies relating to the use of medication for Parkinson's disease and other conditions, for example, *increasing use of Pergolide to reduce motor fluctuations*. The **DIET** section (2B) of the map records the use of strategies relating to diet and eating patterns, for example, *increased intake of fruit to help with problem of constipation*. The **EXERCISE** section (2C) of the map records strategies relating to the incorporation of regular exercise into daily life, for example, *plays the piano each morning to get right hand going*.

The **SUPPORT** area (3) records strategies relating to external support provided by a range of individuals, services, items and environments. Receiving **SUPPORT** can be viewed positively or negatively by individuals themselves. The **INSIDER** section (3A) of the map records support from individuals with an emotional link to the individual – family, friends and acquaintances, for example, *husband has taken over the cooking, "He even chases me out of the kitchen"*. The **OUTSIDER** section (3B) captures input from health and social care professionals, statutory and non-statutory agencies and the wider business community, for example, *hairdresser comes to house once a fortnight*. The **ORDINARY ITEMS** section (3C) reports the use of everyday household items to sustain activity, for example, *uses liquid soap rather than bars of soap to minimise repetitive movement of rubbing hands together*. The **SPECIAL EQUIPMENT** section (3D) reports the use of items specifically designed to reduce disability, for example, *uses a wheeled frame in the home to increase stability*. The **STRUCTURAL** area (3E) reports decision-making about the nature of the built environment to support activity, for example, *removed kitchen door to minimise freezing problems*.

The **INVOLVEMENT** area (4) of the strategy map records strategies relating to the undertaking of everyday activities within the full range of social settings, encompassing the home and the wider community. It is concerned with identifying the complex inter-relationships between the performance of the activity itself, the context within which it is undertaken and the meaning that involvement in that activity has for individuals. The

PERSONAL section (4A) records individuals' strategies in relation to personal hygiene (bathing, toileting, grooming), dressing, eating and drinking, for example, *lets hair dry naturally as difficulty holding hair dryer*. The **HOME** section (4B) records strategies in relation to household management (cooking and cleaning), communication (writing and telephone), hobbies (reading, DIY, gardening etc.) and socialising with family and friends, for example, *making excuses about it being inconvenient to child-mind the grandchildren as increasingly anxious about ability to handle them*. The **COMMUNITY** section (4C) captures strategies in relation to socialising outside the home, shopping and paid employment, for example, *planning holiday abroad in apartment overlooking pool area so able to watch all the activity from the balcony*. The **MOBILITY** section (4D) records strategies concerned with moving about within the home - walking, stairs, transfers into and out of chairs and bed mobility – and outside the home – including using public transport and cars, for example, *often needs to sway backwards and forwards several times to stand up from easy chair*.

5.3 Aims of strategy mapping

The aims of strategy mapping in Parkinson's disease, like the specific sections of the strategy map, were proposed, reworked and refined between the author and collaborating researcher-practitioner during reflection before, during and after the undertaking of Cycle 3 (Table 3.4, p. 81 and 4.9.3, p. 123). Ten aims were identified:

1. *to help physiotherapists, and potentially other health and social care professionals, take a person-centred view of life with Parkinson's disease*

Strategy mapping aims to help professionals approach individuals with Parkinson's disease as individuals first and foremost rather than having the diagnosis as the focal point in the interaction. By focusing on self-management undertaken within the framework of a unique constellation of resources, and on attitudes to their deployment, professionals are encouraged to negotiate an individual intervention that builds on existing work and maintains a balance in individual's lives.

2. to acknowledge the work that individuals undertake to manage their condition

Disease management has traditionally been thought of as a professional activity involving prescribing and reviewing regimes of, for example, medication or exercise. Under this view management can be restricted to the biomedical consequences of the disease. Long-term illness has psychological and social consequences that require emotional work, and professional regimes, which may not be reviewed with any frequency, often need to be adapted by individuals to make them applicable to everyday life. Working to overcome the consequences of the condition is a daily reality. If professional regimes are to be congruent with everyday reality the extent of work undertaken both by the individual and the people around them must be acknowledged and taken into account.

3. to appreciate the existing balance individuals have in place in their lives to match their capabilities to the demands placed upon them

Unless referral takes place during an acute episode such as a fall or infection, there is likely to be a degree of balance in the individual's life. Biomedical interventions are often structured largely around increasing the capability of the individual through restoration and remediation (Ward 1992). Much self-management relates to decreasing the demand of tasks. Strategy mapping has been designed to enable health and social care professionals identify the existing balance between capability and demand (Verbrugge and Jette 1994) in order to negotiate their input in such a way as to enable continued balance, albeit potentially structured in a different way.

4. to identify the resources available to individuals and how they are deployed

The range of resources which individuals can draw on includes their own personal resources, for example the physical resource of strength; the emotional resource of an optimistic personality; the social resource of family and friends; and material resources related to income. It also encompasses resources available in the local community, which includes health and social care in addition to business and local services. Strategy mapping enables resources to be charted but also attitudes to resource use to be identified. For example, friends may be keen to take an individual out for social occasions, however individuals may feel unable to use this resource because of embarrassment about poorly controlled symptoms such as tremor or slowness of movement.

5. to take cognisance of the contribution of significant others

The current workload being borne by the people around the individual with Parkinson's disease needs to be acknowledged. For example, a spouse may be keen to help with personal care but an individual may be reticent, fearing it would lead to a change in their relationship. This sort of insight is important for professionals to gain, especially if their intervention is aimed at adding to the support the spouse will be giving to the individual.

6. to aid communication of role and networking with other health and social care agencies

Strategy mapping encourages the identification of all agencies involved in the care of the individual. Individuals are often confused about the nature and roles of the professionals involved (Yarrow 1999; Plant et al. 2000). Good communication about the extent of a professional's scope of practice, both with the individual and other involved professionals, should aid realistic expectations (Chesson et al. 1996) and reduce duplication of assessment and intervention.

7. to acknowledge the individual's knowledge base and help lay the foundations for partnership in learning about management

There is an increasing information base directed at individuals with specific conditions such as Parkinson's disease, including Internet resources (PDS 2001; Awakenings 2001). Individuals seeking health information are being taught how to evaluate its relevance and robustness (DISCERN 2001). The concept of the 'expert' or 'informed' patient is emerging, with individuals deciding what course of health action to take after considering all available options (Illman 2000). Strategy mapping aims for a partnership model by addressing the issue of power in relation to knowledge bases, to allow the flow of information and learning between individuals and professionals (11.5, p. 278).

8. to identify areas where strategies can be supported, modified or developed uni-professionally or multi-professionally

Individuals with Parkinson's disease have often had symptoms of the condition for some time prior to diagnosis or referral to health or social care professionals. They have developed ways of counteracting their symptoms and routines in relation to activities that help them fulfil the roles they need to undertake. Each will have approached their condition in a unique way. Strategy mapping can help professionals recognise the strategies individuals are using to manage the challenges of living with the condition. This is an important starting point for supporting or modifying existing strategies and identifying areas where new strategies might help.

9. to link with frameworks to aid professional understanding (e.g. models of disability), assessment (e.g. outcome measures) and intervention (e.g. goal planning)

Strategy mapping enables professionals to structure the myriad of information about self-management that is obtained over the normal course of narrative during intervention. It does not require special questioning, although that may be possible if, on completing a map, it is noted that there is no information in a particular section. What it does do is enable this information to form links with models such as ICIDH-2 (WHO, 1997); with potential outcome measures such as patient diaries (Yekutieli 1993); and with mechanisms to plan and assess intervention such as goal planning (Wade 1999).

10. to enable sharing of strategies with other individuals and professionals

One of the reasons given for enjoying group sessions for Parkinson's disease is the ability to hear how others have solved everyday problems (Plant et al. 2000). Focusing on self-management enables individuals to share strategies with professionals and hear about strategies being used by others. Mutual learning occurs between individuals and professionals, with the professionals providing a conduit between individuals. This has the potential to be a seedbed of ideas about potential items of equipment or insights into new therapeutic approaches (11.4.2, p. 269).

5.4 Process of strategy mapping

A Users' Guide to strategy mapping was prepared prior to its use in Cycle 3. The development and concept of strategy mapping was explained, and the aims of strategy mapping were articulated. Examples were given of the areas in everyday life that could pose challenges for individuals and information on the types of strategies to include in each area of the map was provided. How to write strategies was explained, and involved stating what the strategy was, and if appropriate why it was being carried out. A form for recording strategies was provided which included sections corresponding to parts of the strategy map, a column to note the problem area the strategy was addressing that related to physiotherapy e.g. *gait*, and another column to note possible intervention e.g. *conscious cue to overcome freezing*. A strategy may be illustrative of the same resource use but have different meanings in relation to different areas of the strategy map and so may be noted a number of times. For example, if the help of a spouse was required for turning in bed, this would be noted in the **SUPPORT/INSIDER** section and the **INVOLVEMENT/MOBILITY** section. Appendix 11 provides examples of strategies collected during an initial physiotherapy assessment.

Figure 5.2 Strategy mapping within targeted physiotherapy trial

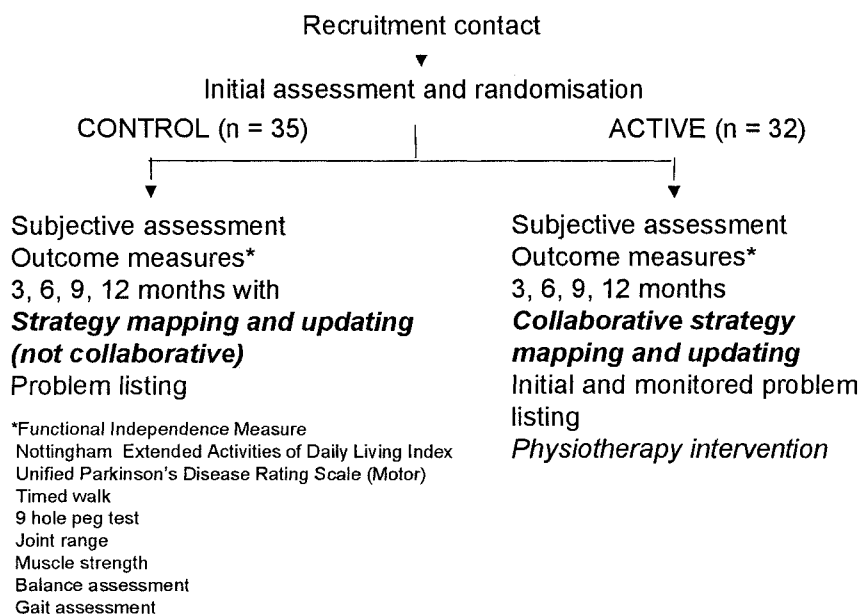
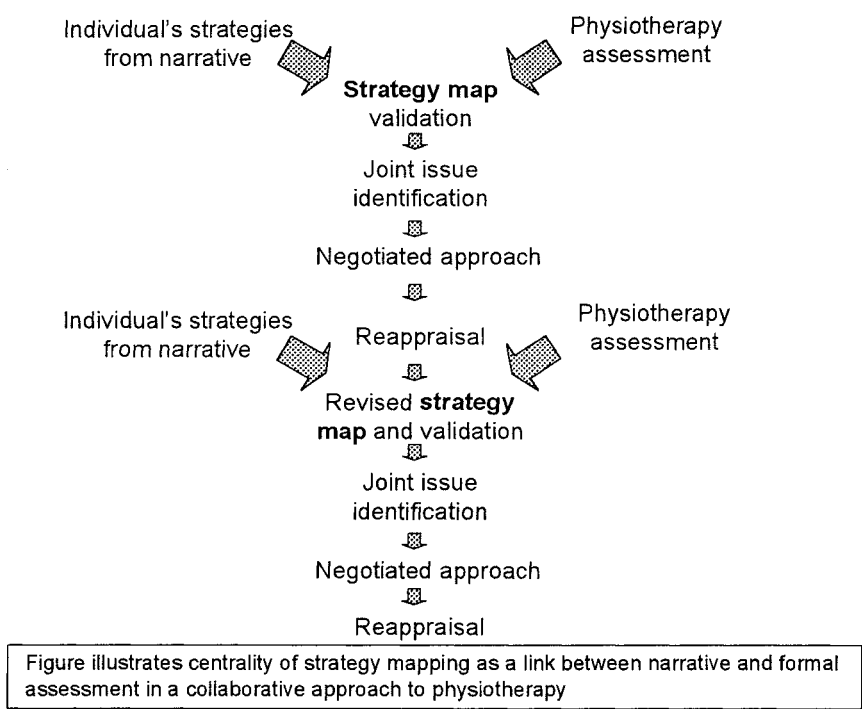


Figure illustrates methodology employed in RCT of targeted physiotherapy service (Chandler and Plant 1999)

Strategy mapping was employed in a randomised control trial of a targeted physiotherapy service (Chandler and Plant 1999) (4.9, p. 121). Patients were randomised into control or active groups following initial assessment (Figure 5.2). A battery of standardised outcome measures was employed at three monthly intervals with both groups. In addition subjective accounts of life with Parkinson’s disease were recorded. Self-management strategies were identified both from narrative accounts and qualitative insights recorded as notes during the quantitative measurement of standardised outcome measures. This data provided the material with which to construct strategy maps for both active and control group participants, however maps were only shared between the therapist and individuals in the active group. The assessment-only interaction with the control group set against the potential for meaningful working and learning relationships with the active group placed considerable stress on the physiotherapist involved in the trial. Collaborative reflection (4.9.3, p. 123) provided a place for tensions to be surfaced and explored.

Figure 5.3 Strategy mapping within a collaborative approach to physiotherapy



With the active group the therapist sought the individual's input to validate the map at the next treatment or assessment visit (Figure 5.3). Viewing the strategy map enabled individuals to see how they were problem solving in relation to life with Parkinson's disease. The therapist was able to feed back to the individual the results of objective assessment that related to the map. A collaborative focus on the map enabled therapist and individual to discuss the congruence of solutions already being employed by them with issues identified from assessment. Negotiation was then possible in relation to therapeutic approaches devised to endorse or support successful strategies, modify less successful ones and introduce and monitor new strategies. The major difference between strategy mapping and a conventional assessment and intervention approach - made up of history taking, physical examination, physiotherapy diagnosis, treatment plan, treatment, evaluation and reporting (Hendricks et al. 2000) - is the emphasis on grounding and negotiating intervention based on existing self-management work.

5.5 Summary

This chapter has detailed the concept, aims and process of strategy mapping. By analysing all the strategies recorded in each section of the four areas of the map for all individuals involved in the targeted physiotherapy trial, control and active groups, it has been possible to build up a picture of the nature of self-management work within each section over all stages of the condition. This overall perspective will form the basis of Chapters 6-10. The impact of physiotherapy involvement, identified through qualitative differences in strategies between the two groups, will be noted. At the end of Chapters 6, 7, 8 and 10 there will be a discussion of the implications of the results relating to each specific area of the map for physiotherapy practice and research.

6 Strategy mapping: SELF strategies

6.1 Overview of chapter

The **SELF** area of the strategy map (Figure 6.1) records strategies which draw upon the physical, cognitive and emotional resources of the individual to counteract specific problems and to approach life with Parkinson's disease. The **PHYSICAL** section records strategies that reduce the effect of specific symptoms through the use of another part of the body. The **THINKING** section records strategies that reduce the effect of specific symptoms through conscious thought. The **FEELINGS** section records strategies that make sense of, and develop an approach to, living with Parkinson's disease.

Figure 6.1 Strategy Map: SELF area

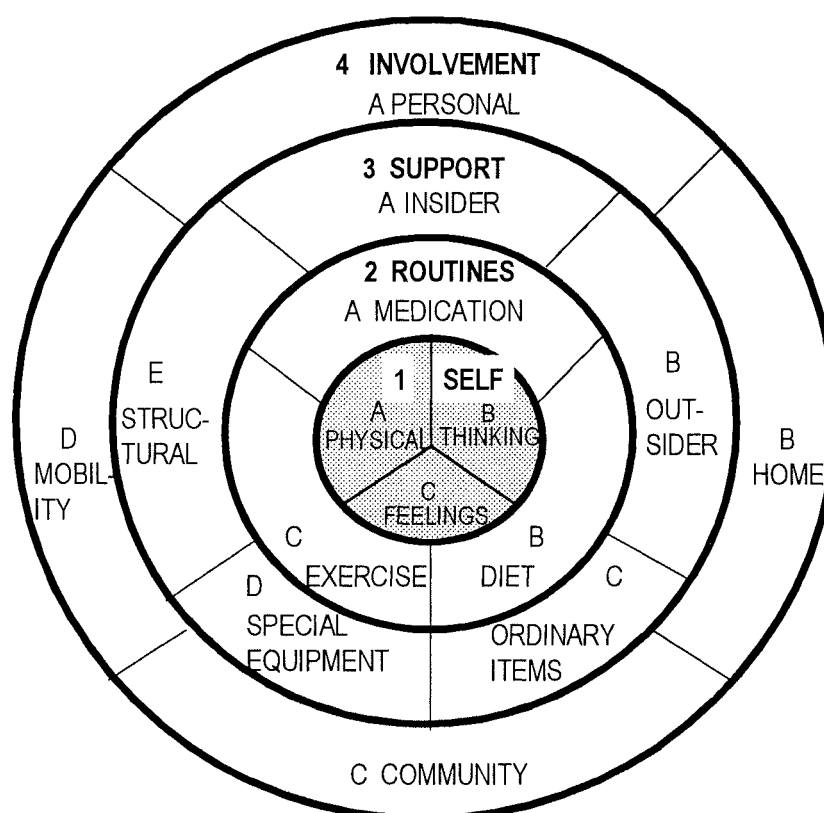


Figure illustrates the four areas of the strategy map, with SELF area highlighted

SELF strategies, in addition to **ROUTINES** (Chapter 7) and **SUPPORT** (Chapter 8) strategies, come together within the context of everyday activities to contribute to **INVOLVEMENT** strategies (Chapters 9 and 10). Recording them separately within the strategy map has enabled discrete areas of self-management work undertaken by individuals to be exposed. The strategies presented in this and the following chapters were identified from the strategy maps of **all** individuals in the targeted physiotherapy trial population, unless stated otherwise. Differences in self-management work between control and active groups, suggestive of the impact of physiotherapy, will be noted. Use will be made, at the end of each section, of material from Cycle 2, the individual case study phase, to provide examples of the lived experience of strategies. The final part of each chapter will discuss the implications of strategies from the specific area for physiotherapy practice and research.

6.2 SELF/PHYSICAL Strategies

The main focus of **PHYSICAL** strategies, which draw on the physical resources of the individual themselves to counteract specific symptoms, centred on the control and disguise of symptoms that would draw unwelcome attention to the individual in social settings. The main stigmatising symptom was involuntary movement. Similar strategies were employed in the early stage in relation to tremor as were encountered later on in the disease course when dyskinesias were likely to be a corollary of increasing levodopa therapy (Figure 6.2).

Figure 6.2 SELF/PHYSICAL strategies

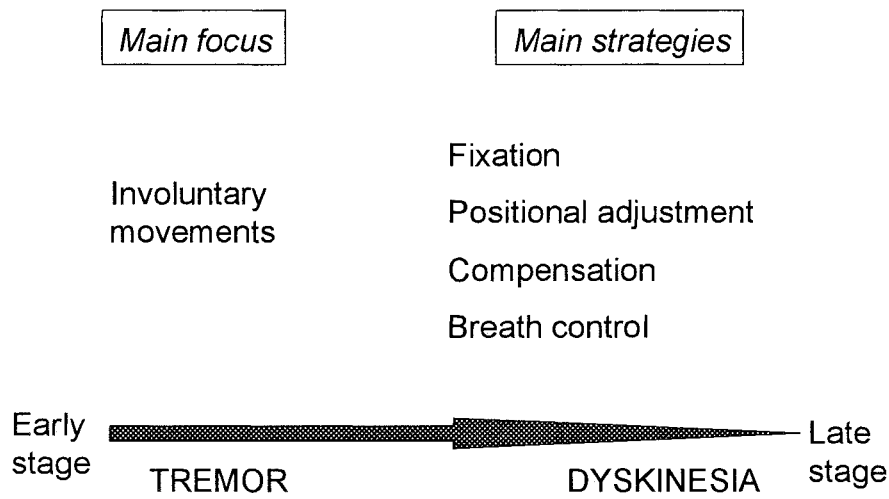


Figure illustrates the main focus and strategies in SELF/PHYSICAL area. Arrow highlights the stability of focus and strategies over time, with differing early and late stage emphases

Fixation was employed to control or disguise the presence of too much or too little movement. Too much movement resulted from tremor and dyskinesia whilst too little resulted from akinesia, in this context the obvious loss of arm swing during walking was the symptom requiring disguise. Tremor or dyskinesia in the upper limb could be approached by clasping hands on the lap or behind the back; placing hands on or between the knees; placing hands on top/above/in front/behind the head; sitting on hands; inter-linking fingers; and holding the wrist of the affected limb with a hand. Arms could be folded; the affected arm could be nursed; and the whole arm or the elbow could be held in to the side of the body.

Weight bearing through the upper limb was employed to still movement. This was achieved by placing weight through the heel of the hand with fingers extended or by leaning forwards onto elbows. Chairs afforded opportunities for stabilisation and disguise. Hands were tucked under chair cushions. Arms were rested on or slotted under chair arms. Chair arms and the edge of the seat could be held or gripped. Sitting on the floor with the back against a sofa and arms outstretched offered fixation to control dyskinesia in the later stages.

In relation to tremor or dyskinesia in the lower limb, pressure could be applied to the affected foot with the unaffected foot. The affected foot could be gripped by a hand. Overpressure could be applied to the knees via the hands, or the knees or a flexed leg could be held or legs crossed. Sitting on a chair or the floor in cross-legged sitting or lying on the floor was also employed. The fixation strategy for loss of arm swing was to hold the arm in to the side of the body. The concept of stability in the self-management of Parkinson's disease emerged as central to the involvement strategy model to be discussed in Chapters 9 and 10.

Constant readjustments to sitting position; transferring weight and "stiffening up" if standing; and making a voluntary movement, such as stamping a foot, were strategies employed in an attempt to overcome involuntary movements. Extending or abducting the arm and trying "to go with the shake" and exaggerate it in the hope of reducing the involuntary movement were recorded.

Increasing difficulty with dexterity and tremor in the most affected upper limb was compensated for by use of the least affected limb or by the use of two hands for a previously one-handed task, such as carrying a mug. As with stability, the concept of compensation emerged as a key factor within the involvement strategy model (Chapter 9). Deep breathing for the control of tremor was reported. Strategies for the control and disguise of drooling were also evident and centred on increased swallowing and holding a hand in front of the mouth.

The full range of **PHYSICAL** strategies was evident from the early to late stages of the condition and there were no differences in reported strategies between the control and active groups.

A 70 year old female participant in Cycle 2 provided an insight into the exhausting experience of living with poorly controlled tremor and its socially stigmatising nature, which makes control and disguise so desirable:

“... and when I look at other people I think, “Eh, they’re sitting lovely and comfortable in their seat,” you know. I think, “Why can’t ... [I]? ... People say, “Well, why do you sit in the ... back seat [of the church]?” but I don’t think they understand. I thought to meself, “Well, if I were sitting in the back seat and somebody in the front of us was sitting with what I’ve got, they wouldn’t be able to keep still either”. Because I’ve looked around and there’s nobody sort of, everybody’s sitting there like this listening to the priest, and I think to meself, “Eh, I wish I could just keep still like that, it would be lovely just for ten minutes ... You know, get a bit of peace.”

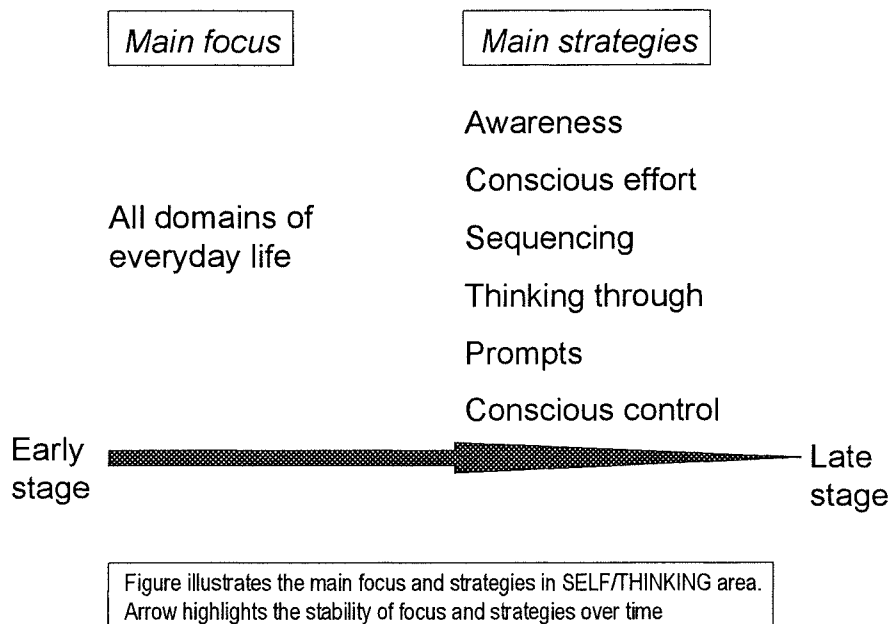
6.3 SELF/THINKING strategies

THINKING strategies in the **SELF** area (Figure 6.3) record the use of conscious strategies to counteract specific problem areas. Because making movement conscious is a rehabilitation strategy (Morris and Iansek 1997), the strategy maps of the **control** group and the **initial** strategy maps of the **active** group were examined to gain an understanding of **THINKING** strategies in a group of individuals, the majority of whom had not received physiotherapy for Parkinson’s disease.

Heightened conscious awareness of areas affected by motor deficits, for example facial expression and conversation, hand dexterity, balance, posture and walking, was reported throughout the course of the condition. Increased overall awareness, described as being “en garde all the time”, formed a background to more focused conscious effort. Effort is defined as “exertion of body or mind; an attempt; a struggle” (Chambers 1991).

Parkinson’s disease is often characterised as a disorder affecting the automatic execution of learned motor activity (Selby 1990). Individuals overcame the loss of automatically regulated movement by focusing consciously on the full range of everyday activities. Conscious effort was a feature of accomplishing everyday activity throughout the whole of the disease course.

Figure 6.3 SELF/THINKING strategies



When sitting or standing individuals needed to monitor the position of parts of their body and correct positioning if necessary. The following components of walking might need to be addressed consciously, singly or in combination: starting to step, moving weight from one leg to another, placing the heel down before the toe, lifting the limb adequately off the ground, making a step of adequate length, maintaining a rhythm and speed to walking, and swinging the arms. Walking posture was monitored and the tendency to step and fall forwards or backwards needed to be counteracted. Special attention was required to negotiate doorways, to make turns, to manage stairs and to overcome freezing in order to avoid falls.

Using a knife and fork, swallowing and chewing food and drinking all required conscious effort. Communication using speech required attention to breath control and sentence length. It was important for individuals to maintain full concentration and to ensure they consciously addressed facial expression and body language such as nodding or shaking the head to assure others that they were responsive to what was being said. Using the telephone required particular conscious effort to counteract slowness of speech or thought.

Conscious effort was needed to undertake personal hygiene activities such as shaving. Activities requiring dexterity such as handling money needed particular attention. Washing dishes, cooking, picking up objects, hanging out clothes and ironing were all reported as requiring conscious effort. Complex activities such as tying a tie, writing, dressing, turning in bed, accomplishing chair, bath and car transfers all needed to be made conscious for optimal performance. Undertaking two activities such as walking and talking or carrying an object, or singing and reading words needed extra attention. Changing gear whilst driving needed conscious effort, as did getting from place A to place B. Individuals felt under particular pressure to perform well if they were being observed.

Breaking down movements, such as getting out of a chair or car, into smaller parts reduced their complexity. Sequencing of getting out of a chair consisted of conscious consideration of body position on the seat, followed by consideration of foot positioning, then use of arms to raise the body and finally attention to balance prior to stepping. Sequencing allowed the two other **THINKING** strategies - 'thinking through' and prompting - to be mounted.

Sometimes everyday activities such as getting in and out of a car seemed unfamiliar, and individuals needed to stop and work out ways to accomplish the sequence of activity. 'Thinking through', or mentally rehearsing, a movement or activity was commonly employed. Movement sequences such as getting into and turning in bed, getting in and out of bath, walking and stairs were mentally rehearsed. Picking up items, dressing, getting on and off escalators and driving were also prepared for mentally in advance. 'Thinking through' was particularly employed in relation to conversation and telephone calls where individuals found it helped participation but reduced spontaneity.

In many areas individuals were using highly specific prompts in an attempt to start, maintain and ensure the quality of movement sequences. (The word prompt will be used in the context of strategies put in place by individuals themselves, whilst the word cue will be used in the context of professional intervention.) Prompts based on thinking, saying words out loud, looking at objects, hearing sounds and moving parts of the body

were identified at all disease stages. Thinking prompts comprised a few words to encapsulate the main action in each phase of a movement sequence. Prompts could be reviewed mentally ('thinking through') prior to performance and then the action sequence could be undertaken with guidance from the prompts. For example, walking could be prompted as follows, "head up, heel down, 1 - 2, arm swing". Movement prompts involved marching on the spot, transferring weight from side to side or stepping backwards. Counting out loud could be used to maintain gait. Visual imagery such as visualisation of squares on a pavement was employed to initiate or improve gait, and visual prompts such as pavement cracks could be sought from the environment ahead. The sound of a shoe scuffing on the floor was used as an auditory prompt to pay attention to walking. It was possible to control tremor for short periods of time using conscious control.

Reported strategies were similar from early to late stages of the condition. It had been hypothesised that there would be increased use of sequencing and cueing in the active group as these techniques formed part of the therapy approach (Chapter 10). However the extent of the use of **THINKING** strategies in both active and control groups was also similar. A major difference between the control and active groups occurred, however, in relation to the relative ineffectiveness of many control group mobility sequencing strategies. The issues of compensation and sequencing will be reviewed in detail within the context of the involvement strategy model (Chapters 9 and 10).

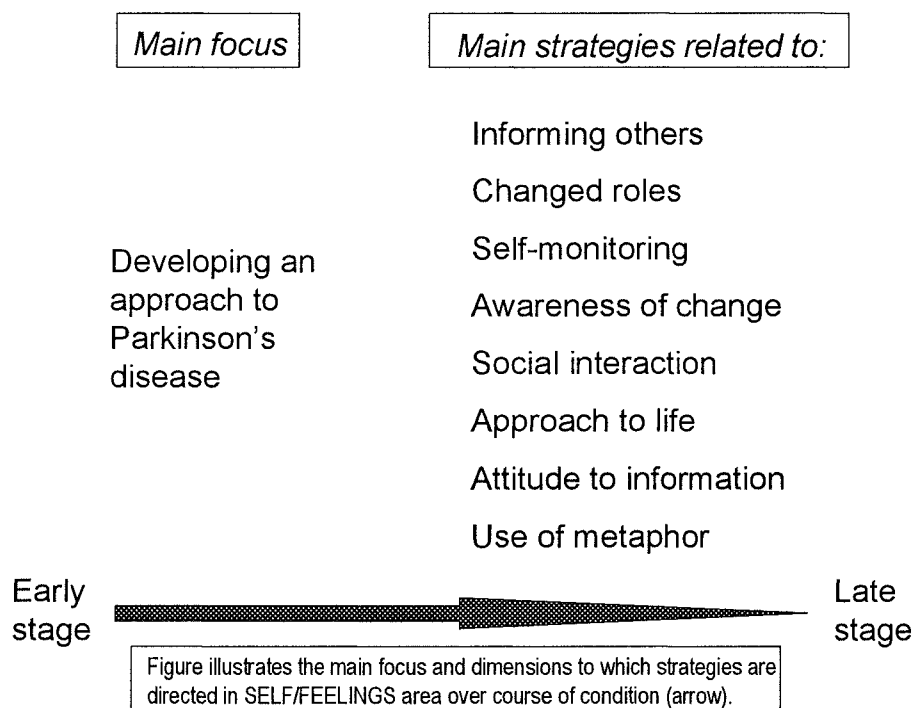
A 49 year old male participant in the case study phase explained his technique for getting through doorways before and after professional advice:

“... I have trouble going through a door ... I sort of get stuck ... don't know what is normal for Parkinson's. It's a bit hard to accept that normally you can't walk through a door.... But as soon as I open the door I've got to like, well he [consultant] told us to visualise putting my foot forward which actually works ... But beforehand I was literally just letting myself, just fall forward.”

6.4 SELF/FEELINGS strategies

FEELINGS strategies in the **SELF** area record how individuals make sense of, and develop a mental approach to, living with Parkinson's disease. This may be explicitly articulated by the individual or inferred by the therapist, in which case her/his judgement would need to be justified by examples.

Figure 6.4 SELF/FEELINGS strategies



There was a marked reluctance to inform people outside the immediate family circle of a diagnosis of Parkinson's disease. Openness about the diagnosis was rare. One individual chose to tell his daughters but not his sister, with another choosing not to inform his son in order not to arouse concerns over the hereditary component of the disease. Hiding the condition from others engendered uncertainty about whether they were noticing any change. If people noticed increasing disability the cause may be given as something other than Parkinson's disease, such as a back problem. Fear of a change in attitude towards the individual was given as one reason for reluctance to inform others about the diagnosis. An individual who had hidden the diagnosis for many years reported a mixed reception from friends and colleagues when informed. Another reported that when an old friend, a doctor, was told her diagnosis he ceased to talk to her and addressed her family instead. However one person who had been open about his diagnosis felt he enjoyed enhanced interaction with people with whom he had a history because "they know what I was and still am". For people of working age the decision to tell an employer was particularly sensitive.

Using the word 'carer' for the main supporter of individuals with Parkinson's disease, whether a spouse, sibling, child or friend, has the tendency to diminish the 'care' individuals with the condition feel for the people around them. Strategy mapping illuminated the care and concern shown by individuals with Parkinson's disease for the significant people in their lives. There was repeated mention of concern for the health of a spouse, with several individuals themselves fulfilling the classic carer role in relation to their own spouse or a disabled sibling or child.

Some individuals felt that the people around them did too much for them, whilst others considered that too much was expected of them. In order to preserve their claim to being a spouse, parent or grandparent, many individuals felt they needed to minimise the effect of their condition and continue to undertake activity related to their role. Individuals who would have preferred to limit social interaction were aware of the effect this would have had on spouses and so tried to continue to socialise and take holidays despite reservations. Sexual problems and the need for help with personal hygiene from spouses or opposite sex children compromised relationships. Inability to undertake what had previously been

part of an individual's role, leading to delegation, for example, of family financial management or housework, had the potential to undermine self-esteem. One individual who had taken time off to adjust to his diagnosis felt this had not been the right decision, and that continuing in this role as a worker whilst attempting to adjust would have been preferable. Reference to role enhancement was rare but one father felt that he was a "better Dad" since the diagnosis of Parkinson's disease.

The monitoring of mental and physical ability over time was a strong theme in the data. Continual comparisons were made in relation to the ability to successfully undertake such activities as: chess; golf; quizzes; crosswords; bicycling; running; crossing roads; and standing on one leg. The ability to perform actions such as carrying a cup of coffee, putting on a pair of trousers, answering the telephone and responding to the doorbell was monitored. Individuals monitored themselves against targets set for the day, such as the challenge of getting from place A to place B. One individual reported making lists for himself but feeling disappointed when he was unable to achieve his targets. Posture was checked in shop windows whilst out.

Comparisons were made with mental and physical performance of individuals of the same age; with able-bodied spouses; and with other individuals with Parkinson's disease. Particular interest was taken in family videos separated by time when changes in features of the condition such as tremor and facial expression could be judged. Individuals had a sense of how well they were doing in relation to their condition: "...had the condition for 5 or 6 years and I'm not doing badly"; "I'm going backwards".

Individuals expressed awareness of their deteriorating condition - loss of facial expression, the need to concentrate more when talking, avoidance of decision making, loss of writing ability, increasing slowness in all activities, reduced driving reaction time. Emotionally individuals reported "ups and downs", feeling upset, aggressive, agitated and irritated. Small things upset them more than before and there was a tendency for "everything to get on top of" them. Change engendered frustration and anxiety, and made people angry and low. A number of individuals described the feeling of "doing everything in slow motion"; another explained, "when I'm out in the real world I feel a size smaller".

Others explained that “everything is twice as heavy”, and another that they were “looking not doing things”. One individual rejected his changed voice, saying, “It’s not my voice”. Another reported feeling that “lots of parts of my brain are affected”. There was a feeling that no one really understood what it felt like, and that increasingly individuals were a burden to people and that “nobody wants me”.

Many individuals mentioned their previous personality type. Most of those that did felt that could be described as: depressive, anxious, a worrier, basically pessimistic, miserable, “all doom and gloom”, nervous, up tight, claustrophobic. Rarely did someone describe themselves as previously happy go lucky, placid or easy going. Of those that did, several felt they had changed to become more introverted.

Acceptance and coping with change was rarely mentioned in the early stages of the condition. However realism, pragmatism, coming to terms with not being able to do what individuals did previously and adapting lifestyles to accommodate limitations became a stronger theme in later stages. Frustration was still the dominant response to enforced change, with an underlying worry about the future, where is it all going to end and “how bad is it going to get?” For some there seemed “no light at the end of the tunnel”, “time no longer has any meaning” and suicide was considered and in one case attempted.

From the earliest stages in the condition individuals reported avoiding social interaction. In the later stages this could become so extreme that individuals would withdraw from the outside world, sit in a corner and not speak. The experience of social stigma was at the root of reduced social interaction. Reasons given from shying away from other people included embarrassment at deteriorating speech and poor walking which may lead people to suspect individuals were drunk; the social unacceptability of involuntary movements and drooling; and the attention drawn to individuals who were unable to eat normally. Loss of confidence resulted from the perception that the individual had made a fool of him or herself. Individuals reported avoiding people they knew, preferring to be out in a place where there was little chance of knowing anybody. Meeting people who were likely to want to stop and chat caused anxiety. Crowded places were particularly avoided; too many people around could prove overwhelming. Individuals much preferred to socialise

with small numbers of people, ideally family and friends, and on a one to one basis. However, even this proved too much for one individual in the later stages who reported taking time out from family gatherings in the garage. Invitations were rejected in an attempt to reduce stress. Reports of lack of concern about the reactions of others were rare. Even in the early stages individuals were reporting that they “couldn’t be bothered with people” and that they had become an “isolated hermit”.

A strong theme in the data centred on “taking a back seat” and becoming “more of a listener now”. Conversation was increasingly not proffered spontaneously, and if people had to converse they would rush through what they had to say to get it over with. Some individuals had become adept at facilitating others to talk, to the extent of taking on a perceived counselling role.

If conscious effort was required to enhance voluntary movement (**SELF/THINKING**), its corollary was found in the emotional and physical effort expended by individuals to keep active and maintain the pre-diagnosis status quo as nearly as possible. Table 6.1 reports the phrases individuals used to describe their approaches to keeping going, maintaining normality, developing an attitude to life and putting up a fight against the disease. These approaches were consistent across the disease span and in both active and control groups.

Some individuals indicated how hard it was to keep active and positive. They reported needing to be in the mood to do things; being reluctant to start things; feeling as if they could not be bothered; experiencing increasing apprehension about everything; and a tendency to put things off.

Table 6.1 Describing approaches to life with Parkinson’s disease

Approaches to life	Narrative accounts
Keeping going	Individuals talked about rallying themselves; avoiding being a couch potato; mind over matter; getting on with it; having a purpose for the day; pushing themselves; setting their minds to something and get cracking; coping better if interested or engrossed in something; doing something worthwhile every day
Maintaining normality	Individuals reported not wanting to be cosseted; and wanting to maintain independence; maintain standards; maintain appearance; maintain the same level of dignity; maintain control; be self-sufficient
Attitude to life	Individuals talked about making light of the situation; looking on the bright side; being positive; making the most of each day; maintaining a sense of humour; “at least I’m here and have a quality of life”; being optimistic, grateful; having a desire to help others with the condition; making the best of a bad job; not dwelling on the down side; trying not to make Parkinson’s disease an excuse; pre-empting problems; “trying not to be too hard on myself”; making the most of the good times; taking pleasure in achievement
Putting up a fight	Individuals reported giving the disease a run for its money; not letting the disease take over; riding the storm

Individuals indicated a range of responses to the need for information at all stages of the condition. Some individuals reported that they were seekers of information, feeling that increased knowledge equated to increased control which in turn reduced stress. The Parkinson’s Disease Society was seen as a source of information, although seeing others with Parkinson’s disease was a concern for some. Individuals also reported avoiding information, feeling that they did not want to “delve too much”. Others reported a desire for staged information commensurate with their needs at the time. One individual in the later stages of the condition saw herself as an information ‘giver’, able to talk about the condition and her response to it in order to help other people’s understanding. People in the later stages of the condition talked about being well read now but having avoided information earlier on. Some individuals came to the condition with established knowledge bases, either from their personal or professional life. Several individuals had had relatives with the condition and another had been a nurse.

The use of metaphor provided insight into how individuals felt about living with Parkinson's disease. One newly-diagnosed individual described himself as "a shiny apple with a worm in the middle, healthy on the outside but a whole heap of problems on the inside". Another said he felt "a fully fit passenger in a clapped out banger". One couple described how they pooled their resources to form a united response to life with the condition: "I'm the brains of the partnership, my husband is the body". In the later stages with increasing difficulties being encountered in all areas, one individual reported that "I am a back seat driver in all activities"; another said, "I am a prisoner in my own home". The experience of going into an 'off' phase was described as feeling "like a doll wound down".

Whilst the range of reported strategy areas and the strategies reported within them were common to all stages of the disease, and both active and control groups, it was possible to identify some subtle shifts in emphasis over time in a number of areas. This is similar to **SELF/PHYSICAL** strategies for the control of involuntary movements, where the emphasis shifted from control and disguise of tremor to incorporate control and disguise in relation to dyskinesia (6.2). In relation to the awareness of change area, some indication of pragmatism about the condition was evident in the later stages which was lacking initially. In the information area there was an indication that people who had initially avoided information had gradually been able to accept more knowledge about the condition.

One 70 year old male in the case study phase provides insight into the use of metaphor to describe feelings about Parkinson's disease generally and starting to take medication:

“Well you know, I think as an engineer, and my mind is, if you’ve got several contacts and some of those have got dirty, and the electricity can’t flow through them ... You’re getting a bad contact and ... poor circuit going through there and eventually there is no circuit going through there. That’s the way I think of it.”

“Yeah but also its like a battery, you take levodopa and its fine, it helps and helps but that battery is running out all the time, then what do you do when the battery’s run flat? You have to start on something else then.”

6.5 SELF strategies - Implications for physiotherapy

Each section of the **SELF** area of the strategy map has identified a discrete area of self-management work undertaken by individuals with Parkinson’s disease.

SELF/PHYSICAL strategies are centred on **disguise work**; **SELF/THINKING** strategies on **awareness work**; and **SELF/FEELINGS** strategies on **making sense work**. These areas of self-management work will be discussed in relation to the literature. Implications for the practice of physiotherapy in Parkinson’s disease management will be articulated. Key research questions will be proposed.

6.5.1 Disguise work

The three main symptoms individuals seek to control or disguise using other parts of their body are tremor, dyskinesia and drooling. Rest tremor, which usually starts in the fingers of one hand and spreads to the lower limb of the same side before crossing to become bilateral and potentially affected the trunk and mouth area, is often little influenced by levodopa pharmacology at the level at which two other cardinal symptoms, akinesia and rigidity, are ameliorated (Pogarell et al. 1997). At least half of patients with Parkinson’s disease develop motor fluctuations or dyskinesia (unwanted drug induced involuntary

movements) within the first five years of levodopa treatment (Quinn 1995). They are more prevalent in younger than older patients. Sialorrhoea, or drooling, results from the loss of subconscious swallowing movements to dispose of saliva, and from immobility of the mouth, tongue, palatal and pharyngeal musculature, rather than from the excessive production of saliva (Selby 1990). Drooling may be compounded in the later stages by flexed posture.

A review of the assessment of involuntary movements and sialorrhoea provides insight into how professionals currently seek to understand these symptoms. The characteristics of tremor are influenced by a range of factors including the individual's overall status, the test setting and the natural rhythms of the tremor, and can be measured in a number of ways – physiological (e.g. accelerometry), subjective (clinical rating and rating spirals or handwriting), objective (functional performance tests) and impact (e.g. quality of life scales) (Bain 1998). An evaluation of tremor occurs illogically in the United Parkinson's Disease Rating Scale (UPDRS), along with other impairments, in the Activities of Daily Living section, as well as in the Motor Examination, which itself also includes disability items (Wade 1992). The 0-4 rating system records whether rest or postural tremor is Absent, through Slight, Moderate and Severe to Markedly present and interfering with activities. Dyskinesias are typically assessed by subjective means through clinical rating or patient self-monitoring in relation to drug therapy over a prescribed time-scale. The Complications of Therapy section of the UPDRS contains a dyskinesia assessment. It rates the proportion of the waking day during which dyskinesias are present and how disabling and painful they are on patient self-report. The clinician may modify the disability rating dependent on observation. As individuals will often try to be at their best for clinic appointments this will often not be a reliable observation.

Sialorrhoea is approached via two areas of the Activities of Daily Living domain of the UPDRS – salivation and swallowing. Interestingly the operationalisation of the rating includes the use of strategies; Constant use of tissue or handkerchief at 4 in the Salivation section, and Use of soft food and Special feeding at 3 and 4 respectively in the Swallowing section. Assessment of the impact of involuntary movement and sialorrhoea needs to recognise its potential to stigmatise the individual. The Stigma section of the

PDQ-39 (Peto et al. 1995) offers assessment at the level of participation, asking how often, on a scale from Never (0) to Always (4) during the last month individuals have felt they had to conceal their condition; avoid eating or drinking in public; and felt embarrassed or worried in public due to Parkinson's disease.

According to Ianseck et al. (1997b), "Resting tremor in Parkinson's disease is not a major cause of disability and as such is not a major symptom requiring treatment". However Chesson et al. (1997) identified that the main problem mentioned by patients in the context of quality of life and Parkinson's disease was tremor, whilst few therapists identified tremor in this context. In a study of physiotherapy and Parkinson's disease individuals reported that they wanted advice on the physical management of involuntary movement (Plant et al. 2000). Optimal pharmacological management is key to obtaining the best quality of life for individuals but has acknowledged limitations and difficult side effects. Physiotherapists may play an important role in the assessment of response to medication (Morris et al. 1998). A full understanding of levodopa-induced involuntary movements is required by physiotherapists in order to be able to identify movement disorders that may be amenable to pharmacological manipulation.

There is currently an inadequate knowledge base in relation to the physical and psychosocial management of stigmatising symptoms such as involuntary movements and salivation. Texts refer to the potentially beneficial effect of individuals practising relaxation techniques in situations where tremor may be particularly difficult for them (Godwin-Austen 1990). As tremor is reduced by movement, consciously making hand gestures whilst talking can help (Coene and Griffiths 2000). It is acknowledged that explaining the symptoms to friends and individuals in the workplace can be helpful. Stress makes tremor worse so reducing the stress of needing to hide the tremor can lessen the symptom (Coene and Griffiths 2000). Strategies to promote stability in static and dynamic postures are required for the management of dyskinesia. Instigating a conscious prompt to swallow, in addition to attention to posture in standing and sitting to combat forward flexion and mobilisation of the oro-facial musculature, could potentially combat drooling. It has been suggested that in order to understand the impact of tremor on individuals more fully, the nature of the detractor – the relationship between the

impairment and the objective disability or handicap it produces – needs to be investigated (Bain 2000). The physical management of involuntary movements and drooling should form an area of collaborative research between individuals with the condition and professionals to an attempt to produce practical advice and meaningful assessment tools.

6.5.2 Awareness work

It is usual to consider the movement difficulties experienced by individuals with Parkinson's disease from the perspective of deficits such as bradykinesia, akinesia, freezing and impaired postural control. Taking a person-centred view might start from the main type of movement that is problematic in Parkinson's disease. Complex movement sequences that are well-learned, usually performed automatically without thought, and predictable are the most affected. These include walking, getting in and out of a chair, speaking and writing, the type of activities which underpin much of our daily life.

On the basis of cerebral blood flow (Brooks 1999) and single cell studies, it would appear that the basal ganglia influence learnt movement sequences in particular via the supplementary motor area (SMA) and the pre-motor area (PMA) (Ianssek et al. 1997a). It is hypothesised that both these areas are involved in pre-movement sequence activity, to which the basal ganglia contribute by sustained activity, allowing a role in initiation of movement. In addition it is thought that the SMA prepares for each sub-movement in a sequence by pre-movement activity which is terminated by phasic neural activity in the basal ganglia at the end of the preceding movement, which then releases the next sub-movement for execution. When the sequence is established the basal ganglia provide internal cues to maintain activity. It is thought that in Parkinson's disease the preparatory activity and internal motor cues are defective with consequent effects on movement initiation and sequencing.

It may be that the self-management strategy of heightened conscious awareness, identified through strategy mapping, is a response to the deficit in preparatory activity in the SMA. It may be that when individuals talk about the need for increased conscious effort this is the perception of attempting to make a movement sequence run in the

absence of optimal internal cues. The need for sequencing would appear to link with the difficulty in running sub-movements; 'thinking through' with preparing for movement; and prompts with the need provide external rather than internal cues. Prompts utilise cortical mechanisms, namely the PMA, to activate and sustain movement and in so doing bypass the defective basal ganglia - SMA circuits (Nieuwboer et al. 1997; Morris 2000). Thinking prompts, the use of self-generated internal prompting, were the most commonly reported prompt in this study, whereas external sensory cues of a visual or auditory nature are the most common in the rehabilitation literature, which will be reviewed in Chapter 10.

Rehabilitation professionals seeking a rational basis for physiotherapy treatment of Parkinson's disease have looked to motor control and motor learning theory for guidance (Mak and Cole 1991; Morris et al. 1994b; Tse and Spaulding 1998). The main features of the current rehabilitation approach include breaking down complex movements into smaller components; arranging the steps sequentially to avoid the need for simultaneous action; performance of each component at a conscious level; use of visual, auditory, proprioceptive or tactile cues (Morris and Ianssek 1997). However a major issue in the literature relates to the carryover of effect of these strategies when the period of rehabilitation has finished.

Morris et al (1996a), in a study comparing visual cues with attentional strategies to improve stride length, state that the effect of attention seems to require constant vigilance to prevent reverting to more automatic control mechanisms. They raise the question of whether people with Parkinson's disease can ever learn to walk permanently with normal stride length, velocity and cadence without consciously focusing on stepping pattern. They also query whether alternative regions of the central nervous system can substitute for the basal ganglia in controlling automatic movements such as walking, given optimal practice conditions. Nieuwboer et al. (1997) ask whether it is reasonable to ask individuals to consciously focus on their gait all the time, and feel that it may be so for a set period only in the day. In the discussion of this paper Playford (1997) also highlights the problem of whether improvement in a laboratory can be translated to everyday life, even if available carers are taught to cue appropriately. Nieuwboer (1999) describes

individuals with Parkinson's disease as being perpetually in the process of motor learning, and suggests that teaching methods to promote generalisation are required in addition to optimising cue action in individual patients. Neural modifiability is seen to parallel learning of movement skill in much neurological physiotherapy, with compensation potentially viewed as second best (Shumway Cook and Woollacott 1995). However, Morris et al. (1996a) cite Fitts' (1964) three stage theory of learning, also cited by Kamsma et al. (1994), incorporating cognitive, fixation and automatic stages, and suggest that the final stage is not available to people with Parkinson's disease because of basal ganglia dysfunction.

Two recent studies (Dam et al. 1996; Marchese et al. 2000) have compared a conventional physiotherapy programme centred on exercise and functional activities with a 'sensory enhanced' physiotherapy programme incorporating the full range of cues. In both studies there was improvement at the end of the physiotherapy programmes. However, those individuals who had undergone the sensory enhanced programme demonstrated longer lasting retention of performance gains. Dam et al (1996) postulate that the increase and maintenance of functional gains in their sensory-enhanced physiotherapy group stimulated the formation of stable motor memories. They speculate that repetitive sensory stimulation and/or increase of selective attention as a result of sensory-enhanced physiotherapy may produce sufficient inputs to activate motor learning and retention mechanisms. They suggest that new drugs targeting neurotransmitters that facilitate learning through cortical plasticity and long-term potentiation such as GABA and acetylcholine should be developed.

Yekutieli (1993) and Kamsma et al. (1995) report that changes in the structure of performance of gross motor activities had carry over into the home environment. The former study addressed making turning conscious and reduced the number of falls. The latter took complex skills such as sit to stand and turning in bed and formed sequences of simple movements which were cued consciously. Individuals learned the strategies, reproduced them and used them in everyday life. However the authors remarked that there was no generalisation to similar activities of daily living.

The results of strategy mapping have highlighted the fact that individuals use similar strategies to enhance movement to those employed within rehabilitation programmes. It would seem important for physiotherapists to acknowledge existing work prior to planning a programme with an individual. In this way existing strategies can be reinforced, modified or challenged, and new strategies discussed. Therapists' understanding of motor control and motor learning theories need to be regularly updated as part of continuing professional development to ensure evidence-based practice in this developing area.

Given the overwhelming level of pre-existing conscious awareness, and the fact that conscious strategies are likely to form part of rehabilitation programmes, it would appear important to investigate any links between constant conscious effort in everyday activity and fatigue in Parkinson's disease. It has been suggested that fatigue may be more troubling than tremor, slowness or gait disturbance (Friedman and Friedman 1993). Investigation of the potential link between cueing of gait and fatigue, identified as part of the current project, forms one arm of a multi-centre international Parkinson's disease research programme entitled RESCUE, The Rehabilitation Strategy of Cueing. This project, to be co-ordinated by the Institute of Rehabilitation in Newcastle upon Tyne, has recently been awarded funding by the European Union.

6.5.3 Making sense work

Popular misconceptions about Parkinson's disease make it difficult for individuals to be open about their diagnosis. McCall (1999) highlights four misconceptions about people with Parkinson's disease: they are old; have tremor; are drunk, stupid, and lazy; and experience the condition in the same way. Healthcare professionals can also harbour misconceptions. In a study by Pentland et al. (1987) therapists were asked for their impressions of silent video-recordings of patients with Parkinson's disease with mild to moderate symptoms and patients with ischaemic heart disease. Although neither group had abnormal scores on psychological tests, the Parkinson's disease group was recorded as, for example, more bored, passive, less involved in the conversation and less likeable. Individuals interviewed in a study by Plant et al. (2001) reported the perception that there

were 'Parkinson's disease exercises' that were given to everyone. Enhanced professional education, developed jointly with professionals, educators and individuals with Parkinson's disease (Baker et al. 1997), should raise awareness of the need to counter stereotyping and work for individualised care (Abudi et al. 1997).

It has been postulated that the tendency to social withdrawal in Parkinson's disease, which will be discussed further in relation to **INVOLVEMENT** strategies in Chapters 9 and 10, may be related to the concept of 'shame' (Nijhof 1995). Shame is said to arise from aspects of rule-breaking behaviour associated with signs of the disease. Behaviour relating to sensitive social values, such as competence, independence and decency, can be threatened by, for example, difficulties with speech, eating and continence. The visibility of the rule-breaking behaviour, countered by **SELF/PHYSICAL** strategies to control and disguise (6.2), means that public disclosure is an ever-present threat. There is an assumption that individuals will be labelled deviant by the behaviour. Factors conspire to cause a retreat from the public to the private world. Addressing social exclusion is a major part of the current Labour Government's policy platform (Social Exclusion Unit 2001). Shame relates Parkinson's disease to societal processes and suggests the need to look at the condition as an example of shame-conditioned social exclusion (Nijhof 1995).

A retreat from the public world is likely to place greater emphasis on the private world and relationships within it. Roles and responsibilities may need to be renegotiated or reinterpreted. Learning to solicit appropriate help and being able to receive that support are likely to be a challenging process (Habermann 1996). However carers often find understanding the needs of the individual with Parkinson's disease the most difficult thing about caring (Yarrow 1999).

Public information is required to redress social perceptions of Parkinson's disease, however individuals and carers also require information directed at their personal situation which is often difficult to access (Yarrow 1999). Pinder (1990) identified three main strategies related to obtaining information about Parkinson's disease, dependent on whether individuals were seekers, weavers or avoiders. For seekers uncertainty was the worst case scenario and actively finding out about what was likely to happen was helpful.

Conversely for avoiders it was easier to live with uncertainty and not finding out was the best approach. Weavers sometimes wanted to know and at other times preferred not to. They selectively accessed and interpreted information to meet their needs. Whilst making information more widely and easily available is important (Guidelines Group 2001), it is also important to acknowledge the need for sensitivity to the fact that individuals employ different mechanisms at different times for dealing with information.

In the therapeutic encounter narratives are the phenomenal form in which individuals experience ill health (Greenhalgh and Hurwitz 1998), and offer the potential for professionals to comprehend issues such as an individual's approach to information and how people view themselves. Language is used to construct the sense of self. Individuals with language disorders may be disadvantaged in constructing a new sense of self in the face of neurological deficit such as Parkinson's disease (McNamara et al. 1995). Taking cognisance of verbal expressions of the sense of self, embodied in the use of metaphor and insights into approaches to life, has the potential to reveal how individuals are attempting to reorganise their sense of themselves to reflect their changed circumstances. Sensitivity to descriptors individuals apply to themselves can help professionals to understand the process of reordering of self individuals are engaged in, and potentially support the development of a sense of self characterised by autonomy and self-efficacy. It has been suggested that Parkinson's disease management that combines both medical and physical treatment and attention to personal control may offer the best route to enhanced quality of life (Koplas et al. 1999).

6.6 Summary

This chapter has focused on the strategies individuals use to address particular challenges as a result of Parkinson's disease, drawing on their own physical, cognitive and emotional resources. The extent of disguise, awareness and making sense work has been uncovered and the implications of physiotherapists explored. This central ring of the strategy map acts as a backdrop and reference point for many of the strategies recorded in the outer rings. **ROUTINES** strategies will be the topic of Chapter 7.

7 Strategy mapping: ROUTINES strategies

7.1 Overview of chapter

The **ROUTINES** area of the strategy map (Figure 7.1) records regular patterns of behaviour in relation to activity concerned with maintenance of body functioning. The three areas to emerge as important in relation to **ROUTINES** were **MEDICATION**, **DIET**, and **EXERCISE**. Strategies in relation to food preparation and eating as a social activity area are recorded in the **INVOLVEMENT** area of the map (Chapter 9). **EXERCISE** also has **INVOLVEMENT** attributes, making it important to consider the performance, context and meaning of the exercise. These will be considered in this chapter within the context of **ROUTINES** of exercise. Strategies were identified from the maps of all individuals in the targeted physiotherapy trial. Differences in self-management work identified in control and active group maps, indicative of physiotherapy input, will be noted.

Figure 7.1 Strategy Map: ROUTINES area

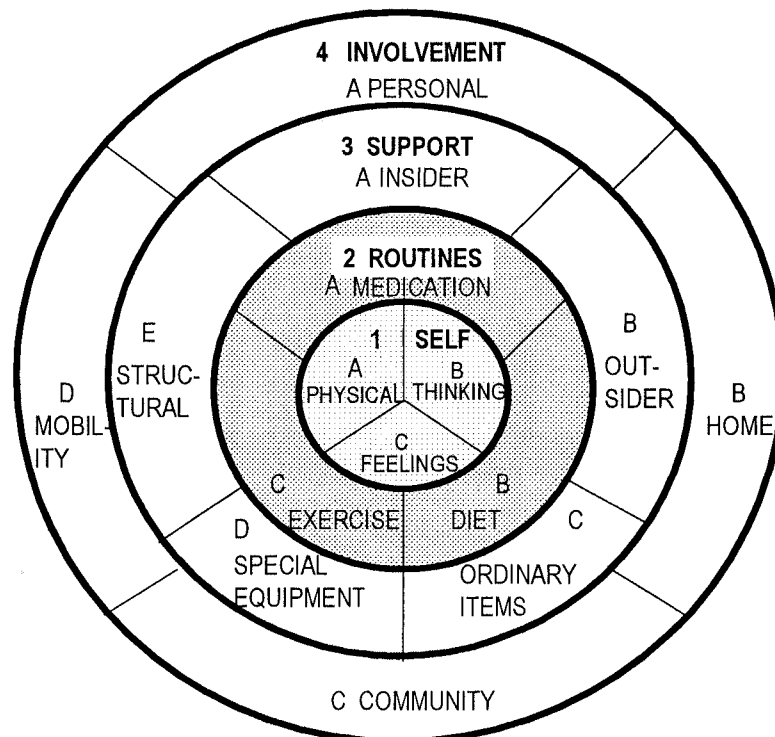


Figure illustrates the four areas of the strategy map, with ROUTINES area in darker highlight

7.2 MEDICATION strategies

The **MEDICATION** section records strategies relating to the use of medication for Parkinson's disease and other conditions, in addition to feelings about taking medication. A classification system was established to reflect the increasing complexity of Parkinson's disease drug management over time (Table 7.1).

Table 7.1 Classification of complexity of drug management

Grading	Drug management
NONE	No Parkinson's disease medication in use
MINIMAL	Early drug therapy using monoamine oxidase inhibitor and/or anticholinergics and/or levodopa and/or dopamine agonist therapy of up to 5 doses a day. Stable medication
MEDIUM	Increasing drug therapy as above (over 5 doses per day with controlled release preparation if necessary) plus increasing instability in medication regime
MAXIMAL	Increasingly complex drug regime. Loss of drug effect and increasing complications. Possible addition of apomorphine

Notes: Grading – descriptor of complexity of drug management; Drug management – outline of level of drug management

During the project MacMahon and Thomas (1998) published a four stage model of management for Parkinson's disease - namely Diagnosis, Maintenance, Complex and Palliative stages – with entry criteria, including drug history, for each stage. The grading of Minimal, Medium and Maximal used in this study could equate to Maintenance, Complex and Palliative stages of the proposed management model. Figure 7.2 details the distribution of medication grading in relation to Langton-Hewer staging of all the individuals in the targeted physiotherapy service trial, active and control groups, for whom strategy maps were constructed.

Figure 7.2 Medication grading of individuals in the targeted physiotherapy service control trial at initial strategy mapping

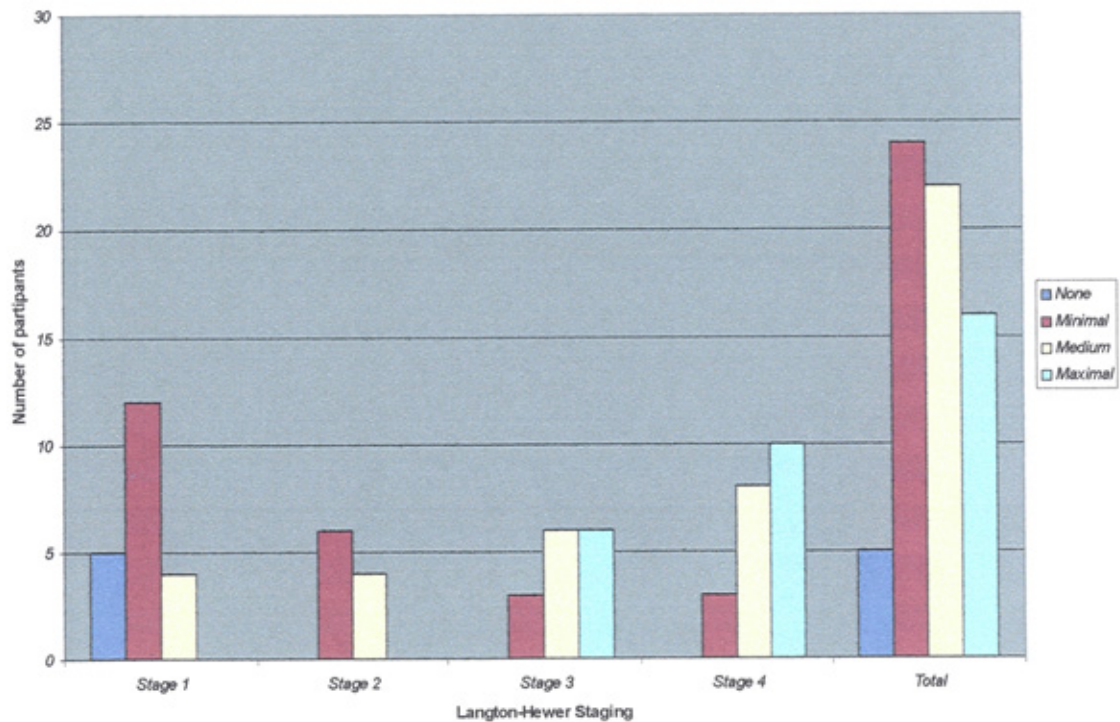


Figure shows numbers of trial participants on the y axis and grading of drug management complexity for Langton-Hewer stages (Stage 1 - diag <2 years, Stage 2 - diag 2-4 years, Stage 3 - diag 5-9 yrs, Stage 4 - diag >10 yrs) (PDS 1994; Chandler and Plant 1999) on the x axis

Those individuals on no medication were only found in Stage 1 of the disease. A minimal medication regime predominated at Stage 1 with decreasing numbers of individuals remaining at that level in Stage 2 and 3. The numbers on a minimal medication regime at Stage 3 were the same as the numbers identified at Stage 4 (3 individuals respectively). Those on medium medication increased with stage from a stable Stage 1/Stage 2 level (4 individuals at each stage). The numbers on a maximal medication regime increased steadily from Stage 3. In this study population minimal and medium medication regimes were encountered most frequently.

Individuals were required to make complex choices, balancing a range of physical and emotional responses, at key points in the medication trajectory: starting medication, maintaining a regime, changing dosage, experimenting themselves with dosage,

recognising fluctuations, combining regimes for different conditions, introducing alternative medicines and facing up to loss of effect.

Several individuals in the earliest stages of the condition preferred to delay starting medication; others' dislike of medication meant that they needed someone to suggest it. A desire to stay at the lowest possible dose led one individual to fail to report worsening symptoms.

Maintaining a medication regime proved problematic for many, especially as Parkinson's disease medication formed only one part of a complex regime involving drugs for a range of other conditions. Setting out the daily dose was a common strategy. Some reported being erratic in medication-taking. Those who felt no noticeable difference had no incentive to tighten up their regime. However when individuals who had felt their increased dosage had made no effect inadvertently missed a dose they were made aware that, in fact, their medication had made a difference to symptoms. There was a marked reluctance, born of lack of confidence, to experiment with dosages and timing, although those that did so expressed pleasure at the enhanced effect. The boost a small extra dose provided when a good level of function was required, such as a special visitor, was appreciated.

A dislike of taking medication predisposed to a poor regime. In some cases spouses were "against any form of medication". This made individuals reluctant to tell them when their medication was deemed to need increasing. In other cases spouses were the first to notice when medication was needed, "he doesn't appear like himself". They may also take over the task of setting out the day's dosage.

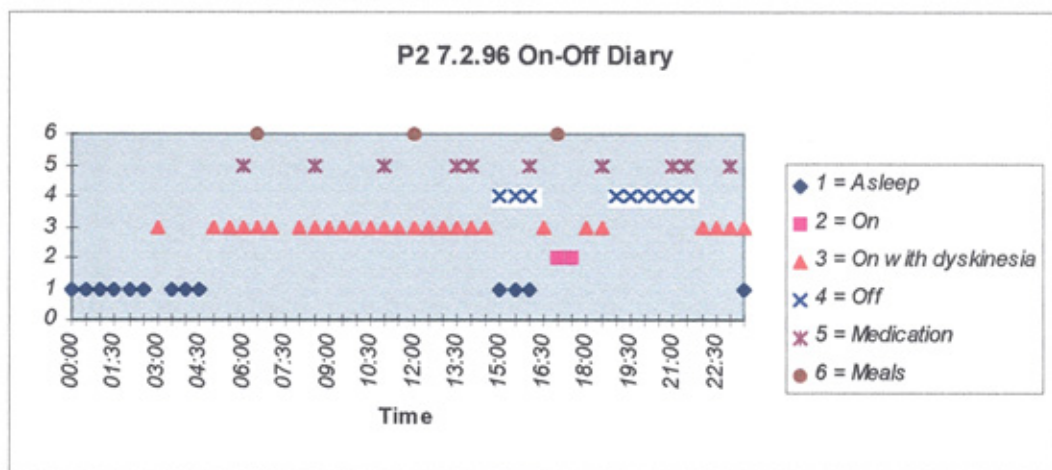
Individuals reported fluctuations from Stage 2. The Parkinson's Disease Specialist Nurse was a key professional in relation to gaining optimal medication effect. Increased swallowing difficulties made pill taking problematic and prompted a move to liquid preparations if appropriate. Discussion of neurosurgical approaches took place with suitable candidates when dyskinesia became refractory.

The use of proprietary medicines for the relief of constipation and pain were commonly reported. There was interest expressed in the use of alternative medicine.

Data from the case study phase serves to illuminate the complexity of **ROUTINES/MEDICATION** in the later stages of the condition. Case study participant 2, aged 65, on a maximal medication routine and at Langton-Hewer Stage 3, agreed to keep a detailed half-hourly ‘on-off’ diary for a week, and in fact maintained the diary over a three week period in total. The diary, which combined both quantitative and qualitative self-assessment, was designed to capture his attempts to optimise his medication to provide the best quality mobility. Examination of one day of the diary (Figure 7.3) in conjunction with his own assessment of his condition offers insight into just how difficult this was proving to be:

“As the day progressed and it got colder outside, the more aware I was of my legs. They were seemingly on fire and I had great difficulty in moving them, as though they were becoming much too ponderous, adding to the discomfort. Mentally tiring, physically also, but that goes without saying. The most mundane of tasks becoming, dare I say, monumental in achievement.”

Figure 7.3 P2 ‘On-off’ diary for one day



Notes: Figure shows time of day on x axis and code related to legend box on y axis
 ‘Diary instructions – Mark the description which best describes your level of mobility for each 30-minute period. If you are resting but not asleep during the day, try to engage in some activity such as standing or walking in order to accurately record your level of mobility. Your carer may help you to complete this chart if necessary.
 Definition of terms: 1. ON – Useful mobility; 2. ON WITH DYSKINESIA – Able to move but troubled by involuntary or unintentional movements; 3. OFF – Only able to move slowly or not at all’

With the exception of a one hour period between 5 p.m. and 6 p.m. when this individual recorded useful mobility, the remaining waking hours were spent either being able to move slowly or not at all (5 hours) or having movement affected by involuntary movement (13.5 hours). Medication was taken 10 times during the day. The medication regime consisted of 2.5 Kmicrograms of Celance, 7 Sinemet Plus at 2.5 hourly intervals, 3 Sinemet CR and 1 Eldepryl. ‘On’ time during the diary recording period ranged from 1 – 9.5 hours per day (mean 5 hours), ‘off’ time from none to 6 hours per day (mean 3 hours), and on with dyskinesia from 7 - 16.5 hours per day (mean 11 hours).

7.3 DIET strategies

The **DIET** section of the map records strategies relating to diet and eating patterns. **DIET** strategies (Table 7.2) were used to counteract constipation, swallowing difficulties, slowness of eating, chewing difficulties, dryness of mouth and salivation; to compensate for poor dexterity affecting eating and motor fluctuations; to reduce urination at difficult times (if out and at night time); to address weight loss; and to optimise medication strategies and counteract side effects.

Table 7.2 DIET strategies associated with specific areas of difficulty

Area of difficulty	Strategy
Constipation	Increased fibre – cereals, fruit, vegetables, salad, brown bread; Liquorice Allsorts; figs at night; prunes; hot water with lemon in the morning
Swallowing difficulties	Takes drink (water/juice) with meal
Slowness of eating	Reduced portions; increased frequency
Chewing difficulties	Smaller amounts to mouth; counteracts tendency to gulp food down; change to ‘sloppy’ food; softer foods to avoid choking; mashed food; avoids pasta/spaghetti; avoids steak
Dryness of mouth	Drinks fluids – fizzy drinks e.g. Lucozade, ginger beer, tonic water; juice – fruit, blackcurrant, apricot and passion fruit, vitamin drink; suck pastels, mints; chews gum
Salivation	Chews gum; sucks sweets

Area of difficulty	Strategy
Poor dexterity	Eats curry when out in public; avoids soup if out; help to cut meat; drinks juice rather than hot drink if alone to reduce risk of burns; move to Chinese/Indian food
Motor fluctuations	If up during night and 'on', snacks to increase nutrition which is difficult to obtain when 'off'; help to liquidise food if 'off'; need to reheat food when 'on'; occasionally misses meal if unable to feed self
Frequency/urgency of micturition and toileting at night	No drink if out; cuts down on drink after 4 p.m.; no drink after 7 p.m.
Weight loss	Takes dietary supplements – Fortisip; increased liver for iron deficiency; glucose
Optimising medication	Sucks extra strong mints to counteract sickness with Celance; experimentation with interaction of food and medication; attempts to manipulate protein intake; eats banana with medication

Strategies were in place in all areas except salivation, weight loss and motor fluctuations from Langton-Hewer Stage 1. Strategies were recorded for these areas from Stage 2, 3 and 4 respectively. There were no differences between control and active group strategies.

Individuals reported changed dietary preferences, such as reducing tea in favour of water; reducing alcohol; eating plainer foods. One individual found whisky promoted sleep at night. Several reported being overweight or needing to monitor their cholesterol intake. There was a tendency to reduce or exclude fats (cheese), fried foods, eggs, chocolate and meat. Whilst some reported having a routine for preparing 'square' meals, with widowers being particularly proud of carrying on what their wives would have done, one individual preferred to eat when hungry. There was a move to lighter meals and more sandwiches and snacks. At times when it was difficult to maintain a routine, such as Christmas, individuals realised how much they relied on regular meals and good diet to maintain optimal efficacy of medication.

Individuals identified threats to their dietary status. Loss of appetite led to weight loss. Increased difficulty in meal preparation led to a move from fresh to pre-prepared foods, which could be reheated in the microwave. As meals took longer less food was

consumed. Food got cold, became unappetising and was often thrown out. This made several individuals feel guilty and ashamed. Ill-fitting teeth compounded chewing difficulties. Eating as a social time became difficult when ‘on/off’ status dictated different mealtimes.

Again data from the case study phase serves to illuminate the complexity of **ROUTINES/DIET** strategies in the later stages of the condition, and their link with **MEDICATION** strategies, activity levels and perceived well-being. Figure 7.4 illustrates ambulatory monitoring data for case study participant 8, aged 43, and on maximal medication. Mean amplitude of step is plotted hourly over a 24 hour monitored period and linked with medication routine, activity diary and perceptions of well-being

Figure 7.4 Linking step amplitude with diet, medication, activity and wellbeing

P8 Relationship of Mean Step Amplitude to Medication, Activity & Wellbeing

WELLBEING Mood OK, Feeling Poor (early afternoon) Fair (late afternoon)

ACTIVITY

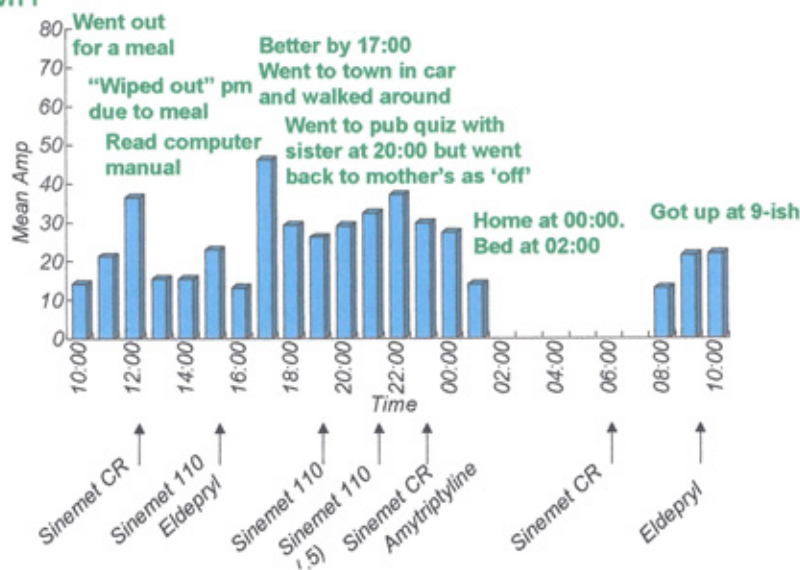


Figure illustrates time of day and associated medication regime on x axis, mean amplitude of step on y axis, main categories of activity associated with time of day in green, feelings of wellbeing associated with period of day in red above

This case study participant had been diagnosed for 14 years and had had a pallidotomy one year prior to monitoring. A keyboard player in a band, who often required a paramedic bass guitarist to inject apomorphine to enable him to play, he had been at a gig on the night prior to monitoring and unable to follow his normal routine of eating his main meal at night in order to push his 'off' period into his period for sleeping. He ate at lunch time on the monitored day, even though he knew he would suffer in relation to drug effectiveness. The protein in his meal meant that levodopa was not absorbed correctly and his diary and step amplitude trace record an 'off' period in the early afternoon followed by a period of feeling better associated with activity in the late afternoon. Another 'off' period cut short social activity in the evening.

7.4 EXERCISE strategies

The **EXERCISE** section of the map records strategies relating to the incorporation of regular exercise into daily life.

Many individuals drew on previous experience of exercising and exercises, either from a leisure or therapeutic perspective, to address symptoms experienced in Parkinson's disease. Several individuals had been keen participants in activities such as cycling, running, badminton, rambling, bowling, golf, yoga, keep fit and dancing. These individuals were more likely, when unable to continue their chosen activity, to take up an alternative such as T'ai chi or to attend a leisure centre to use the fitness equipment. Other individuals had received physiotherapy treatment and exercise advice in relation to conditions such as myocardial infarction, rheumatoid arthritis, post-operative laminectomy and musculo-skeletal disorders such as back pain and tenosynovitis in the hand. In addition GPs and Parkinson's Disease Specialist Nurses were identified as offering exercise advice. Often co-morbidity such as angina or osteoarthritis necessitated modifying exercise approaches to Parkinson's disease. One individual at Stage 2 preferred to use an exercise rather than a medication approach to symptoms.

Overall there was a high level of awareness amongst individuals in both the active and control groups of the need to counteract Parkinson's disease symptoms that threatened to compromise movement through the use of movement itself. Stiffness, pain and cramp were the most commonly identified symptoms toward which exercise approaches were addressed. At the simplest level individuals reported their need to keep moving and avoid maintaining one position for any length of time. This meant getting out of chairs regularly to walk around and avoiding standing for long periods. Individuals acknowledged poor sitting posture as a source of pain. In the later stages a recliner chair was used to make regular seating adjustments.

Stretches were the most common response to stiffness. Stretching up against doors, hanging from door-frames or home made bars, and lying on the floor supine or prone were reported. Specific stretches to relieve dystonia often involved tucking the feet under a bed, chair or radiator to stretch the calf muscles. One individual reported the need to keep her feet warm and the toes moving all the time to avoid dystonia. Massage offered relief. Massage, pressure, rubbing the legs, applying cold water and placing the foot on a cold floor were all employed for cramp. Dyskinesias were addressed by finding a stable, symmetrical position, such as lying on the floor, or undertaking a weightbearing activity such as walking. Restless legs syndrome was counteracted by walking. Range of movement exercises were reported particularly in relation to the neck, hands and facial muscles, although the former were often employed with caution to avoid eliciting dizziness. The use of relaxation techniques was also reported.

The timing and place of doing exercises varied. For some early morning stretches made a difference to the start of the day; others preferred to exercise in the bath. One individual found that playing the piano in the morning helped with subsequent computer use. Some individuals had special fitness equipment, whilst one in the later stages used a walking frame as support for an exercise regime. Some people reported feeling self-conscious about exercising, preferring to exercise unobserved. Others elicited the help of spouses, in some cases exercising together. As disease stage advanced individuals reported the need to take walks when in the 'on' state, and to use walking to reduce stiffness if waking at night. Breathing exercises and control were increasingly employed for chest infections and to help speech affected by dyskinesia.

Local walks to the shops, pub or church, and pushing a grandchild in a pushchair, provided many individuals with their main source of non-specific exercise. Several individuals found that walking a dog offered them a rhythm to their gait. Housework, caring for a spouse, gardening (especially the walking associated with cutting lawns), decorating and shopping were all acknowledged as exercise. Stairs were used as a source of exercise for a number of people and included avoiding use of the stair rail to increase the difficulty of the task. Several attending Day Centres or living in sheltered accommodation complexes reported identifying exercise circuits comprising lengths of corridors, stairs and outside walks if possible. Several people reported structuring tasks to afford extra opportunities for exercise such as refusing to have a newspaper delivered; parking the car at a distance from a destination to offer a longer walk; not using lifts; and walking to open the front door rather than using an intercom opening system.

The active group was supplied with individual exercise regimes plus tapes and videos of exercise regimes for Parkinson's disease in general. Individuals reported selecting exercises for those areas that were causing them particular difficulties at the time. Many reported incorporating their exercises into their everyday routine, such as when they got dressed. One individual took his exercise tape on holiday to play on his Walkman. Relaxation, massage and aromatherapy were promoted. Individuals were helped to monitor their physical condition, and if appropriate encouraged to think about re-instating previously undertaken physical activity or to consider taking up some form of activity for the first time. Therapy supported visits to golf and leisure facilities took place, sometimes in the company of another person with Parkinson's disease. Reported benefits included help to maintain an active lifestyle; improvement in mood; enhanced ability to dry off after a bath or shower and to do up seat belts in the car; and greater ease of turning the head to look over the shoulder whilst driving.

Whilst both specific and non-specific exercise was being undertaken in both active and control groups, the active group was being both supported and extended in their exercise activity. This involved addressing a wider range of areas than was found in the control group, for example the introduction of pelvic floor exercises for urinary incontinence, and exploring new options for management such as teaching a massage technique to a spouse. It also involved an awareness of the need to change the emphasis of exercise strategies

with stage. This included the need to use 'on' time effectively, and address medication complications such as dyskinesia and musculo-skeletal complications, which could compromise respiratory function.

Case study data serves to illustrate the link between **ROUTINES/EXERCISE** strategies and other health issues. Longitudinal data collection using NUMACT allowed comparison of amplitude histograms, the percentage of steps related to different step amplitudes, over time. Figure 7.5 compares amplitude histograms one year apart for a man in his late 60's who had had Parkinson's disease for 6 years (case study Participant 5). The top bar chart represents the first 24-hour monitoring period and shows the full range of step amplitudes being accessed. During this monitoring this participant had taken a one and a quarter hour evening stroll with his wife. The lower chart, representing the second monitored period one year later, illustrates a reduced range of step amplitudes and a preponderance of steps in the lower range indicating reduced vigour of step. Detailed analysis showed a drop in the total mean amplitude of all types of walking - occasional steps, short walks and continuous walks - in the second monitored period. This participant was curtailing his activity out of the house due to unexplained breathlessness. Frustrated by this symptom and unable to pinpoint a cause, as part of the project the participant and his carer kept a detailed diary, again over a much longer period than anticipated (90 days in total), of episodes of breathlessness. We analysed the diary together. The picture to emerge was subsequently shared with the referring consultant. Physical causes of breathlessness were excluded, anxiety was deemed the root cause and therapeutic intervention was put in place.

Figure 7.5 Comparison of amplitude histograms

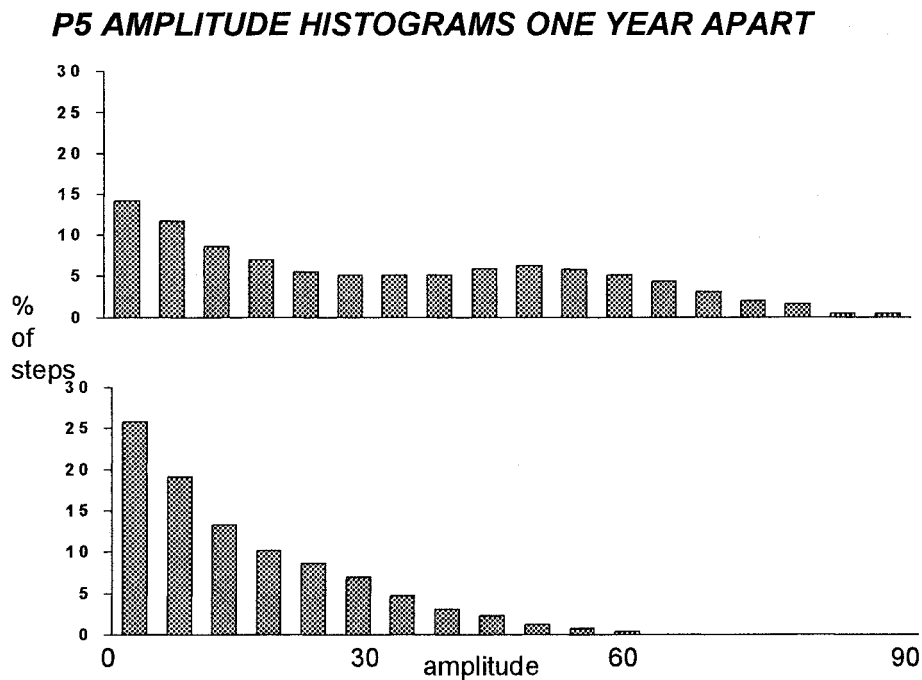


Figure illustrates mean amplitude of step on x axis and percentage of steps per amplitude level on y axis for two monitored periods one year apart

7.5 ROUTINES strategies - Implications for physiotherapy

The **ROUTINES** area of the strategy map has highlighted self-management work in relation to **MEDICATION**, **DIET** and **EXERCISE**. The relationship of physiotherapy to these areas will be explored in relation to the literature, and key implications for practice and research highlighted.

7.5.1 MEDICATION strategies

The relationship of physiotherapy to medication therapy has long been a subject of debate (Figure 2.2, p. 32). It has been suggested that initially treatment for Parkinson's disease is an individualised physiotherapy programme, information and support (MacFarland 1993). There are reports that using physiotherapy early may delay the need for the commencement of medication (Schenkman et al. 1989), which is important given the known side effects of gold standard treatment. Similarly, there are reports that

physiotherapy enables individuals to reduce the dosage of medication to levels that were previously insufficient to control symptoms (Cerri et al. 1994). It has been hypothesised that physiotherapy may potentiate drug therapy at its initiation, for example by addressing postural instability, a non-dopaminergic symptom, at a time when rigidity and bradykinesia are likely to be improved by levodopa therapy (Carr and Shepherd 1980). The beneficial effects of levodopa may be masked by, for example, the development of axial symptoms that cannot be improved by treatment (Agid 1996). Individuals report little or no improvement in axial problems such as turning in bed as a result of medication (Kamsma et al. 1994). The recent literature is supportive of the complementary and adjunctive relationship of pharmacological and non-pharmacological approaches at all stages of the condition (Cutson et al. 1995; Thomas et al. 1999), even if this is not born out in referral patterns (Table 2.2, p. 34).

Morris et al (1998) highlight the role of the physiotherapist in measuring movement fluctuations in order to optimise motor performance, target physiotherapy advice and intervention appropriately, and inform decision-making within the multi-disciplinary team. Clinical fluctuations make measurement difficult in Parkinson's disease and measuring in both "best" and "worst" states has been suggested (Wade 1992). "Best" will equate to the 'on' phase when medication level is at its peak, and "worst" will equate to the 'off' phase at the end of the dose when fluctuations are most pronounced (Morris and Iansek 1997). Different measurement tools and schedules are required depending on whether measurement is being undertaken to determine response to medication, progression of the condition or response to physiotherapy (Morris et al. 1998). Involving physiotherapists in the detailed assessment and communication of movement fluctuations should encourage interdisciplinary sharing of knowledge about neuro-pharmacology and outcome measurement.

However objective measurement can only be fully understood within the context of individuals' perceptions of their symptoms and of their control over them. Strategy mapping identified a medication trajectory with key points where complex choices had to be made. A model of symptom management in Parkinson's disease that emphasises the dynamic nature of the symptom experience, with management strategies shaped by interrelationships between individuals, their carers and health care professionals has been

outlined (Wallhagen and Brod 1997). The model links beliefs about ability to control daily symptoms with well-being of both the individual and carer. The authors suggest that enhancing symptom management skills is likely to increase perceived control and thereby well-being. Physiotherapists have an important role to play in relation to understanding symptoms related to movement and their link to medication through listening, measuring and communicating perceptions and outcomes.

7.5.2 DIET strategies

Dietary issues affect the general health of individuals with Parkinson's disease as well as their response to levodopa therapy (Carter and Nutt 1995). These are important issues for physiotherapists to be aware of, especially when combined with movement problems affecting dexterity and positioning, motor fluctuations making timing of eating difficult and psychosocial issues associated with deterioration of standards of eating (Chapter 9).

Weight loss is a common feature of Parkinson's disease and may be associated with overall energy imbalance (Stewart and Gregoriou 1997). Autonomic nervous system disruption leading to increased basal metabolism together with involuntary movements may increase energy outputs, whilst nutritional risk factors such as chewing and swallowing difficulties may affect energy intake. Autonomic neuropathy may cause slowed movement of food through the gastrointestinal tract leading to a wide range of symptoms including constipation. Because levodopa is largely absorbed from the small bowel the rate of gastric emptying is important for timing of effect. In addition protein digestion produces large amino acids similar to levodopa which require active transport at the blood brain barrier and competition for entry can occur (Carter and Nutt 1995).

As with optimising the efficacy of medication, optimising dietary regimes can benefit from a multidisciplinary approach to assessment and management. Ambulatory monitoring within this study has shown potential for use in the assessment of the link between medication and dietary routines, mobility and well-being (Figure 7.4). A trans-disciplinary approach, one in which each professional's skills are shared to enable the professional most involved with the individual to reinforce a range of interventions (Hickling 2000), is particularly important when there are few professionals in the field, as

is the case with dieticians. Ideally the team, with input from a dietician, would draw up guidelines based on best practice in relation to optimising medication effect and nutritional well-being through dietary management. These would include timing of medication in relation to eating (e.g. with meals in the early stages to lessen nausea; 30 minutes before meals later to reduce problems with absorption due to gastric emptying); control of constipation; and dysphagia management (Stewart and Gregoriou 1997). Each team member is able to monitor and support optimal dietary strategies whilst pursuing their professional objectives. Physiotherapy input to optimise seating, posture, sitting balance, upper limb dexterity and facial mobility should aid the safety, enjoyment and efficacy of dietary intake. Individuals can be directed to sources of dietary self-management information (Coene and Griffiths 2000). In the increasing climate of the 'expert patient' (Illman 1999) professionals should be briefed by the relevant team member and prepared to answer individuals' questions in relation to topical issues such as the role of free radicals in the diet and the pathogenesis of Parkinson's disease (Carter and Nutt 1995).

7.5.3 EXERCISE strategies

Exercise forms a central part of the consensus physiotherapy treatment concept in Parkinson's disease termed METERS, Movement Enablement Through Exercise Regimes and Strategies (Plant et al. 2000). In a recent review of the evidence in relation to exercise and Parkinson's disease, Protas et al. (1996) conclude that further research studies are needed in relation to the acute response to exercise; the interaction between exercise and medication; and the effect of exercise programmes. The current evidence base relating to exercise in Parkinson's disease can be broken down into three distinct areas - exercising in the context of physical activity such as walking or swimming; general therapeutic exercise programmes targeting the whole body; and specific therapeutic exercise programmes targeting a limited number of areas of the body. A brief review of the evidence will be presented.

Individuals with mild to moderate Parkinson's disease have been shown to be able to maintain normal exercise capacity with regular aerobic exercise such as walking or cycling (Canning et al. 1997). Support to maintain an active lifestyle incorporating

physical activity is important in Parkinson's disease because of the tendency to reduce physical activity; specific difficulties encountered with several common activities such as swimming; and the maintenance of optimal drug effect whilst exercising (Fertl et al. 1993). Regular physical exercise has been shown to influence the survival rate in Parkinson's disease by preventing decline from disuse (Kuroda et al. 1992).

Typical components of a general therapeutic exercise programme for people with Parkinson's disease, whether delivered in group format (Pederson et al. 1990; Vilianni et al. 1999) or individually (Formisano et al. 1992; Comella et al. 1993), include exercises in lying, sitting and standing to promote strength, flexibility, co-ordination and balance. Facial, speech and breathing exercises may be included, in addition to gait and circuit training and relaxation. Carers may be involved in general exercise programmes (Patti et al. 1996). The finding of positive results and patient evaluation from widely differing exercise programmes - slow stretching routine and upper body karate (Palmer et al. 1986) - highlights the importance of the physical and psychological effect of supervised exercise programmes.

In relation to specific exercise programmes, home exercises focusing on trunk and lower limb function (Banks and Caird 1989), trunk strengthening exercises (Bridgewater and Sharpe 1997), spinal flexibility programmes (Shenkman et al. 1998), and balance and lower limb strength training programmes (Hirsch 1996; Forkink et al. 1996) have recorded improvements in functional activities, trunk muscle performance, axial mobility, and equilibrium respectively. However many of the studies in this section are concerned about the carryover of exercise regimes after a period of physiotherapy (Comella et al. 1993; Banks and Caird 1989; Patti et al. 1996). Regular home visits have been shown to support continuation of exercise (Hurwitz 1989). The repeated delivery of top-up programmes has been proposed (Patti et al. 1996; Yekutieli et al. 1991). A wide range of media, for example, leaflets, tapes, videos and CD-ROMs (Turnbull 1992; Coene and Griffiths 2000), can be employed to support home based exercise. If exercise can be undertaken in a community setting, such as a keep fit class, it has the potential to help maintain social interaction (Coene and Griffiths 2000) (Chapter 10).

The fact that carryover of exercise is an on-going issue results from a top-down and professional, rather than a bottom-up and experiential, research emphasis (11.4.3.2, p. 273). Individuals report feeling guilty about not exercising as advised (Plant et al. 2000). Lacking from the evidence base is an understanding of exercise from the perspective of individuals with Parkinson's disease. Strategy mapping has highlighted the importance of an individual's exercise history, and of taking cognisance of individuals' own movement and exercise routines. Case study data has shown that regular ambulatory monitoring as part of on-going assessment within the home environment offers the potential to track changes in activity levels, which may require further investigation (Figure 7.5). Collaborative research and practice, involving individuals with Parkinson's disease and physiotherapists in a shared understanding of the incorporation of activity and exercise in lives where movement is impoverished and time for movement may be compromised, is needed.

7.6 Summary

This chapter has focused on the regular patterns of behaviour individuals employ to try to ensure the maintenance of body functioning. A key theme running through the sections of the **ROUTINES** area is the difficulty of maintaining a routine, in the strict sense of an unvarying course of action (Chambers 1991). Fluctuations may be inherent within a **MEDICATION** routine in the later stages of the condition. **DIET** strategies are needed to reduce and accommodate medication fluctuations. Different **EXERCISE** strategies are required for the times when medication allows good body functioning and when functioning is poor. It is the fact that individuals are engaged in self-management work that allows some form of **ROUTINE** to be crafted. The success of **ROUTINES** strategies influence **SELF** strategies (Chapter 6), and the need for **SUPPORT** strategies, which will be the focus of Chapter 8.

8 Strategy mapping: **SUPPORT** strategies

8.1 Overview of chapter

This chapter presents the results of strategies captured in the **SUPPORT** area of the strategy map (Figure 8.1). This area records strategies relating to external support for the individual with Parkinson's disease from a range of individuals, services, items and environments. The **INSIDER** section of the map records support from individuals with an emotional link to the person with Parkinson's disease – family, friends and acquaintances. The **OUTSIDER** section captures input from health and social care professionals, statutory and non-statutory agencies and the wider business community. The **ORDINARY ITEMS** section records the use of everyday household items to sustain activity, whilst the **SPECIAL EQUIPMENT** section records the use of items specifically designed to reduce disability. The **STRUCTURAL** area captures decision-making about the nature of the built environment to support activity.

However **SUPPORT** is not a neutral concept and the perception of proffered support by the recipient may be problematic. For example an able-bodied partner may take over financial management of the household because of the poor writing ability of the less able partner. However financial decision-making may be central to that individual's sense of worth within family relationships. Similarly a therapist may suggest an item of specialist equipment to enhance participation, which may be rejected as it may draw attention to the condition. Strategy mapping encourages making explicit the meaning of **SUPPORT** strategies in relation to those offering and receiving support. Strategy maps from **all** individuals in the randomised control trial have been drawn on to gain insight into strategies in this area. Differences in strategies in relation to disease stage and between groups will be highlighted. Case study data will be used to illuminate sections of the map where appropriate.

Figure 8.1 Strategy Map: SUPPORT area

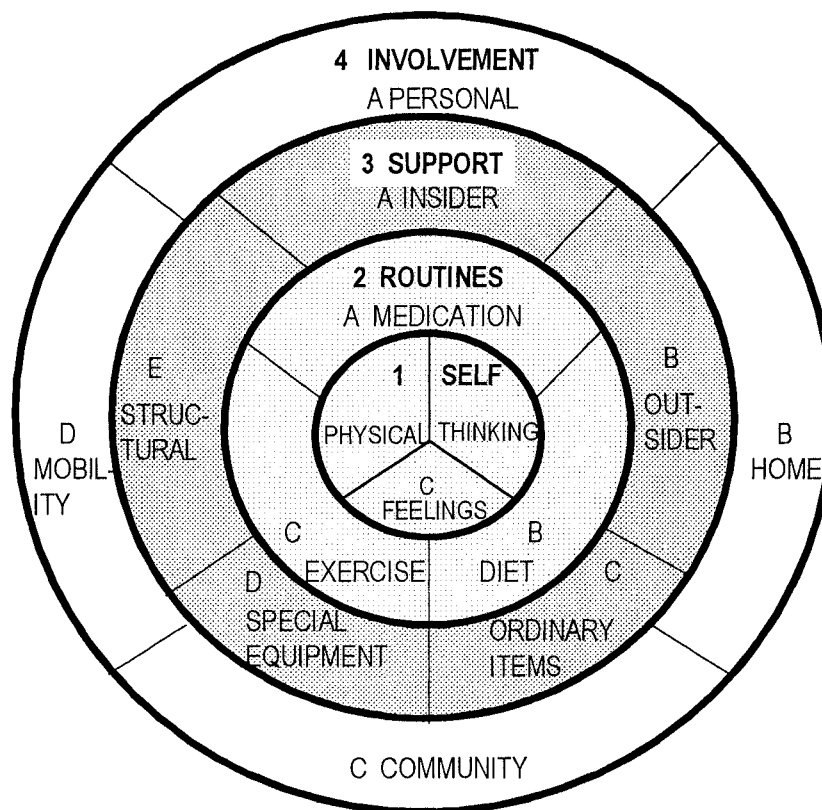


Figure illustrates the four areas of the strategy map, with SUPPORT area in darker highlight

8.2 INSIDER support

The **INSIDER** section of the map records support from people with an emotional link to the individual. Reference was made by individuals to support from spouses or partners; parents; siblings and siblings-in-law; children and children-in-law; grandchildren; friends and neighbours; and work colleagues. Support was received in relation to a wide range of activities: personal hygiene and dressing; household activities including food preparation; communication by writing or the telephone; maintaining the house and garden; and getting out and about in the community. In addition individuals also talked about receiving emotional support.

Just as the word ‘carer’ tends to diminish the ‘care’ the individual with the condition felt for the people around them (6.4, p. 146), so the word ‘support’ has the potential to diminish the reciprocity in supportive, or caring, relationships. Household management will be used to illustrate this reciprocity. Rather than support flowing in one direction, household tasks often required negotiated partnership with a spouse. Heavy Hoovering was often delegated to the most able partner, with cleaning and laundry accomplished through teamwork. One man in the early stages recognised that he was being “coaxed” to do light household chores such as hand washing. Even though they were slow and unsafe, individuals wanted to be allowed to contribute to tasks; however they recognised the temptation for spouses to “take over”. When negotiated partnership failed some individuals continued to undertake household tasks without the knowledge of their spouse despite feelings of guilt. One woman confessed to getting the duster out when her husband was out and occasionally moving furniture on her own. She was “not really allowed in the kitchen”.

Table 8.1 SUPPORT from spouses or partners

Strategy Mapping (PwPD ⁺)			PDS Survey*	
Activities	Early (diagnosed under 5 years)	Late (diagnosed over 5 years)	Carers	PwPD ⁺
Bed mobility	38%	55%	38%	25%
Dressing	65%	69%	59%	26%
Toilet	19%	31%	30%	8%
Household	73%	55%	75%	22%
Bathing	54%	79%		
Walking	62%	72%		
Feeding	42%	52%		
Speech	31%	35%		
Car transfers	42%	41%		

Notes - Table details level of support for key activities from spouses or partners identified from accounts of people with Parkinson’s disease (PwPD⁺) through strategy mapping, and levels of support identified from responses to Parkinson’s Disease Society survey (Yarrow 1999) (PDS Survey)* from both carers and people with Parkinson’s disease (PwPD⁺)

The actual level of support for a range of activities offered by different supporters was quantified for all individuals in the active and control groups. Table 8.1 details the level of support from spouses or partners for the main categories of activities identified for the early (diagnosed under 5 years) and late (diagnosed over 5 years) stages of the condition. The figures were recorded from documentary analysis of physiotherapy notes, which noted individuals offering particular types of support and any perceptions about that support. It is acknowledged that direct questioning on the issue of support using a survey format would have produced more comprehensive results. Nonetheless the picture to emerge provides the opportunity to discern patterns that may be worthy of follow up investigation. It has also allowed comparison with figures obtained in a recent survey of the PDS membership (Yarrow 1999). This survey asked carer respondents if they offered support in a variety of areas and also asked respondents with Parkinson's disease whether they received support in those areas.

It could be hypothesised that a progressively deteriorating condition would lead to a slowly increasing level of support over time. By contrast strategy mapping recorded a *high* level of support being received from spouses or partners in the *early* stages of the condition. That *level* of support did not rise sharply in the later stages, although the *nature* of support changed. For example, in the strategy mapping sample two thirds of individuals mentioned receiving help with dressing in the early stages and this level of support was maintained in the later stages. Over half the carers in the PDS survey reported offering help with dressing, however only a quarter of individuals with the condition reported receiving help. Over a third of individuals in the strategy mapping sample received support with bed mobility in the early stages. This was mirrored by the proportion of carers offering help with bed mobility in the PDS survey. In the later stages over half the strategy mapping sample was receiving help in this area, although only a quarter of people with Parkinson's disease reported receiving help in the PDS survey.

Levels of reported help received by individuals were universally lower than levels of help reportedly offered by carers in the PDS survey, although the statistical significance of the difference was not calculated. This finding has implications for self-report of levels of assistance which are the basis of most disability scales. However Brown et al. (1989) report that the judgement of the individual with Parkinson's disease is the best single

index of disability, with depression causing only a slight underestimate. Early stage strategy mapping figures concord with carer figures from the PDS survey in all compared areas apart from help with toileting, where the late stage figure concords. The fall in level of support for household activities in the later stage in the strategy mapping sample is likely to relate to reduction, avoidance and stopping strategies highlighted in the involvement strategy model (Figure 9.2, p. 211).

Although overall levels of support from spouses or partners remained relatively stable over time within the strategy mapping sample, the nature of the support was likely to change. For example, in the early stages support often meant supervision or minimal direct input. In relation to bathing initial support could involve simply having someone in the house in case of difficulty. Similarly in relation to feeding help in the initial stages was likely to involve occasional cutting up of meat. Help with small buttons might be the extent of dressing support. Many individuals reported welcoming an arm to link with when walking outside from the earliest stages. However in the later stages more direct input was often required. Help in and out of the bath or shower and with drying; the re-heating of meals in a microwave after they had gone cold due to slowness of eating; the setting out of clothing to facilitate dressing; and help to overcome freezing whilst walking might be needed. Support with speech largely related to ensuring time was given for the individual to participate in conversations. The stability of levels of support with car transfers may relate to a reduction in moving about in the community in the later stages, a trend confirmed in the involvement strategy model (Figure 9.2, p. 211).

Children were most likely to be recorded as offering emotional support. Whilst less likely to be involved in direct personal care, they were an important source of support in relation to writing, shopping, household activities, DIY, gardening and outings. Friends and neighbours also offered important emotional support, and could be active in helping with shopping, household activities and outings. For people living alone family members and friends were crucial sources of support.

Physiotherapy assessment with both the control and active group could provide an opportunity for individuals and their carers to explore both the nature of and the response to the support offered. One couple in the control group found after their initial assessment

that they were able to talk to each other frankly for the first time about the stresses on their relationship. They went on to seek further advice from their GP. Sensitivity to dynamics within a supportive relationship was central to physiotherapy with the active group, with practical advice, access to information and emotional support offered to carers. In the case of older carers, whose strategies for helping their partner had been established over many years, modifications were only suggested if they would improve safety (10.7, p. 252).

The support of spouses or partners can extend to 'sharing' symptoms at the level of awareness. Case study Participant 2, who had been diagnosed for 7 years, was experiencing increasing difficulty in achieving acceptable spells of 'on' time with his medication routine. A further medical review was awaited with great expectation:

“... because the quality of life for both of us due to this [fluctuation] this last two months, well its affecting [wife], I know that. To me its just another thing you've got to put up with”.

His wife replied,

“What affects me, when he goes off and he goes [mimics the sound and action of dyskinesic movements] ... It's distressing to watch, very distressing ... I'm not used to him being 'off' as long, I think ... He's never been like that.”

8.3 OUTSIDER support

The **OUTSIDER** section of the strategy map captures input from health and social care professionals, statutory and non-statutory agencies and the wider business community. Table 8.2 details the full range of professionals, agencies and organisations identified from strategy maps of all the participants in both the control and active groups of the

randomised control trial. This analysis provides a picture of the range of services rather than precise figures on their usage.

Table 8.2 The range of OUTSIDER SUPPORT identified from strategy maps

Health, Social, Business Sector	Personnel/service/trade
Statutory Agencies	
Health care	Medical practitioners – Movement disorders specialist, GP, Medical and Surgical consultants (eg specialists in diabetes, dermatology, rheumatology, gynaecology, care of the elderly, psychiatry, rehabilitation medicine, neurology) Nursing practitioners – Parkinson’s disease specialist nurse, District nurse, Practice nurse, Continence advisor, Community psychiatric nurse, Occupational health Professions allied to medicine – Chiropodist, Physiotherapist, Occupational therapist, Speech and language therapist, Dietician, Psychologist, Orthotist, Dentist Specialist services – Elderly Resource Team, Loan Equipment Service, Disability North, Disablement Services Centre, Mobility Centre, Sex and Relationship Clinic, Ambulance service Alternative practitioners – Osteopathy, Chiropractic, Homeopathy, Acupuncture, Massage, Reflexology, Aromatherapy
Social care	Occupational therapist Social worker Home care workers, Bath attendants Access and Carer Support Services Day Care Meals on Wheels Mobile Wardens
Benefits	DHSS – Invalidity benefit, Disability benefit, Attendance allowance, Mobility allowance
Local authority	Orange Badge Parking Scheme
County authority	Mobile Library
Other	Driver Vehicle Licencing Authority (DVLA)
Non-statutory organisations	WRVS, PDS, Luncheon clubs, Housing associations
Business	
Care	Residential care, Nursing care
Shops	Local shop, Supermarket, Shopping centre, Pharmacist, Optician, Disability aids shop, Launderette, Garage, Bank, Restaurant
Mail order	Clothing catalogue, Aids and equipment catalogue
Transport	Bus and train companies, Taxi, Carebus
Trades people	Private cleaners, Hairdressers, Decorators, Gardeners, Builders

The majority of participants in the trial were in touch with their GP. A GP with an interest in their needs in all their complexity - medical, social and psychological - was important, and one individual moved practices to achieve this. In another case an individual moved from the care of a neurology service to a service operating an integrated multi-disciplinary team approach in order to access more easily the full range of professionals he felt he needed. A wide range of consultants was accessed in relation to pathologies other than Parkinson's disease at all disease stages. Over half of all participants were in touch with a Parkinson's disease specialist nurse. Small numbers of individuals accessed specialist health care services, such as the wheelchair service, throughout all disease stages. The keeping of a diary of contacts with health and social service professionals was part of data collection for the trial (Chandler and Plant 1999). These diaries are currently being analysed to discern any differences between the level and nature of professional contacts in the control and active groups.

Use of Social Services personnel and facilities was very much greater in the later stages of the condition. Social workers were involved in putting together increasingly complex packages of home care, day care, carer support and respite, residential and nursing care. Nearly 30% of trial participants were members of the PDS, which proved an important resource for information and support. Although it is a requirement for drivers to notify the DVLA when diagnosed with Parkinson's disease, it was apparent that people were reluctant to do so for fear of losing their driving licence.

Whilst the complexity and proliferation of statutory agencies was unsurprising, what was surprising was the picture which emerged from adding the wider business community into the analysis. The local shop was often within walking distance and played an important role as a goal for walking each day or regularly throughout the week. It was often the place that an individual could manage to reach unaccompanied. Staff could get to know that handling money could be a problem for an individual and help by giving extra time or taking money out of a hand or purse. Supermarkets may have a free bus in a specific locality, and again staff could become familiar with the problems of regular customers, helping by packing bags or facilitating the exchange of money. Shopping centres with wheelchairs for hire might be the first place that an individual tries out a wheelchair. Success could promote a request to the relevant agency for long term loan of a wheelchair

in order to increase participation. In addition many shopping centres also house specialist disability aids shops.

The local pharmacist was an important resource for individuals on increasingly complex medication regimes and who often needed to take over-the-counter preparations to counteract side effects of medication and the condition such as constipation. Parkinson's disease itself could affect visual functioning e.g. the ability to judge distances or to see shapes clearly, and blinking could be reduced. Anticholinergic drug therapy could cause blurring of vision (Sagar 1991) Flexed posture could cause glasses to slip down the nose. A sympathetic optician could help optimise vision. Eating out was often something that people with Parkinson's disease gradually stopped doing. Individuals reported that finding a quiet restaurant with helpful staff could be a means of keeping up the ability to eat out. Having to write a signature in public could be a source of anxiety. A bank or building society that knows this is a problem could help by providing a customer with time and space to complete paperwork. Direct debits could be utilised, which like catalogue shopping, minimised the need to leave the home. Taxis became an increasingly important means of transport in the later stages of the condition, when driving and public transport could become problematic.

With increasing difficulty with household activities and house and garden maintenance, individuals accessed the input of a range of trades' people such as gardeners, decorators and joiners. This was often designed to reduce risk but added to the expense associated with disability. These issues and resources will be considered again in the context of the involvement strategy model (Chapters 9 and 10).

Taking part in the case study phase of this project made a difference to the financial status of Participant 6, aged 49. Just asking about allowances as part of the research interview alerted the family to their options. However this should also alert professionals to the need to disseminate information about benefits more widely as part of their practice (Guidelines Group 2001).

“After your visit I got the disability allowance backdated ... Actually I would never have thought about putting in for that. [Wife] went down to the Social Services because she wanted to get the form and they ... sent her down to the Benefits office ... We filled it in and low and behold they backdated it ... I expect nothing from anybody and when I get it it's a great surprise.”

8.4 ORDINARY ITEMS support

The **ORDINARY ITEMS** section records strategies in relation to the purchasing, positioning and use of items, such as household equipment, furniture and clothing, to counteract difficulties experienced in everyday life as a result of Parkinson's disease (Jones et al. 1999c). Appendix 12 provides details of all items identified in each category.

8.4.1 Seating, Beds and Bedding, and Furniture

From the earliest stages individuals were choosing seating for increased height and firmness and adding a variety of cushions and boards to optimise comfort, positioning and the bio-mechanics of sitting to standing. In the later stage of the condition a riser/recliner chair could support both transfers and positioning to avoid excessive forward flexion and to allow elevation of the lower limbs. Likewise beds were chosen for height and firmness. A variety of pillows were used for positioning. Bedding and nightwear of a silky material were used to facilitate turning. Fitted bed sheets and the sides of the mattress provided opportunities for pulling up on or pushing against when turning. Duvets simplified bedding and a duvet without a cover meant there was less opportunity for becoming tangled in bedding. Protection was sometimes required against salivation at night. Single beds provided respite from a partner's restlessness. In the later stages a bed might be brought downstairs to avoid stairs. Strategically positioned furniture provided hand holds for stability whilst moving about the home; a surface to rest a newspaper on; a stable base for drying and dressing; elevation for legs; and somewhere to gather items together to obviate unnecessary moving from place to place.

8.4.2 Bathing and Showering, Toileting, and Personal Hygiene

Getting into and out of a bath could become increasingly difficult and showers were often preferred. If help was likely to be required, a strategically placed bell could alert a member of the household. A variety of aids were used to increase reach including long handled bath aids, and an old, clean paintbrush for getting between the toes. Electric razors, electric toothbrushes, liquid soap and towelling bathrobes reduced the need for repetitive movements in personal hygiene activities. Using a smaller towel or a towel with holes in it aided manipulation. Shower seats and stools by the sink aided stability. Problems with continence and salivation were evident from an early stage. Sanitary towels and towels on chairs were used in case of accidents. Handkerchiefs, face cloths and then towels were employed to manage salivation.

8.4.3 Eating and Drinking, Cooking, and Household

Simultaneous activity of both hands was avoided whilst eating if one implement was used, either a fork or spoon, or in the case of salad one individual reported finding ice tongs helpful. Using a utensil that was bigger than necessary increased the margin for error, for example, a mug not a cup, and a high wide cereal bowl to increase scoop. If a knife was required, a sharp one was preferable. Straws were used for drinks. In the face of slowness in eating, food could be kept acceptably warm on a child's hot plate and so encourage the eater to continue. Effort was reduced in food preparation if prepared items such as ready-made meals, pre-washed potatoes, pastry mix and frozen foods were used. Organising the kitchen for ease of use, together with devices that reduced the amount of dexterity required, such as electric tin openers and dishwashers, was reported. Use of the grill and the microwave were increasingly preferred over the oven to minimise lifting and carrying. Automatic washing machines reduced the handling of laundry. Trolleys obviated the need to carry food and drink over distances. Placing a thermos flask of hot drink by a seat in a living room reduced the need to walk to the kitchen.

8.4.4 Clothing, Footwear, and Dressing/Make up/Jewellery/Accessories

Changes to the nature of clothing provided a major opportunity to reduce the demands of dressing tasks. Leisure wear was favoured for its lack of buttons, stretchy fabrics and

looseness of fit. Extending the thread on the top button of shirts was helpful, as was layering light and loose clothing. A variety of bra types were identified: front fastening, all in one, camisoles. Corsets could be used to support posture. Both tights and stockings had their disadvantages and stay up stockings, knee high stockings and long socks were substituted. Socks with stretch and boxer shorts were preferred by men. Pockets and long sleeved garments helped to disguise tremor and loss of arm swing. Cotton clothing helped reduce sweating, and dark clothing helped minimise embarrassment from excessive perspiration. Extra nightwear might be required due to excess sweating at night. Shorter tops were an aid to toileting. Trousers could protect from bruising as a result of severe dyskinesia. Easy dry, non-iron fabric reduced the work needed to maintain clothing. Slip on shoes, Velcro fastenings and wider shoe fittings helped independence. However lace up shoes fitted better, gave more support and were more flexible in the case of feet swelling. In one case metal tips were used on the shoes to give auditory feedback when walking. Ankle boots could provide increased support. Some individuals preferred to wear shoes, sandals or firm slippers indoors to improve gait. Dressing was helped by items that hooked or pulled such as the hook of a long handled shoe-horn or a clothes hanger. Women reported wearing pale makeup to cover up inaccuracies, and moving to clip on earrings even if the ears were pierced in order to be able to continue to wear earrings.

8.4.5 Writing, Telephones and Reading

With deterioration of handwriting ink pens, thicker nibs and lead pencils were all tried to increase writing flow, with lined paper used to cue print size. Typewriters and word processors were also employed. Telephones were often resorted to when writing failed. However individuals with poor speech, involuntary movements, manual dexterity difficulties and freezing could find telephone use problematic. People reported strategically positioning phones so that they were never too far away in the house; using portable cordless phones; using speaker phones; relying on the memory function; and using last caller redialling. Both tremor and dyskinesia made reading newspapers difficult. People moved from a broad sheet to a larger tabloid and used bulldog clips along the fold to increase manageability. Stability was helped by resting the paper on a table, or a book on a book rest.

8.4.6 Walking and Shopping, and Driving

Shopping expeditions were helped by use of a grandchild's pushchair, wheeled shopper or shopping trolley as a walking aid. Having access to a perch for a rest e.g. by the use of a shooting type stick, was helpful. A metronome was purchased to aid walking rhythm. Tray or draw-string purses could help with coinage. Continuing to drive was facilitated by the move to power assisted steering or fully automatic models. The latter reduced the need for complex simultaneous and sequential cognitive and motor tasks. People carrier type vehicles with higher seating helped access.

8.4.7 Health, Medication, and Remembering

A range of health equipment items was employed. Sports knee-pads were bought for an individual whose gait was so poor that crawling was the safest way to move about the home. Inflatable head and neck supports were purchased. In one extreme case masking tape was used to try to stop tremor at night. Old remedies such as the use of corks wrapped in old nylons to prevent cramps were resorted to. It was important to ensure that items such as glasses, hearing aids and dentures were of an optimal prescription to aid balance, communication and nutrition. It was also important to ensure the best hearing in the partner in the face of potential softness of voice (hypophonia). Timing medication was aided by the use of an alarm clock, and correct dosages aided by setting out daily medication in home made and specialist containers. Notice boards, diaries and calendars helped day to day organisation and appointment keeping.

8.4.8 Hobbies, Lighting/Security, and Work

Continuing with hobbies such as gardening, DIY and needlework was supported by a variety of different devices widely available in the shops which would: reduce the need to reach (e.g. garden kneeler, also used to help access kitchen cupboards); increase stability (e.g. use of scaffolding rather than a ladder; use of a tapestry frame); and reduce repetitive movements (e.g. electric screwdriver). Ensuring that areas were well lit meant that additional visual information was available to make gait safer. Some individuals were still in employment and there was evidence of task demand reduction in the workplace. For

example, delivering Meals on Wheels was facilitated by using a trolley to load up the van and a carrier bag to place meals in to deliver them.

8.4.9 Strategy change

There was evidence of development of strategies with disease progression. For example in the area of seating, initially chairs were chosen for height and firmness but later there was consideration of electronic riser/recliner chairs to minimise task demand. Aids to support independent bathing were important in the initial stages, with emphasis on space to allow carer support later on. Increased size of cloths to deal with salivation was reported - from handkerchiefs, to face cloths, to towels. If clothing became too problematic it was substituted for and then ultimately abandoned if possible. This was evident in the case of socks, tights and bras. As writing became more difficult typewriters and word processors were accessed and in some cases abandoned in favour of the telephone. However this was often an activity where the help of others was elicited due to problems with slowness of thinking (bradyphrenia) and speech. The tendency to continue, modify, avoid and then stop the use of ordinary items corresponds with the involvement strategy model (Figure 9.2, p. 211) articulated in Chapter 9. Physiotherapy involvement with the active group meant that there was cross fertilisation of ideas about the use of ordinary items, e.g. in relation to the use of different purse shapes and the use of a bathrobe to dry off in.

Finding the right ordinary item for a task was an on-going challenge. Case study Participant 3 had worked in an office and found the differential in power between her affected and her unaffected hand difficult when using an electric typewriter. Now retired at home when typing with her manual typewriter she used proper fingering with her unaffected hand but only one finger on her affected side. Her husband had bought her an electric typewriter but the touch was so sensitive she produced a double letter as a result of tremor. She still maintained her writing skill through sending short letters to her daughter abroad.

8.5 SPECIAL EQUIPMENT support

The **SPECIAL EQUIPMENT** area records the use of specialist items designed to reduce disability. As with other sections in the **SUPPORT** area, it is acknowledged that a specific audit of, in this case, special equipment would have provided more precise results. However the picture obtained here from documentary analysis of special equipment recorded in physiotherapy notes provides a baseline from which it is possible to discern patterns which could inform further investigations. In common with other strategy map areas, the meaning of the use of special equipment was also important to discern. Appendix 13 provides details of the numbers of each item identified.

8.5.1 Seating, Beds and Furniture

Chair raisers were used throughout the disease course to provide increased height from which to mount sit to stand transfers and to aid stand to sit manoeuvres. Seat boards were employed to provide a stable base for transfers. Later in the disease course sit to stand and stand to sit transfers were aided mechanically or electronically by spring-loaded or riser/recliner chairs respectively. Poor standing balance as a base for activities was addressed with the increasing use of perching stools.

Bed boards were used to give increased firmness for turning and bed transfers, with bed levers, monkey poles and rope ladders used to aid bed mobility and bed raisers employed to increase bed height. Electronically operated beds and mattress raisers were employed in the later stages. The large mechanism required for the mattress head raiser was disliked in one case. A special mattress to relieve skin pressure was used not on the bed but on the floor to enable an individual in the control group to maintain their normal transfer of falling out of bed without injury. A glide sheet proved unsuccessful for helping a spouse turn an individual at night. However it was noted that the aid had been delivered with few instructions and no demonstration of its use had been arranged.

Cantilever tables were used throughout the disease course, with high-handled trolleys evident later.

8.5.2 Bathing and Showering, Toileting and Continence

Bath boards and seats were the most common aid to bathing throughout the disease course. On several occasions it was noted that the bath board was not in use. Sometimes aids obtained for an older relative living with the family or for a disabled child were used by the person with Parkinson's disease. This again highlighted the issue of people with Parkinson's disease as carer rather than cared for (6.4, p. 146). Various types of bath lifters were employed throughout the course of the disease but increasingly in the later stages. Comments were made about the amount of space bath lifts took up in small bathrooms. Many individuals preferred to shower rather than to continue to have a bath, and shower seats were increasingly used.

Raised toilet seats and surrounds were often tried by professionals when toilet transfers became a problem. There was a particularly high level of dissatisfaction expressed about this aid by this client group, with a large number returned to loan equipment stores. There was a preference for grab rails to aid toilet transfers. Increasing continence problems with disease progression were highlighted in aid usage, including incontinence pads and pants and specialist bedding. Considerable manual dexterity was required to use a urinary bottle, and at night some individuals preferred to use a bucket.

8.5.3 Eating and Drinking, Dressing, and Household

Stability of plates was addressed by the use of adhesive mats, and plate guards ensured a surface against which to stabilise food for cutlery use. Specialist cutlery and drinking aids became increasingly necessary as disease progressed. However dressing aids such as sock and tights aids were obvious early in the disease course. Household aids such as lever taps, plug grips, Helping Hands, kettle and teapot tippers were used throughout the disease course to compensate for reduced manual dexterity, strength, balance and co-ordination.

8.5.4 Support/Braces, Pain Relief , Symptom and Medication Management

Lower back pain, often of long standing duration, generalised musculo-skeletal problems and circulatory problems required a range of supports e.g. cervical, wrist, lumbar, knee

and ankle supports and support stockings. Pain relief was pursued through the use of massagers, hot packs and transcutaneous nerve stimulators. Ice packs and vibrators were employed to aid the management of nodules that could be a side effect of apomorphine pump treatment. As medication regimes became more complex so use was made of pill meters that could be set to sound when the next dose was needed, and dispensers with compartments into which pills could be counted to ensure correct dosage.

8.5.5 Walking Aids, Wheelchairs and Cars

While walking sticks were used throughout the disease course there were many references to difficulties with their use. Sticks were used outside as “a cautionary item”, “a third leg”. One participant in the early stages commented that the “stick was less to walk with than to lean on” and to help him remain upright if standing still for any length of time. Another at the same stage said he swung his stick “Charlie Chaplin style”. Although one individual in the late stages was aware of catching her toes and walking “lop-sided”, she reported her walking stick to be “more of a hindrance; ‘lethal’, has tripped herself up in the past, ‘a John Cleese walk’”. Following an orthopaedic operation she had been given elbow crutches that she found not only assisted her gait but reduced back strain and stabilised dyskinesia.

Wheelchair use rose with stage with over half the individuals in the latest stage having access to a wheelchair. Car adaptations were rare, only occurring at the latest stage. Aids for car transfers were employed early in the disease course.

8.5.6 Reading, Writing and Speaking

There was limited evidence of the use of special equipment for reading and writing. A speech amplifier was essential to maintain communication in a relationship between a wife with hypophonia and a husband with severe deafness.

8.5.7 Security

Whilst the use of intercoms and emergency pull cords was likely to be found in sheltered accommodation, there was increasing use of personal alarm systems in the community.

8.5.8 Rails and Stair lifts

There was extensive use of additional rails in this client group, with stairs, bathroom and toilet areas being the most common areas for additional hand holds. Funding for stair lifts was often problematic (8.6), as were technical difficulties associated with their installation. Their use increased in the later stages.

8.5.9 Strategy change

Several participants had made do-it-yourself aids and equipment including an access ramp and cot side. Modifications to equipment included mounting a bucket on a walking frame for night-time toileting, and adding a tray with non-slip covering to a walking frame to facilitate carrying items. Specialist equipment was used from the earliest stages, however the complexity of the equipment and its use in combination with equipment required in a variety of other areas increased with stage. The numbers of items of special equipment in each area were similar for active and control groups.

The experience of case study Participant 2 highlights the ad hoc nature of advice on special equipment and the importance of informed trades people (8.3). Having seen a grab rail in the bathroom during a tour of the house, I asked if he had seen an occupational therapist:

“No. No, that was based on the plumber who was just putting a toilet in for us. He had done a toilet for an elderly lady in the street, using the coal-house, which was situated in the garage. He says, “I think you could do with a grab rail”.

8.6 STRUCTURAL strategies

The **STRUCTURAL** section of the map records the use of, or modification to, the structure of the built environment. It was the section that captured the least data but contained information on difficult decisions faced by individuals that were of significance for physiotherapy intervention.

Chapter 10 highlights challenges moving around in the home, including stair usage. The installation of a stair lift could prolong a stay in a house. However from the earliest stage individuals were considering or making a move towards single storey living, most frequently in a bungalow. Sometimes however this was achieved through alterations to a house, involving conversion of a downstairs room to a bedroom and the creation of a downstairs bathroom and toilet. Even if life was thereby made safer and easier it could none the less feel “restricted”. One individual reported reluctance to live in a bungalow as he felt safer sleeping upstairs; another reported reluctance to consider moving from a home in which he had lived for 40 years. Moves could cause tensions in relationships. One woman in the later stages reported loving her new flat because it made it possible for her to participate fully in its upkeep. However she was aware of the restrictions their new home imposed on her husband which prevented her from enjoying her new environment fully. Physiotherapists may be involved in the decision-making process about housing. One carer whose husband was in the later stages suggested a move to a bungalow to a physiotherapist but had been put off the idea by the physiotherapist’s comment that doing stairs was the only exercise her husband got.

Challenges involved in bathroom transfers are also discussed in Chapter 10, and this chapter has highlighted the support received from individuals, ordinary items and special equipment in relation to personal hygiene. Redesigning bathrooms to enable installation of shower cubicles was an early, common and enduring strategy. However the precise design of showers installed was important. One individual was unable to manage the step up into a new shower. Another chose a corner bath with integral seat and lowered side access in preference to a shower cubicle.

This section of the map highlighted the difference in access to support if individuals were in owner occupied or Council housing. Individuals found it more difficult to move from the owner occupied sector into sheltered accommodation because of the shortage of supply and the points system in relation to need. It was a surprise for people to realise that despite their difficulties they were often not able to qualify for Social Service assistance if in privately owned property. Installation of stair lifts was particularly problematic for owner occupiers, and sometimes difficult to fund in a Council scheme. However a request for assessment of bathing in Council accommodation could often result in redesigning of the whole home to take account of the full range of problems. In one case glass doors were replaced with solid panels due to the perceived falls risk. One family was already living in an adapted bungalow designed for the needs of a disabled daughter.

One late stage individual reported hanging his bedroom door from the opposite side to afford more space and taking his kitchen door off altogether to help with difficulty with narrow doorways. Attention to lighting improvements was a strong theme at all stages, both inside and out. Redesign of the immediate environment outside the house was also undertaken. Consideration was given to the use of labour saving materials such as UPVC window frames and doors. When out and about awareness of the built environment was demonstrated by consideration of location of disabled toilets, islands or crossings to enable roads to be crossed, escalators (although some reported finding them more difficult than stairs) and lifts.

References to considering factors such as moving or installing showers in the early stages had largely changed to reporting the undertaking of adaptations or moves to accommodate mobility difficulties in the later stages.

Case study Participant 2 was experiencing increasing frequency and urgency of micturition which, combined with motor fluctuations, often made reaching an upstairs toilet difficult. He was an owner occupier.

“I would like a downstairs toilet ... I approached my company regarding that and they sent the Welfare Officer, who I hadn't seen for two years, and he said, had I approached the Social Services? ... the Trustees wouldn't do anything unless the Social Services had turned it down.”

Social Services turned the application for funding down and the adaptation was self-funded.

8.7 SUPPORT strategies - Implications for physiotherapy

The **SUPPORT** area of the strategy map has illustrated the nature and levels of **INSIDER** support; the variety of **OUTSIDER** support; the problem-solving in terms of **ORDINARY ITEMS** which precedes the use of **SPECIAL EQUIPMENT**; and the challenges posed by **STRUCTURAL** support. The following account will discuss the key implications for physiotherapy practice and research in the context of the literature.

8.7.1 INSIDER support

Plant et al. (2001) identified a range of issues in relation to involvement of carers in physiotherapy. There is a tendency for physiotherapists to equate carers with spouses and partners when in fact a range of individuals may provide different kinds of 'insider' support. The involvement of carers in physiotherapy is problematic. Logistics, such as working hours, ambulance transport and the delegation of home visits to other members of the multi-disciplinary team, often make it difficult for physiotherapists to make contact with carers. This issue is addressed if there is a formal policy on carer involvement within a rehabilitation service (Wade 1999). Some individuals do not want their carers involved, and some carers feel physiotherapy offers their partner space without them. However carers can provide important information on activity levels and levels of support required in the home and community. Comparison of levels of support reported within this project with data from the PDS survey (Yarrow 1999) (Table 8.1) illustrates greater congruence with levels of support reported as being given by carers than levels reported as being

received by people with Parkinson's disease. Individuals with the condition appear to under report the level of support they are in receipt of.

Carers have their own needs, although these are often seen in relation to supporting professional activity. A physiotherapist can explain to carers how Parkinson's disease has affected the movement of the person they care for and provide information and advice on the best way to help the person and to avoid injury to themselves (Coene and Griffiths 2000). Carers offer high levels of support with activities associated with core areas of physiotherapy practice such as turning in bed (Yarrow 1999), and find advice on practical handling particularly helpful (Plant et al. 2001). Carer involvement in physiotherapy can provide important carry over of treatment concepts, such as cueing gait in the event of freezing (Nieuwboer et al. 1997). Their involvement is especially important in the face of cognitive deficit or depression in the person they care for (Plant et al. 2000). If carers have access to good information about the movement consequences of Parkinson's disease they can provide important feedback about symptoms and response to intervention (PDS 1994).

Thomas et al. (1999) suggest that health care professionals should ensure they identify the carers of individuals with Parkinson's disease who are referred to them; make sure individuals are prepared for information to be shared with carers; check that carer health, physically and emotionally, is being regularly assessed, including use of the Caregivers Strain Index; and inform them about assessment of need in their own right, and about local support groups. Just as strategy mapping is suggesting a grounded approach to working with individuals with Parkinson's disease, so finding a way to work in a grounded way with carers is important. Watching the person they are caring for deteriorate, witnessing their personality change and fear of illness in themselves are key stressors (Davies et al. 1999). Working on carer-centred strategies in these areas is likely to make a difference to the experience of caring.

8.7.2 OUTSIDER support

A wide range of health and social care professionals and non-statutory organisations may be involved in delivering care to and supporting individuals with Parkinson's disease.

Physiotherapists are likely to work as part of a team of professionals that may be providing care for individuals with Parkinson's disease specifically or for a wider range of patients, for example the elderly (Plant et al. 2000). Where their teams are based - in primary, secondary, intermediate or community settings - will influence the range of other professionals and agencies they interface with directly or indirectly (Guidelines Group 2001). In the study by Plant et al. (2000) most physiotherapists felt their teams worked well, citing as the main drivers a common commitment and shared interest in working with people with Parkinson's disease, the sharing of information and the breaking down of barriers between professions. However it was acknowledged that further work on communication and teamwork was required, which is mirrored in the conclusion of the Audit Commission (2000) report on rehabilitation for older people.

Use of a model of care, such as the Thomas et al. (1999) stages of Diagnosis, Maintenance, Complex and Palliative, with associated aims, assessments, management and outcomes, can help planning and communication within a team. Integrated teams of professionals developing local pathways of care in partnership with the users of the service within a care management approach offer another way forward (Bilclough et al. 1999). The latter model operates a trans-disciplinary approach (Mackey and McQueen 1998) in which each professional's skills, typically delivered to the individual directly by the specific professional, are shared and transferred across people. In addition a key worker provides links between the individual and carer and the team. This model should help to address the problem of uncertainty from the perspective of individuals and their carers in relation to the multiplicity of job titles and roles amongst the professionals with whom they come in contact (Plant et al. 2001; Yarrow 1999).

Individuals with Parkinson's disease identify marked difficulties accessing information on a whole range of issues (Plant et al. 2001; Yarrow 1999). Physiotherapy services for people with Parkinson's disease need to address three specific areas of information dissemination. The first area is related to the local physiotherapy service itself (names of staff, contact telephone numbers, transport arrangements, times of sessions etc); the second relates to an individual's physiotherapy programme (details of exercises and strategies, using a range of media, e.g. written, audiotape, videotape, and addressing ethnic needs if necessary); and the third relates to a comprehensive signposting to the full

range of services, agencies and businesses which individuals may benefit from access to (Guidelines Group 2001).

Strategy mapping has highlighted that support received from businesses and trades people can be important in promoting participation in activity outside the home. Widening the professional vision to include working with the local business community has the potential to raise awareness of the needs of people with Parkinson's disease at the same time as developing services to meet their specific needs. The Disability Rights Task Force (1999), set up by the Labour Government to review the Disability Discrimination Act of 1995, challenges the perception that the needs of disabled people and those of business are in conflict. They suggest that reaching shared solutions to problems faced by disabled people must be the model for the future. Their recommendations for strengthening anti-discriminatory legislation in areas of employment, health, access, transport, and housing adaptations have the potential to make a major difference to the lives of people with Parkinson's disease.

8.7.3 ORDINARY ITEMS support

Verbrugge and Jette (1993) suggest that disability occurs for a given activity when there is a gap between the capability of the person and the demand of the task. Disability can be addressed by either increasing the capability or reducing the demand. Whilst health care professionals may focus primarily on improving capability, individuals themselves lead the way in reducing task demand. Ordinary items play an important part in reducing task demand, and in so doing promote activity and participation dimensions of ICIDH-2 (WHO 1997). Activity is the integrated activities expected of people as they perform daily tasks such as bathing and shopping, and participation is the experience of individuals within their physical, social and attitudinal environment. Many ordinary items support activity e.g. ready prepared food, and also participation, e.g. continuing in the role of someone who contributes to feeding the family.

The purchasing and use of ordinary items highlight the extensive range of clinical features involved in Parkinson's disease - movement difficulties as well as the cognitive and autonomic problems (Paulson and Stern 1997). Dyskinesia may be severe enough to

cause bruising which can be helped by wearing trousers. Night-time tremor can be so distressing that recourse is made to binding the hands with masking tape. Night sweats may necessitate many changes of clothing and bedding at night. Single beds may be needed for sleep disturbance. Night-time is an under assessed problem area in Parkinson's disease (Walker et al. 2000).

Mapping strategies in relation to ordinary items in Parkinson's disease shows individuals addressing issues of motor control (Mak and Cole 1991; Morris et al. 1994b; Rothwell 1995). Difficulty with axial movements is helped by silky sheets to facilitate turning. Problems with maintaining sequences of movement such as walking can be helped by metal tipped shoes. Simultaneous movement can also be problematic. Automatic cars obviate the need for sequencing clutch and accelerator pedals whilst changing gear. Repetitive movements tend to degrade with time so the use of an electric toothbrush or electric screw-driver helps maintain a standard level of performance. Slowness of movement affecting eating can be addressed by the use of a heated plate, and deterioration in writing by the use of a word processor.

Education of health professionals is traditionally based on a top down, biomedical perspective, focusing on pathology and impairment. It could usefully be restructured to include a bottom up or user perspective approach, addressing activity and participation. A focus on the lived experience of neurological conditions promotes sensitivity to a wider range of knowledge bases (11.4.2. p. 269). Understanding demand reducing strategies using everyday items can help physiotherapists pinpoint areas of concern for individuals and understand pre-existing problem-solving work to counteract them. Use of this knowledge coupled with objective assessment can inform joint decision making and provide an opportunity for learning in partnership, valuing individuals' expertise in disease management.

Mapping strategies in relation to ordinary items offers the potential to build up an information resource for professionals and individuals alike (11.4.2, p. 269). This might be considered an appropriate joint activity between health care professionals and the local Parkinson's Disease Society branch. Catalogues and names and addresses of suppliers of useful items could be collected. This type of exercise also has the potential to inform the

debate about the economic cost of disability. Two thirds of members in the Yarrow survey (1999) stated they spent more because of Parkinson's disease.

8.7.4 SPECIAL ITEMS support

Before making recourse to specialist equipment individuals are likely to have exhausted the options available to them through ordinary items. For example, before dressing aids are employed much thinking has gone into modifying clothing purchases to reduce difficulty. The categories of aids identified in this study map onto those highlighted in previous studies (Beattie and Caird 1980; Oxtoby 1982; Mutch et al. 1989; Yarrow 1999). The main areas identified in these studies were bathing, toileting, feeding, kitchen, dressing, manipulating, mobility and communication aids. A study by Beattie and Caird (1980) found considerable under-provision of simple aids to daily living, despite the fact that a third of the sample had already seen an occupational therapist. The study involved the provision of aids for assessed need. At follow up these were reported to be of considerable practical value. The cost of supplying all the necessary aids was modest, amounting to £23.10 at 1979 prices. At that time this was equivalent to four weeks' supply of levodopa or less than 12 hours in hospital (PDS 1994).

In a survey of a PDS branch membership, Mutch et al. (1989) found that despite a high level of dependency amongst the respondents relatively few aids were in use. The majority of aids used were in the areas of bathing and self-care. They highlight the need for proper assessment, advice and information for patients and professionals about the range of aids available. A study by Clarke et al. (1995) found 64% of the study group using some form of aid or adaptation, most commonly for walking and bathing. Yarrow (1999) identified these areas, in addition to toileting, as the main areas for the use of aids. However individuals found considerable difficulty gaining advice and information about specialist equipment, with half the respondents identifying this area as an information need (Yarrow 1999). There is considerable overlap in the roles of physiotherapists and occupational therapists in the supply of aids and equipment (Chesson et al. 1996). However the low rates of referral of individuals with Parkinson's disease to both professions (Table 2.2, p. 34) must affect the supply of aids and equipment to this client group.

Whilst medical equipment shops, large chain-store chemists and mail order catalogues offer a full range of products, Beattie (1991) highlights the benefits of professional advice to avoid expensive mistakes. The use of aids and equipment in relation to areas such as bed mobility, sit to stand transfers and walking needs to be grounded in an understanding of motor control and motor learning theory. For example, the provision of a bed lever to aid turning and transfers should be part of a movement strategy which can include using the lever as a visual cue to initiate a series of steps to accomplish the activity (Kirkwood et al. 1997). There was evidence within the current project of lack of attention to training in the use of handling equipment (8.5.1).

Even in the area of gait, there has been little formal work on assistive devices and Parkinson's disease (Mutch et al. 1989; Paulson 1995). Despite the fact that walking sticks were shown in this study to be in use throughout the disease course, many reservations about their utility were recorded. Whilst often difficult to co-ordinate, they appeared to have a use as an aid to standing balance. Morris et al. (1997) highlight the fact that individuals often festinate while concentrating on carrying, rather than using, their stick. One individual in this study found elbow crutches afforded enhanced control of dyskinetic gait via additional stabilisation. This links with findings in the involvement strategy model relating to stabilisation (10.3.5, p. 242) and is worthy of further study (11.6, p. 283). Walking frames may restrict the individual's stride length and encourage forward flexion, and in some cases the frame is carried (Morris et al. 1997). Wheeled walking frames have the advantage of not requiring sequential placing and of bringing the weight forward in individuals with a tendency to fall backwards. However, they do not encourage axial rotation, and they should be avoided in individuals with a tendency to festinate as they may advance too quickly (Morris et al. 1997).

It has been estimated that purchasers should plan to provide about 40% of their Parkinson's disease patients with wheelchairs (PDS 1994). This study demonstrated that just over one third of the total sample used a wheelchair, compared to a quarter of the latest PDS survey (Yarrow 1999). However over half of the individuals in Stage 4 were using a wheelchair, with many reliant on younger relatives to push wheelchairs. Wheelchair prescription, which is often a very sensitive area with individuals and their families, seeming to denote a negative step, needs to be discussed in the context of

allowing participation in family and community activities which would otherwise be difficult, exhausting or impossible.

Problems with movement as well as cognitive changes may result in major difficulties with driving which should be assessed by suitably qualified therapists and driving instructors (Kirkwood et al. 1997) ideally at specialist Mobility Centres (10.7, p. 254). In addition there may be car transfer difficulties for individuals who only travel as passengers, and Mobility Centres are equipped to assess specific needs in this area.

There should be audit of satisfaction with aids and those not promoting function returned. It is not uncommon to find aids supplied for other people, e.g. an elderly relative or disabled child, being used by individuals subsequently diagnosed with Parkinson's disease. Their appropriateness requires assessment. The wide range of areas covered by specialist equipment underlines the importance of multidisciplinary team management, e.g. liaison with continence nurses, dieticians, occupational therapists and speech and language therapists, together with links with the local Mobility Centre, non-statutory organisations for people with sensory problems such as visual or hearing loss and Disability Centres (Guidelines Group 2001). It is not uncommon for a carer to have health problems that exacerbate the problems of the person with Parkinson's disease, for example, a deaf carer of someone with speech difficulties, a frail carer of a heavily dependent spouse. Management must be holistic and encompass the needs of both parties to be successful.

8.7.5 STRUCTURAL support

Strategy mapping has highlighted that difficulty with mobility is the main driver for changes in the built environment, most notably in relation to bathing facilities, and for a move to single storey living. Decisions about structural changes are affected by complex physical, emotional, social and economic factors. Housing issues tend to form a small part of larger studies but published literature is supportive of strategy mapping results. In a study by Clarke et al. (1995) 19% of the sample had moved because of their Parkinson's disease, mostly to a bungalow or ground floor flat, and a further 19% wanted to move as a result of their condition, most of whom were living in a house. Likewise 14% of

individuals in the Yarrow (1999) survey felt their current housing was unsuitable for their needs, either because of stairs or steps which were difficult to negotiate or because adaptations were needed. Physiotherapists need good multidisciplinary and interagency links, in addition to sensitivity to the needs of both individuals and carers, if a house move is being discussed in order to contribute to decision making in this area.

8.8 Summary

This chapter has highlighted the wide range of **SUPPORT** - from people, through objects to the environment - that may be drawn on to counteract the effects of Parkinson's disease. However accepting, acknowledging, locating, using, timing and financing support can all be problematic. Strategies in the first three rings of the strategy map (Figure 5.1, p. 128) now come together in the outer ring in relation to **INVOLVEMENT** strategies, the focus of Chapters 9 and 10. **INVOLVEMENT** strategies relate to the undertaking of everyday activity in and outside the home, and capture the linkage between performance, context and meaning. An individual's **SELF**, **ROUTINES** and **SUPPORT** strategies coalesce uniquely to make involvement in everyday activity more or less likely. Awareness of this process offers the physiotherapist insight into how best to negotiate maintenance and enhancement of that involvement.

9 Strategy mapping: INVOLVEMENT strategies 1

9.1 Overview of chapter

The **INVOLVEMENT** area of the strategy map (Figure 9.1) records strategies relating to the undertaking of everyday activities within the full range of social settings, encompassing the home and the wider community. It is concerned with identifying the complex inter-relationships between the performance of the activity itself, the context within which it is undertaken and the meaning that involvement in that activity has for individuals. The **PERSONAL** section records individuals' strategies in relation to personal hygiene (bathing, toileting, grooming), dressing, eating and drinking. The **HOME** section records strategies in relation to household management (cooking and cleaning), communication (writing and telephone), hobbies (reading, DIY, gardening etc) and socialising with family and friends. The **COMMUNITY** section captures strategies in relation to socialising outside the home, shopping and paid employment.

The **MOBILITY** section records strategies concerned with moving about within the home - walking, stairs, transfers into and out of chairs and bed mobility – and outside the home – including using public transport and cars. This final section, central to the practice of physiotherapy in Parkinson's disease, will be reported separately in Chapter 10, although using the same model of presentation as Chapter 9.

Figure 9.1 Strategy Map: INVOLVEMENT area

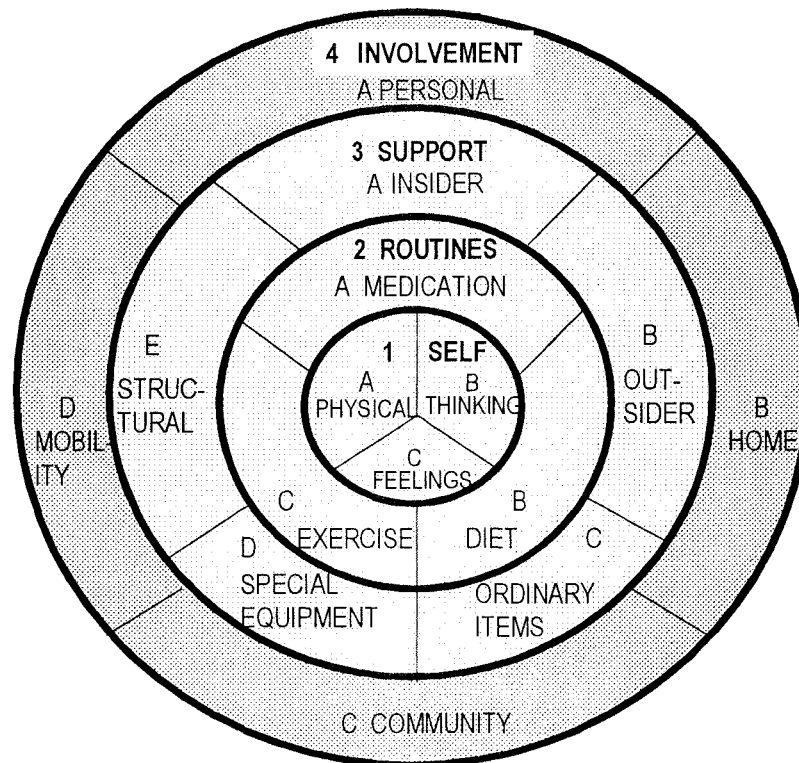


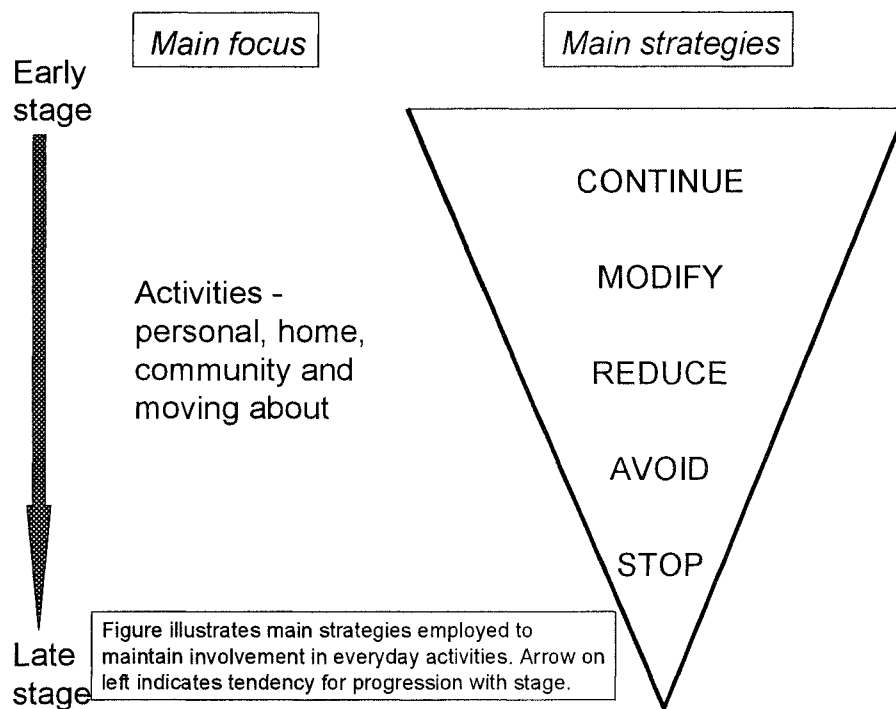
Figure illustrates the four areas of the strategy map, with INVOLVEMENT area in darker highlight

Previous sections of an individual's strategy map will provide background information of importance when recording and analysing **INVOLVEMENT** area strategies. For example, the detail of strategies recorded in **SELF/FEELINGS** (Table 6.1, p. 150) in relation to 'keeping going' will make it more likely that individuals will continue to be involved in a range of activities. The effectiveness of **ROUTINES/MEDICATION** (7.2, p. 163) strategies will determine the extent of the window of opportunity for activity. The perceptions of individuals' in relation to utilising the **SUPPORT** of individuals, ordinary items and special equipment for everyday activities (Chapter 8) will determine its acceptability.

9.2 INVOLVEMENT strategy model

During analysis of **INVOLVEMENT** area data a model emerged involving a series of linked domains relating to continuation, modification, reduction, avoidance and stopping strategies in relation to activities (Figure 9.2).

Figure 9.2 INVOLVEMENT strategy model



From beginning to end stage continued involvement in activities as they were previously undertaken, despite increasing difficulty in performance, was preferred. However, when continuing was no longer a viable option, modification strategies were put in place that altered the way the activity was carried out. Modification strategies included compensation for reduced motor ability on the most affected side by use of the least affected side; performing activities at times when individuals felt they would be at their best; allocating extra time in order to pace activities; planning activities in advance; and ensuring a stable base from which to perform activities. Whilst reduction could be viewed as an additional modification strategy, these strategies formed a distinct group relating to

judgements about reducing task complexity, frequency, amount and ‘standards’. Once modification and reduction strategies ceased to allow an acceptable standard of performance for the individual, avoiding or stopping the activity altogether was the likely scenario. The **SUPPORT** strategies detailed in Chapter 8 were most likely to be incorporated at the first three stages of the involvement strategy model to enhance continuation, modification and reduction strategies and minimise the need for avoidance and stopping strategies. The picture to emerge from the data was one of strenuous effort on behalf of individuals to counteract a range of factors that appeared to conspire to encourage withdrawal from activity in all aspects of life. The challenge for professionals appeared to be to find the best way to support them in their efforts.

Each domain of the **INVOLVEMENT** strategy model - continuation, modification, reduction, avoidance and stopping – can be identified within all sections of the **INVOLVEMENT** area of the strategy map. The following sections 9.3-9.7 will examine each of the model’s domains using illustrative data from the **PERSONAL**, **HOME** and **COMMUNITY** sections of the **INVOLVEMENT** area of the strategy map. Section 9.8 examines the model in relation to overall daytime and night-time activity. Case study phase material illustrative of this section, gained through the use of ambulatory monitoring and associated methods, is provided in Appendix 14. Section 9.9 will focus on the differences identified in relation to the model for various stages of the disease and between active and control groups. Chapter 10 will examine the **MOBILITY** section in relation to the **INVOLVEMENT** strategy model. It will also contain a discussion of the implications of the model for physiotherapy practice.

9.3 Continuation strategies

Continued involvement in activities, often in the face of increasing difficulty, was the preferred option for individuals. For some it was a matter of necessity. An early stage individual in the control group was aware of literally losing his grip in relation to shaving and dental care but felt he had no option but to continue to perform the activities. For one woman in the early stages there was no option but to continue the household management

role as her husband chose to ignore her difficulties. Continuing to write was imperative for one late stage individual whose husband was deaf. Writing notes to him was an essential part of their communication pattern.

Continuing activities could increase feelings of wellbeing. Baths were used to reduce stress and to help rigidity despite difficulty with transfers. Regular showers helped maintain hygiene in the face of continence or salivation problems. Despite difficulties with wet shaving or the application of makeup, the fact that individuals felt better having managed the task made it worth the struggle. Continuing to do craft activities, tackle DIY and decorate, and garden if possible proved therapeutic at all stages. Being able to help family and friends with DIY and produce presents for people gave pleasure.

Independence was maintained by continuing activities. Some individuals expressed the preference to battle with aspects of dressing rather than ask for help. This could be a source of frustration for partners. Continuing to cook for himself although he had a “standing invitation” to eat with his sister locally was important for one early stage man who lived alone. Even a move to residential accommodation in the later stages could provide opportunities for continuing household activities such as hand washing, bed changing and light cleaning.

Involvement in activities served to underpin an individual’s role. For some men in the early stages who left work as a result of Parkinson’s disease and whose wives and children worked, the household duties allowed them to continue a pivotal role within the family. For women whose able-bodied husbands were due to retire there was fear of being usurped from their domestic role. One woman in the later stages reported continuing to make her own snacks through sheer determination not to be “pushed out of the kitchen”. Another expressed the feeling that it was her “duty” to look after her husband and she wanted to continue despite acknowledging her husband’s fear of accidents. Continuing activities served to bolster self-esteem. For one woman in the later stages continuing to manage a full clothes wash offered a sense of self worth. Being allowed to undertake household tasks when visiting children in their homes was also valued by individuals. One early stage individual chose to write in preference to using a word processor, although that was easier, because the preservation of writing skills was of

paramount importance psychologically. Despite reduced hand dexterity managing tasks such as sewing on buttons was a source of satisfaction. In the later stages continuing DIY activities despite increasing effort and offers of help – “it took me half an hour to put a screw in” – could be important for maintaining both independence and self esteem.

Early stage individuals often reported involvement in important family events such as arrangements for weddings, birthdays, anniversaries and funerals. Child-minding grandchildren and looking after family members’ pets were enjoyed, and were able to be sustained through to late stage if shared with an able bodied partner. Grandchildren could show great perception in relation to the needs of their grandparent. One grandmother in the later stages said that although exhausting her grandchildren were “a breath of fresh air, a delight” and gave her “an energy boost”. She was often amazed at what she could achieve in their company.

In the early stages strategies to promote socialising outside the home were rich and varied, with individuals enjoying active hobbies which took them out and about such as walking and caravanning, short breaks in this country and holidays abroad. Many individuals reported active involvement in local churches, clubs, societies and organisations. However continuing involvement was increasingly accompanied by comments about the effort required to maintain the activity, to the point of forcing themselves to do things, and concern about whether something that was planned was indeed realistic and would be possible. Continuing activities could be a consequence of realisation that a partner would not get out if the other did not make the effort. Unexpected enjoyment of an event that had not been eagerly anticipated engendered confidence to maintain the activity.

Shopping was a motivator to get out. One individual’s local shop had suggested he rang his order in for delivery but he preferred to walk to the shop with his order twice a week. Local shopping was often something that individuals could manage alone (8.3, p. 187) whilst major shopping trips had to be accompanied.

Very few individuals in the trial were still in paid employment. Several in their 50’s who had recently been diagnosed initially carried on working. One woman working for a

Meals on Wheels service took some time to inform her employer about her diagnosis. She expressed concern about how sympathetic her employer would be, and made excuses when her work colleagues commented on her poor mobility.

9.4 Modification strategies

The main modification strategies identified in relation to activities were compensation, timing, pacing, planning and stabilisation.

9.4.1 Compensation

Initially, when Parkinson's disease symptoms were likely to affect one side of the body more than the other, the use of the least affected upper limb was reported for personal hygiene activities such as shampooing and drying hair. Changing arms or using both hands for a previously one-handed task such as shaving or tooth brushing was commonplace throughout the disease course. Individuals reported difficulty tensioning the skin if they needed to use both hands on the shaver. Several individuals reported moving their heads rather than the toothbrush to clean their teeth because of difficulty with repetitive movements.

For some individuals it was important to position their least affected side to provide them with the greatest power from available hand-holds when getting into and out of the bath. This might mean stepping into the bath and then turning to face the opposite direction to ensure maximum force when getting out. Shortening the lever arm and using elbow support to get out of the bath was reported by one individual who was beginning to experience difficulties.

Compensation with the least affected side was also reported in relation to dressing. The most affected arm was placed first into jumpers and jackets and the most affected leg into trousers, leaving the limb with the greater manoeuvrability to complete the necessary action. Back fastening of bras would be accomplished with stabilisation offered by the

most affected side and manoeuvrability for hook fastening afforded by the least affected side.

Feeling less adept with a knife and fork was reported early in the disease course with a need for increased conscious effort to grip utensils harder. If both a knife and fork were being used and the right side was most affected, the fork was often put down to enable the left hand to reposition the knife in the right hand. One early stage individual referred to his most affected hand as a 'vice', devoid of manipulative skills. Use of the affected hand to eat could be painful. Increasing use was made of one utensil only, usually an upturned fork, in the least affected hand. This was particularly important in order to hide clumsiness if eating in company. The least affected hand was employed for difficult actions such as getting soup from plate to mouth or holding a drink. Moving the cup not the spoon to stir drinks was reported in order to compensate for loss of repetitive movement on the most affected side. In relation to household activities compensation with the least affected limb and increased conscious effort were early and enduring strategies e.g. when carrying items, rolling out pastry or chopping food. However one individual reported preferring to carry cup and saucer in different hands to stop any rattling as a result of tremor. Another used both hands on one cup to carry it from room to room. Carrying skill on the affected side was used as a barometer of physical performance.

Written prompts were used to compensate for poor memory. Continuing to write necessitated increased concentration to counteract "spidery" writing. Some individuals attempted to learn to write with the least affected hand if their dominant side was affected. Speech was used to compensate for poor writing, with dictation of letters to family members or making tapes in lieu of letters. Communication was an area that depended heavily on the support of ordinary items. Typewriters and word processors could compensate for deterioration in writing. They were used for special letters particularly if individuals were tired or lacked concentration. They were even used for notes as written ones were difficult to read back. The telephone was used "to correspond" to compensate for poor writing. Holding the receiver in the most affected hand meant that the least affected hand was available to key in the numbers. The telephone receiver was switched to the hand least affected by tremor if shaking started whilst on the telephone.

Adjustments were needed to lifestyle and hobbies to accommodate physical and cognitive changes. One late stage individual continued to maintain his allotment by combining forces with a neighbour. Being ambidextrous enabled one individual to change to play snooker with the least affected arm. Early stage individuals reported “looking at things instead of doing them”, and the frustration of knowing that they used to be accomplished so easily. Lack of ability to participate physically in tasks was often compensated for by developing a “foreman” role, planning, advising, encouraging a partner, who may have had to take over and develop a new skill. Maintaining a physical role in the face of loss of confidence at sequencing a task could involve a partner giving prompts throughout the activity.

From the earliest stages money was kept in pockets on the side that corresponded with the least affected upper limb. If the back pocket of trousers was on the affected side removing and replacing a wallet could be difficult without the help of the least affected hand. Compensation strategies were also evident in the workplace. One individual delivering Meals on Wheels struggled to carry meals in a bag with her most affected arm to enable her to knock on clients’ doors with her least affected arm.

9.4.2 Timing

Invariably individuals referred to having a time of day when they were at their best and activities were easier to perform. Some men reported using an electric shaver in the morning and having a more comprehensive wet shave at night when they were at their best. Later in the disease stage the best time was during ‘on’ time. Grooming may be delayed for several hours after getting up to allow medication to be effective. The same pattern emerged in relation to dressing, when waiting for the best time allowed individuals to be independent, even if taking two hours to dress. However one late stage individual commented ruefully that her unpredictable ‘on/off’ with dyskinesia could mean she waited to get dressed until 3 p.m. Others experiencing similar motor fluctuations sometimes found they were unable to get ready for bed at bed time, and prepared for bed earlier in the evening when ‘on’ to ensure they could complete the necessary tasks.

Timing of eating also became an issue in the later stages because of 'on/off' fluctuations. One late stage individual attending a Day Centre ate on his own to a timetable designed to fit in with his medication routine, which had been organised by the Parkinson's Disease Specialist Nurse. Another also attending a Day Centre missed his meal there and ate at night when he was able to control the timing of eating and was able to feed himself. He only drank a hot drink when 'on'. Other late stage individuals reported needing to have simple meals such as sandwiches or meals ready to microwave to enable enhanced abilities to chew and manipulate food when 'on' to be taken advantage of.

For some individuals 'good' days or times were used to accomplish activities such as baking. One late stage individual reported making scones through the night. In the later stages if motor fluctuations were experienced individuals reported using the time when the medication was most effective to tackle tasks such as washing up and Hoovering. One woman reported being tempted to move awkwardly in the kitchen in her hurried attempts to complete tasks whilst 'on'. Another had to wait until 'on' to pick up objects that had been dropped. In the later stages 'on' time was used for activities requiring dexterity, such as writing letters, even if this was through the night.

For some maintaining social contact meant changing the time of going out, for example going to the pub in the afternoon rather than the evening. Having to use 'on' time for activities and outings was a major constraint in the later stages. Ideally shopping trips needed to be planned for 'on' time. One individual reported finding somewhere for refreshment if out and going 'off' until useful mobility returned. Another late stage individual living in sheltered accommodation was enthusiastic about a new manager's plans for social events within her complex. However her social isolation was increased due to 'off' time. If this coincided with social activity she needed to wait until the medication was optimal to let her participate.

9.4.3 Pacing

From the earliest disease stages more time needed to be allocated to personal hygiene activities. Individuals with family members who were in a routine of going out to work or school tended to fit in with that routine, often providing transport. However, allowing

themselves extra time for their part of the family routine by getting up earlier reduced stress. One early stage individual required two hours to bath and dress, another needed to rest between bathing and dressing. Easy to manage clothing was chosen if individuals were in a hurry. Putting on watches or tights required extra time. One individual only accepted help with buttons if rushed. However, even with pacing, the fact that dressing could take so long could induce sweating in the later stages. Increasingly more time was needed to adjust clothing after toileting.

Difficulty manipulating cutlery to prepare manageable mouthfuls of food, getting food to the mouth, chewing and swallowing all contributed to slowness during eating meals. Consequently food got cold and others finished their meal quicker. One late stage individual started to eat his meal 10 minutes before his wife so they could finish together. As with dressing, assistance with food was occasionally accepted if in a hurry.

Recognising that increased time was needed and making allowances for this meant that participation in previous activities could be prolonged. Increased time was allowed for tasks such as washing up, opening jars and hoovering. One early stage individual, recognising his reduced energy levels, reported continuing with his DIY activities when he felt able and pacing himself to enjoy the task rather than viewing it as a chore. Communication benefited from pacing. One individual recalled chipping in to a fast moving conversation and being aware that his contribution had the effect of slowing the pace down. A strategy of consciously dictating the pace of conversations facilitated participation.

Allowing more time to access public transport was important, and when out more time was needed to get money out of purses and to handle change. One individual who could not afford to leave work changed from plumbing to being a school caretaker, a job in which he could pace himself. Other individuals, such as an accountant and a musician, managed to keep on their professions in a restricted way by taking on only the number of clients or pupils they could manage.

9.4.4 Planning

Even in the earlier stages prior thinking through of all the stages of an activity such as getting into and out of the bath assisted execution (6.3, p. 143). One early stage individual reported shaving the night before if he had a morning appointment. In the later stages bathing was aided by forward planning ensuring items were in the correct place. Dressing in the morning was also helped if clothes were set out the night before. Individuals often realised how much they appreciated being able to plan their activity when faced with albeit welcome disruption to their routine, such as a family visit, which could prove disorientating.

For some early stage individuals eating was best if planned for set times. Planning throughout the meal was also evident, in relation to amount of food to put in the mouth, the need to swallow, to clear the throat, and to take regular sips of water. One late stage individual reported planning to eat and drink enough during his 'on' phase to last through his 'off' periods.

Because of writing difficulties it was often easier to prepare material at home rather than in public. One individual wrote out the necessary cheques at home prior to going to the bank. He recognised that direct debits would be easier but felt uncomfortable with that method of payment. Christmas was a time that made particular demands on writing skills and took planning to complete. Written prompts of key words were often required for outgoing telephone calls. Face to face conversations required planning. Individuals described mental rehearsal of what they wanted to say before choosing a time to enter the conversation. Carefully chosen words in concise sentences made it easier to participate in a conversation at an opportune moment. Sitting opposite the person you were conversing with increased understanding of context and awareness and interest in content. The use of target key words in a conversation as a prompt to maintain the gist of the subject matter was reported. Planning did not support spontaneity however, and individuals ruefully reported that they were unable to take part in rapid witty repartee and quizzes proved problematic.

Having a shopping list, a regular routine of shops visited and shopping at a quiet time all proved helpful. Despite planning shopping was often viewed as stressful. Individuals may

need to access toilet facilities and one needed to take a change of clothing due to excess sweating. Poor mobility meant that access to regular seats was important. People felt that planning took the spontaneity out of trips, which became targeted to specific objectives. If individuals were persuaded to eat out, planning a table in a secluded area was helpful. One late stage individual planned holidays in locations with cable cars to overcome problems with walking up hillsides. For others planning not to plan was important, choosing motoring holidays where as much or as little could be accomplished each day to suit the mood. Another late stage individual recognised the importance of holidays and the impossibility of going away on one and so organised a holiday from home. Special trips were arranged in the locality over a period of time. Energy saved not having to cope with unfamiliar surroundings could be used to enjoy excursions during the day.

9.4.5 Stability

Postural instability was an early and enduring difficulty which individuals addressed by ensuring maximum stability for activities. Because of the enclosed space in most toilet/bathroom areas individuals were able to make use of a range of handholds, which were often inherently unsafe e.g. towel rails, shower curtain rails, shelves, window ledges, sides of baths and basins, toilet seats, soap holders and taps. Doors were left open to enable the door handles and door-frames to be used as support both to pull on to get off the toilet and to balance, especially while adjusting clothing. The use of special equipment such as grab rails and toilet surrounds increased with stage (Appendix 13, Tables 2 and 8). For men steadying themselves using the wall or a rail in the toilet during urination was replaced increasingly by sitting to urinate, especially at night.

In relation to showering, leaning against the cubicle wall and the use of grab rails in the early stages progressed to increased use of shower seats at later stages. Letting the bath water out and placing a flannel at the bottom of the bath to kneel on provided a more stable base to get out of the bath. Sitting to dry after bathing was an early strategy; moving to the bedroom for increased stability was a later strategy. Sitting to shave proved helpful.

In relation to dressing, some individuals used the continued ability to stand on one leg whilst putting on trousers as a test of balance. Making balance conscious and waiting until feeling balanced was reported. However leaning the back or shoulder against a wall or door; placing the side of a leg against a bed; leaning against a piece of furniture; and sitting whilst dressing the lower half, particularly socks and tights, were early reported dressing strategies. If sitting balance was compromised in the later stages a return to standing but with the use of hand holds on rails, radiators, furniture or chairs could prove preferable to sliding off the bed onto the floor. Some individuals reported needing to lie down to put on tights and trousers; others managed tights if they sat on the top stair. Raising a foot onto a stool or chair was used to help both reach and stability whilst putting on socks, and fastening trousers zips and shoelaces.

Stabilising the knife and fork in order to reposition the hand grip on utensils was important during eating. The technique of interlocking the knife and fork to accomplish this was reported from the early stages. This made the fork handle stand up at an angle, which enabled it to be grasped. The knife could subsequently be lifted to allow a grip to be taken. One early stage individual reported the need to stand to cut meat as the position offered greater power for the cutting action.

Falls during activities such as dressing and household tasks were reported even in the early stages. One early stage individual reported getting down on to hands and knees to load and unload the front loading washing machine to avoid falling. A late stage individual reported planning a route from room to room with a drink to ensure areas to place the drink and regain stability intermittently during the journey. Leaning up against the sink and sitting down to wash up or iron were reported in the later stages.

Some individuals reported that telephones increased their tremor. Sitting on a chair resting the arms on a table helped to minimise tremor, which would cause the telephone to rattle. Bringing the arm in to the side of the body whilst holding the receiver also helped control tremor.

Newspapers provided a major manipulative challenge throughout the course of the condition. Reading them spread out on a firm surface –table, chair or floor – was the most

reported strategy. Later in the disease course individuals addressed their own stability in addition to that of the newspaper by kneeling or lying on the floor to read the paper which was spread on the floor. Kneeling to weed the garden reduced the risk of overbalancing. Sitting down rather than standing made it possible to continue going to pubs.

Pushing a pushchair or using a wheelchair with a trolley attached could enable shopping activity to be maintained in the face of balance difficulties. Individuals reported balancing against walls in changing cubicles in clothes shops whilst trying clothes on if seats were not available.

9.5 Reduction strategies

Reduction strategies related to changes in the nature of the complexity of the activity, the frequency and amount of the activity performed and the 'standards', born of cultural expectations, which would be applied to the activity.

9.5.1 Complexity

Women reported moving to shorter, more natural hairstyles that did not require styling and a simpler make up routine, using lighter lip colours in case of inaccuracy. Drying off in the heat of the bathroom or using a towelling robe minimised the need for repetitive movements of the towel. Even in the early stages there was a marked trend away from bathing, with the complexity of transfers involved, to showering. Standing in the bath for a wash down; moving from bath board to kneeling and back to bath board to avoid sitting in the base of the bath; and sitting on the edge to wash feet were often preferable to getting down into the bath. In the later stages however bathing with a bath lifter might provide the safest environment (Appendix 13, Table 2). When individuals were feeling more able they were likely to attempt to manage without the special equipment items.

Fastening bras and skirts from the front and swivelling them into place reduced the need for fine manipulative movements in difficult positions. Leaving laces and buttons done up

or buttons unfastened also reduced the need for dexterity. Women reported early changes to easier items of clothing, such as trousers, especially within the home, and abandoning previously worn items of clothing such as corsets. Men abandoned shirts for leisure tops (8.4.4, p. 190).

Changes to the nature of what was eaten could reduce the task of eating (Table 7.2, p. 167), especially important if eating in company. Avoiding the dual tasks of eating and speaking at the same time was reported from early stages onwards. Even in the early stages a meal at home with family members was often the only social eating individuals would countenance. However increasingly family visits for meals could prove stressful, necessitating time out within the home away from the visitors. The complexity of cooking tasks was reduced by the use of a microwave. Cold snacks were substituted for hot snacks if alone. Hot drinks were consumed where prepared rather than carried from room to room. Dishes were left to drain if drying was difficult.

Answer phones reduced the stress associated with incoming calls. Use of a smaller newspaper rather than a broad sheet made handling a paper in the normal way less difficult. Splitting it up, doubling the pages over, stapling the pages together and ironing the paper were some strategies that made it easier to read. One early stage individual who used to knit reported changing to tapestry which did not require such exact performance of both upper limbs. A musician photocopied two pages of music onto one sheet to avoid turning pages. A move away from active hobbies to more passive activities such as watching the TV and listening to the radio was evident. Many individuals who had previously taken an active part in pursuits such as cycling, fell walking or football followed their interest by reading specialist magazines or targeting television coverage. Gardening could be maintained as an interest if the design reduced effort. In the late stages involvement in the garden could take the form of managing to get out and spend time sitting in the garden.

Individuals involved with organisations such as charities and who had previously played an active, physical role, often found they could continue involvement but in a role tailored to their changed resources. Examples of this included moving from actively making charity collections to organising them; and from playing competitive bowls to coaching

club members. In this way individuals or groups could be helped to an understanding of the issues associated with Parkinson's disease. Maintaining attendance at keep fit classes involved an open relationship with the instructor and acceptance of not being able to keep up with the rest of the class. Parkinson's Disease Society meetings were occasions when individuals knew concessions would be made to accommodate their difficulties. The same was true of holidays organised by the Parkinson's Disease Society. Similarly socialising was often possible to maintain within the context of sheltered accommodation.

Maintaining the ability to socialise as a couple was helped if there was an acknowledgement that the able bodied partner would participate as before, for example to dance, whilst the less able partner enjoyed the music and watched. Deciding to stay in a wheelchair rather than attempting a transfer in a restaurant could prolong visits out.

Shopping was a complex activity and manipulating and paying for items in shops was a source of anxiety that could exacerbate tremor. Individuals reported trying to keep specific coins in particular pockets. Some refused to use the smallest 5p coins. One early stage individual reported growing longer fingernails especially to enable coinage to be picked up. Getting a note out of a wallet and placing it in a jacket pocket before getting to the check out, and paying by notes generally meant that coinage did not have to be manipulated in public. This strategy did however mean that individuals ended up with a lot of change that needed to be sorted subsequently. If not paying by a note then working out the cost and getting money ready in a quiet area prior to checking out was important. Cashiers were often asked to take money out of open hands, purses or wallets, especially if individuals were 'off'. Very few people mentioned the use of credit cards to pay and this may be associated with difficulty with signatures. Packing shopping once through the checkout rather than at the time of checking out reduced stress, as did waiting to put change back into a purse until away from the check out. Manipulating coinage that had been placed in the hand by an assistant was problematic from the early stages. Being able to make the condition known to staff meant that assistance was given.

Carrying shopping in one hand rather than in both was reported to be preferable. Carrying shopping in the same hand as a walking stick was preferred as individuals were unable to carry a bag in one hand and manipulate the stick with the other. Even in the early stages

some individuals were unable to do their own shopping but were still able to retain some involvement if they made shopping lists for family or home carers to collect. Others were able to go on shopping expeditions but stay in the car rather than actively participate.

9.5.2 Frequency and/or amount of activity

For several individuals bathing became an increasingly exhausting procedure which was restricted to once or twice a week. Makeup was another activity that became restricted to the minimum acceptable to the individual. Rather than removing items of jewellery regularly, women reported wearing them over time. One man reported growing a beard to obviate the necessity to shave regularly. Another reported that he had been “dressy at one time” with four to five changes of outfit per week, but that he now had two, and he no longer wore a tie. One individual reported being unable to tie his shoe laces effectively and his strategy was to reduce the time over which he expected them to stay fastened, re-tying them several times during the day.

Smaller portions were an early strategy to counteract slowness of eating and food getting cold. However one later stage individual commented that he still had a good appetite even though he was slow. Reduced hand dexterity with dual activities meant fresh vegetables, such as potatoes, proved difficult to prepare from the early stages and their use was restricted to a number of days per week, often the weekends when there were less additional pressures. The amount of liquid carried in glasses, cups or mugs from place to place was reduced. There may be a reduction in the heat of hot liquids carried to avoid scalds. In the later stages there might be only 2 or 3 times a week when individuals felt capable to making themselves a hot drink. As the number of items carried between rooms was reduced so the number of trips was increased. A late stage individual reduced trips up the stairs by collecting what needed to be taken up at the bottom.

Difficulties were reported with sequencing the actions and movements involved in washing up. One individual waited until the sink was full before washing up drinks mugs. Others reported the need to reposition the tea-towel for each drying action, and drying glasses by pushing the tea-towel into the glass and turning the glass. Eggs were beaten slowly as the movement could not be controlled fast. One early stage individual described

setting the breakfast table at night in slow motion. Recognising an inability to stand for long periods of time necessitated re-organising tasks i.e. doing a reduced amount of ironing over a number of shorter time periods.

Writing in short spells only proved helpful. One late stage individual commented that it could take him 3 days to write a letter. The amount of writing lessened overall. One early stage individual reported previously writing letters on a weekly basis to her sister but now “had to be in the mood” and had substituted telephone communication. Individuals reported abandoning sentence form for short notes only. Early in the condition the only writing many individuals were doing was their signature, with partners taking on the role of completing forms and writing letters. Being relaxed, putting extra force through the pen nib, use of lined paper, printing letters to maintain height and legibility, and taking more time helped writing technique.

There were early references to loss of concentration, particularly when reading newspapers and books. Papers were picked up and put down without taking in the contents, or only glanced through. Sections of books may need to be reviewed because of comprehension difficulties. Length of time spent doing jigsaws also suffered from reduced attention span. One early stage individual recognised that he had a reduced concentration span in relation to TV programmes. Another reported only feeling able to do one job at a time.

The amount of fine work such as knitting may have to be reduced. Tremor interfered with activities such as picking up stitches and rewiring a plug. Stopping the task and returning to it again later was employed to overcome difficulty. Heavy activities such as decorating were curtailed as individuals reported not being able to do enough to make them worthwhile. One individual restricted how high he would go on step-ladders to three rungs. Performing tasks such as gardening for shorter periods avoided excess fatigue.

Whilst enjoying the stimulation, grandchildren could prove too active to manage with confidence. Individuals acknowledged that they required more activity than they could provide. Increasing reference was made to not looking after grandchildren as much.

Lack of confidence in speech was a major reason cited in the early stages for not going out as much socially and for choosing not to talk as much when in company. Individuals reported restricting their speaking due to hoarseness, and reducing the overall amount of conversing due to difficulty finding words and a tendency to lose the gist of conversations when several people were involved. Individuals were reluctant to make a first approach in a conversation for fear of getting “tongue tied”. One early stage individual recognised a reluctance in herself to do things she used to enjoy such as shopping or visiting her sister. It felt to her as if she was putting it off and she felt guilty. Spouses who had accompanied their partners to the shops reported the need to return to the car before the end of the shop if conditions became too crowded for them to tolerate. Going out for dinner was restricted to special occasions. The inability to drink with medication caused individuals to restrict previous activities that would have involved a drink out. If going out at night, one individual reported dressing in the morning in what was to be worn later so as not to exhaust herself with getting changed.

One late stage individual who enjoyed fishing took his car as near to the water’s edge as possible to reduce the distance needed to walk. Even if individuals did get away on holiday the amount of sightseeing they could do was often restricted. Travelling by train proved helpful for some because they could decrease the amount of time spent sitting by walking along the carriage. Reducing the time spent in shopping centres from a whole afternoon to a one hour time period was reported. This helped minimise a less successful reported strategy of abandoning shopping half way through a planned session.

9.5.3 Social ‘standards’

Going out of the house was a reason to maintain standards. Men reported using electric shavers most of the time or sometimes not bothering to shave, but having a wet shave if going out. In the later stages several women reported that they were not going out any more and so had no need for makeup. Keeping up appearances was also reported in relation to dressing with individuals prepared to devote extra time to putting on jewellery, skirts and tights for outings. However for one individual in the later stages dressing was so difficult that she remained in the same clothing night and day, experiencing a related loss of dignity.

Although toileting and bathing were essentially private activities, individuals were aware that the way activities were being accomplished sometimes fell short in terms of 'acceptable' performance. Whilst feeling for the toilet seat to sit down, often using another handhold, was commonly reported, the enclosed nature of toilet areas often induced shuffling gait and one individual in the late stages reported "diving" for the toilet seat. Another reported attempting to overcome freezing on entering the toilet by going in at right angles, standing on a mat on the floor, holding on to a grab rail and swinging onto the toilet seat using the mat as a pivot. An early stage individual reported sliding down the back of the bath when getting in because then he knew he could not fall back any further, another admitted to "thumping" down into the bath. Bed baths were occasionally reported.

Eating, because of its more public nature, was particularly vulnerable to observed loss of acceptable norms of social behaviour. Meat often needed to be "torn" rather than cut; loss of dexterity made it easier to take the mouth to the food or the bowl to the mouth; cutlery may be held and used in an awkward, "silly" way; tremor could cause severe rattling of cutlery on the table or plate; finger feeding might be the most efficient technique; poor posture made choking more likely; and pinafores might be used in an attempt to avoid excess mess on clothing and the floor. Ill-fitting dentures could be problematic. Individuals reported being "told off" for leaving food that was unpalatably cold. Eating out was a situation in which others could notice an individual's difficulties. One early stage individual had to confess to having Parkinson's disease when eating out in public because of the mess he had made during the meal. One late stage individual managed his meal but had difficulty putting on his coat and managing a shoelace that had come undone. Being slow at finding pages in the hymnbook at church was also embarrassing and could draw unwelcome attention.

Individuals felt guilty about using more prepared food and not doing as much spring-cleaning. It was difficult to get pans clean, and spills were an accepted part of carrying liquids. One late stage individual reported moving hot drinks from room to room on a plate "shoved along on the ground". Another machine washed even hand wash only items, and ironed sheets on the floor to avoid adjusting position on the ironing board. Individuals developed their own form of shorthand as writing deteriorated. One individual

reported forgetting to stop when writing deteriorated in a letter. Writing was something about which individuals often felt ashamed. Another individual said that when writing to the family she stated, “Going off”, and ended the letter. Individuals reported “keeping doing what things I can manage” in terms of the garden or the house but feeling that things were not getting their usual attention.

9.6 Avoidance strategies

Avoiding items of clothing was reported, for example bras, tights, socks and footwear in the house. Tying a tie was problematic for many individuals. This difficulty was approached by avoiding the task for a short period after experiencing difficulty and returning to it sometime later, a strategy employed in other tasks such as washing up, writing and DIY activities. In the later stages of the condition individuals reported avoiding the process of getting dressed, with one individual choosing to wander around in a dressing gown.

Risks associated with making hot drinks, snacks and meals, particularly those involving lifting heavy pans, were increasingly reduced by avoiding the task. One individual reported avoiding hoovering as the vibrations from the Hoover exacerbated his tremor. Activities requiring stretching were avoided due to poor balance. Ladders were an early risk to be avoided.

There was a trend to avoid writing as dexterity deteriorated. Signing in public was avoided by many, with individuals reporting practising beforehand if they needed to accomplish this. The telephone might be substituted for writing and then avoided as difficulties with speech, saliva management and understanding increased. Several individuals commented that they only answered the telephone when partners were not available, however it was sometimes difficult to get to the phone in time. In one case crawling was resorted to. Telephone calls could become restricted to family members only. Conversation was avoided when tired. In the later stages there was evidence that social contact even within the family was avoided or stopped.

Tremor deterred individuals from going out in public. Crowded situations were avoided from the earliest stages due to feelings of claustrophobia, confusion and problems with freezing, with one individual referring to the experience of a “panic attack”. Avoiding crowded shops was essential. Invitations for meals out in public with friends were avoided, with a preference for eating out if at all with family. One early stage individual reported drinking in another town to avoid having to converse with neighbours, and particularly avoiding friends associated with previous interests. Problems adjusting clothing after toileting meant individuals avoided drinking or using the toilet if out. Individuals reported avoiding help that was offered them when out, preferring to manage alone rather than accept assistance from someone unfamiliar with their needs and who could make matters worse.

9.7 Stopping strategies

Make up was the one category of personal hygiene activity that was reported to stop. The principal reasons for stopping household activities altogether in the later stages were safety and slowness. Manipulating hot pans and liquids in the face of poor dexterity and balance placed individuals at risk of scalds and burns. Housework took so long it became exhausting.

Later stage individuals reported being no longer able to write, experiencing difficulties from conceptualising to undertaking the task. Others were reported by partners to have stopped conversing, interacting only if a subject was of interest. For some the telephone had little utility, unable to reach it if alone, hold it next to the mouth and speak with a distinctness that others could comprehend.

Nausea, poor eyesight, a tendency for the eyes to close, lack of concentration, tremor and the weight of books caused even early stage individuals to stop reading. Lack of concentration, reduced dexterity, difficulty with dual handed activities and poor balance were reasons given for stopping DIY activities. A number of individuals were musicians who had previously performed for people but had had to stop due to deteriorating

performance. Inability to write forced individuals to abandon crosswords. Late stage individuals who had had to abandon all activities other than sitting and listening reported needing to stop trying to listen and concentrate on management of their pain or florid dyskinesias. With increasing stage references were made to delegation, to partners taking over activities completely (8.2, p. 182), and to paying for others to undertake activities (8.3, p. 185).

Some individuals realised that they were unrealistic about what they could do and appreciated a partner holding them back from offering to be involved in activities. The stopping of social activities requiring fluency and mobility such as snooker, golf and dancing was reported early in the condition. However the rhythm of dance music could help sustain participation. Eating out socially was unthinkable for some individuals from the earliest stage, with one commenting “What would I have without causing embarrassment?” For some previous interests were unsustainable, with enforced selling of much-enjoyed caravans and the sale of a yacht.

Fear of freezing in narrow or crowded shop aisles and the potential for falls caused individuals to stop shopping. Being away from home could mean that a structure in terms of routine and geography was lost and one early stage individual reported that failure to take medication and a tendency to get confused in unfamiliar surroundings meant he could no longer go away alone. Holidays were often abandoned altogether in the later stages after one last bad experience which shattered confidence in the ability to cope away from familiar surroundings. For one individual this was a silver wedding coach trip to Switzerland which provide “sheer hell”; for another a caravan holiday proved to be “disastrous”; for yet another shouting in the hotel due to florid nightmares necessitated a return home. In the later stages social encounters outside the home may be restricted to hospital appointments and very occasional family events.

A decision to take sick leave to let the condition stabilise post-diagnosis without the stress of work was common in individuals diagnosed whilst still working. However very quickly confidence to return to work was lost and the most likely course of action was ill health retirement. This happened in one case where there were supportive employers, a positive attitude to disablement resettlement and retraining and regular monitoring via

medical reviews. Many individuals had had to give up work due to medical conditions other than Parkinson's disease, for example musculo-skeletal problems (shoulder or back injuries), ulcerative colitis, depression, rheumatoid arthritis and angina. However Parkinson's disease was also a major cause of leaving the workplace early. It was difficult to sustain jobs such as higher education teaching with a pronounced tremor and precision engineering or architectural drawing without maximal manual dexterity.

9.8 Overall daytime and night-time activity

Individuals employed similar strategies in relation to the organisation of overall daytime and night-time activity as they employed in relation to specific activities. Pacing activity, increasing the time available to accomplish activities in the face of slowness, was the single most important strategy in relation to daytime activity throughout the course of the disease. Individuals confessed that if they did not operate this strategy they felt rushed, stressed and frustrated. Planning and maintaining a routine contributed to a feeling of control, and there was an acknowledgement that individuals found the unexpected difficult to accommodate. For a few people, however, a lack of plans had the best effect. Feeling they had all day to do things lessened stress. One individual described a daily balancing act of trying to achieve an activity level that would suit his condition and needs. Even in the early stages, with individuals on no or minimal medication, there were high levels of reporting of the experience of 'slowing down'. Sometimes slowing down was accompanied by unpleasant bodily sensations such as heady, crawling feelings. Recourse was increasingly made to short rest periods to "recharge batteries". However if involved in activities individuals could keep going, although this could also result in "overdoing it". Individuals reported timing activity at times when their effort was likely to be most effective. In the later stages 'on' time was used for activity. As this window of opportunity got shorter activity could become "manic" in an attempt to accomplish an unrealistic amount of jobs before loss of 'on' time. Avoidance of activity when seriously slowed down was designed to avoid risks and keep safe.

An extensive range of night time difficulties were experienced from the earliest stage of the condition, with implications for sleep partners (Walker et al. 2000). Difficulties included: tremor disturbing the ability to get off to sleep; difficulty relaxing; insomnia; waking early and not being able to get back to sleep again; excessive sweating; bladder frequency and urgency; vivid dreams with shouting and restlessness; and difficulty turning (10.4.3, p. 247). To counteract these problems individuals reported: avoiding cat naps during the day; going to bed late; getting up and moving about during the night; making a drink and perhaps a snack; reading; listening to the radio or watching the television; changing night wear; and moving on to a settee as it was easier to turn than in bed.

Dyskinesia and hallucinations as a result of drug therapy put spouses sharing the same bed in danger. Individuals reported sleeping with their backs to their partners in case they hit out inadvertently; one partner had been pushed out of bed. Concern for her partner meant that one individual would sit on the commode in the bedroom for hours rather than ask for help back into bed. Others reported sitting for long periods on the edge of the bed. Increasingly separate rooms were resorted to.

9.9 INVOLVEMENT area (PERSONAL, HOME AND COMMUNITY) – Nature of physiotherapy

Chapter 10 will present the **INVOLVEMENT** model in relation to **MOBILITY** strategies and address the implications of the model for physiotherapy practice and research. This section will focus on the differences identified in the **PERSONAL**, **HOME** and **COMMUNITY** sections between stages of the disease and between active and control groups.

Continuation, modification and reduction strategies were identified at all stages of the condition, with avoidance and stopping strategies largely restricted to the later stages. Physiotherapy intervention with the active group reinforced the pacing and planning of

activity, with the effect that strategies indicated a sense of control over the condition rather than being controlled by it. For example, control group strategies contained more references to not being organised, to being late, to not having a structure to the day and to being mixed up. Active group strategies during intervention contained references to making lists, taking rests, allocating time, readjusting roles, prevention of strains, avoiding risks, controlling stressors, and being more organised. In relation to activities in the **PERSONAL** section of the strategy map for active group participants, whilst compensation was acknowledged, optimal symmetry was encouraged if possible, for example with hair washing. Revision of safe transfers in the toilet and bathroom took place, in addition to the provision of aids and equipment. Balance, range of movement, manual dexterity and planning was stressed in relation to dressing, and posture, preparation and conscious chewing and swallowing of food reinforced.

In relation to the **HOME** section of the strategy map for active group participants, there were examples of the therapist encouraging and supporting individuals' strategies such as reducing the complexity of cookery, craft and DIY activities to facilitate continued involvement. In addition to enhanced pacing and planning of activities, a heightened awareness of the need for risk avoidance, especially in relation to gardening and DIY activities, was evident in recorded strategies. There was evidence of therapy activity to support **COMMUNITY** involvement strategies. Two individuals in the active group visited a golf driving range with the therapist to investigate whether they could support one another to continue their interest in golf. For others the therapist was able to identify a tendency towards social withdrawal. By opening up discussion about this it was sometimes possible to agree a change in behaviour, such as resumed participation in a previously enjoyed activity albeit at a different level, which could then be encouraged, supported and monitored. For the few active group participants who were still in work, the therapist provided a sounding board in relation to decisions about whether and how to continue.

9.10 Summary

Singer (1973) found individuals with Parkinson's disease were less likely to engage in household tasks or work, and to have close friends, and more likely to spend time in solitary leisure activity such as watching television and to report ways of spending time which were not really 'activities' at all such as "napping" when compared to the general population. Her identification of a pattern of increasing social isolation resonates with the progressive withdrawal seen in the **INVOLVEMENT** model. However the model contains examples of many effective self-management strategies to promote continued participation. Physiotherapy was seen to support those effective strategies and challenge those that were less effective. The concept of more or less effective strategies will be explored in the context of the **MOBILITY** section of the **INVOLVEMENT** area in Chapter 10, in addition to a discussion of the implications of the model for physiotherapy practice and research.

10 Strategy mapping: INVOLVEMENT strategies 2

10.1 Overview of chapter

This chapter takes the **INVOLVEMENT** strategy model (Figure 9.2, p. 211) and applies it to the remaining **INVOLVEMENT** section, **MOBILITY**. This section records strategies concerned with moving about within the home - walking, stairs, transfers into and out of chairs and bed mobility – and outside the home – including walking, and using public transport and cars. However, as with previous **INVOLVEMENT** sections, it is also concerned with the interplay of the actual performance, the context in which it is undertaken and the meaning of the activity. Moving about indoors and out of doors will be examined in relation to each domain of the **INVOLVEMENT** strategy model. The data drawn on for this account was gained from the *initial* strategy maps of the active group and *all* control group strategy maps. The **MOBILITY** strategies were those that individuals *themselves* were putting in place over time without physiotherapy intervention. In section 10.7 physiotherapy strategies employed with the active group will be examined to enable comparisons between the work done with and without physiotherapy intervention to be drawn. Finally in this chapter the implications of the **INVOLVEMENT** strategy model for physiotherapy practice will be discussed. Case study material illustrative of this section of the map, based on interview and ambulatory monitoring data, will be presented in Appendix 15.

10.2 Continuation strategies

Unlike **PERSONAL**, **HOME** and **COMMUNITY** sections there was little evidence that **MOBILITY** strategies could continue unchanged. Even the continuation of the ability to drive was threatened by the need for individuals to notify the Driving Vehicle Licencing Authority and their insurance companies about their condition. Whilst this was a

formality and did not result in the removal of a licence, it was none the less a time of considerable concern. Driving was viewed as a “life line” by many individuals.

10.3 Modification strategies

The main modification strategies were compensation, planning and stabilisation, with less emphasis on timing and pacing than in the other **INVOLVEMENT** sections (Chapter 9). This reflects the nature of mobility activities, which serve to underpin all other everyday activities and therefore are less able to be timed or paced.

10.3.1 Compensation

The strategies of awareness, conscious effort and prompts, identified in **SELF/ THINKING** (6.3, p. 141), provided compensation for difficulties organising, starting and maintaining movement throughout the full range of mobility activities.

Even in the early stages within the home doorways, small spaces and obstacles posed difficulties with shuffling steps, retro- or propulsion and freezing. Making a conscious effort to stride out through doors; making wider turns; and keeping calm, steadying oneself and setting off again were reported. Correcting festination was approached by the prompts, “Stop, up tall, stride out”. Loss of heel strike when walking or commencing a turn was approached by the prompt, “Heel”. Freezing was countered by counting to 5 and giving the order, “Move legs”; retropulsion and propulsion with the prompt, “Stop, up tall, wait, step”.

In the later stages initiation difficulties, motor fluctuations and continued freezing affected walking inside the home. Problems with initiation were often associated with frustration so swearing, self chastisement (e.g. “Come on get going”) and provocative thoughts were used to initiate movement. Movement prompts involving marching on the spot, transferring weight or stepping backwards were also employed to aid initiation. Rocking to the opposite foot to start a turn in confined spaces such as the toilet was

utilised. Increased conscious effort and heel down prompts were required to avoid shuffling with end dose deterioration. More extreme prompts were reported to counteract initiation and freezing difficulties, such as shouting and kicking a wall to stimulate movement. One individual knocked each step against his stick to maintain rhythm when 'off'. Another had been able to use a cognitive prompt to stand up straight and lift his foot high to enable him to get through doorways. This technique had become ineffective and he had to physically lift his leg with his hand to achieve the step. Reference was made to spouses providing verbal prompts for freezing episodes – “Stop, relax, step up”.

Walking outside could be prompted by the phrases, “Head up, heel down, 1 - 2, arm swing”. Counting was used to maintain gait. Variations in walking speed were accomplished by the prompt, “Slow down”. Even at the early stage freezing in crowded places outside the home could be a problem, with one individual needing to swear to himself, prompt himself to stand up tall, step back and turn to avoid people noticing his predicament. The metaphor of “walking like a toy soldier” was used by several individuals to describe their gait outside. The sound of a shoe scuffing on the ground provided some with a prompt to make a conscious effort to walk better by picking up their feet and swinging their arms. One individual commented that it was less embarrassing to shuffle in the home. Visual imagery such as imagining lines on a pavement was employed to initiate or improve gait. For others the visual stimulus of someone approaching spurred them to make a conscious effort to improve their gait. The avoidance of hesitation at the start of crossing a road was overcome by the prompt – “Foot forward, start”.

Sit to stand transfers were characterised over time by increased effort comprising multiple attempts to initiate the movement and increased problems attaining an upright position on standing. One individual needed to slap his thighs to stimulate sit to stand. Standing was prepared for by prompting, “Steady, go”. Improvement in posture was attempted by the prompt, “Up tall, shoulders back”. Turning in bed was aided by sequencing prompts – “Knees up, arm over”. From the early stages there was evidence of carer prompts to maintain good sitting posture, get from sitting to standing, and get into and positioned in bed.

Driving was enhanced by verbally prompting, “Clutch control, gear stick”. Due to difficulties with neck mobility it was common for individuals to report turning their whole body rather than just their head when needing to look over their shoulders whilst driving. Increased use was made of wing mirrors to minimise turning. Individuals were aware of using their least affected upper limb in steering manoeuvres to compensate for lack of precision in the more affected side.

10.3.2 Timing

Timing strategies were most evident for mobility outside the home. One late stage individual had to abandon a bus journey and return home because of going ‘off’. Driving during particular parts of the day could be more difficult than at others due to fluctuations as a result of medication. Partners were increasingly concerned about variability in driving skills, especially when individuals were driving alone and abroad. Increasingly driving was restricted to local journeys that were only undertaken when well. Partners might themselves learn to drive and initially take over for periods when a spouse was not able to. Gradually they might take over more of the responsibility for driving if appropriate.

10.3.3 Pacing

It was reported that walking outside allowed a rhythm to develop which was not possible walking indoors. Increased trunk flexion led to the tendency to propulsion whilst walking and individuals reported quickening the pace of walking to stop themselves falling forwards. Walking the dog could help maintain a rhythm to the gait. However dogs that previously provided walking companionship could become too strong to handle. There was a need for increased rests whilst out. A stick might be used outside the home, sometimes as a signal for others to take care and allow more time. For some the faster pace of their spouse caused them difficulties. One individual reported that if he met a friend and could not keep up with their pace, he suggested that they go on without him.

Occasionally individuals had to stop and rest when undertaking stairs, and problems were worse at night. Whilst stair lifts were more common in the later stages (Appendix 13, Table 8), their use was often restricted to 'off' times.

Car transfers were a source of difficulty from the earliest stage of the disease, with the need to take increased time, the need for assistance both in and out and difficulty remembering how the transfer was executed reported. One person commented, "A 2 minute ride and it takes me 10 minutes to get out".

10.3.4 Planning

There was evidence at all stages in the disease course of individuals thinking through or mentally rehearsing movement sequences e.g. walking, turning and getting into bed, changing gear in the car, prior to attempting them in order to enhance performance (6.3, p. 143). Planning particularly difficult manoeuvres in advance such as getting out of a dining chair at the table and stepping in a confined space was helpful. One individual at a later stage took weight forward with hands on the table while a carer removed the chair to allow space to turn. An individual reported turning the heating up and sleeping on top of the bed to obviate the need for covers which made turning difficult.

Crossing roads was a major challenge containing elements of compensation and pacing as well as planning. Individuals reported that the traffic movement and general environmental noise led to a level of distraction that caused them to feel confused. One individual described herself as being "not 100% aware, of feeling dulled". Poor posture limited the ability to use vision and necessitated a reliance on listening to judge traffic position and speed. More use was made of designated crossings and if none was available then more care and time was needed. Even using crossings individuals reported difficulty starting to walk and varying their speed.

Some everyday activities such as getting in and out of a car could seem unfamiliar, and individuals needed to stop and plan ways to accomplish the activity. More time was spent planning journeys to avoid traffic. Individuals reported re-routing car journeys to avoid manoeuvres involving steering excessively with the affected side. Planning was also

reported as important when using public transport. The lack of time to effect safe transfers, jolting, the tendency to freeze and the inability to make rapid changes of direction in a crowded situation meant there were dangers of falls, which one individual had experienced. Choosing a time when the bus would not be too busy; having your bus pass or fare ready; sitting at the front of the bus on an aisle seat so the driver could see you; pressing the button for the stop in advance; communicating your desire to stop to the driver; and waiting until the bus had stopped before getting up, despite the pressure to rush up, all helped ensure safe travel. Unsympathetic drivers were a cause of stress. Use of a Care Bus for disabled people ensured attention to risk factors.

10.3.5 Stability

From the earliest stage a number of individuals were aware of warning signs indicating the need for support whilst walking even within the home – legs shaking, experiencing a rippling effect or a leg giving way, and dizziness. References to falls were found from early stages, with reported difficulty in working out how to get up from the floor. Making a turn stepping from side to side; minimising stretching up, which was associated with loss of equilibrium; avoiding thick pile carpets or slippery surfaces; and increasing the level of light at night helped to prevent falls. However using support, and lowering the centre of gravity by stooping and crawling were the principle strategies from the earliest stages.

Walking aids such as sticks and frames were increasingly used within the home both to walk and maintain standing balance. Whilst some furniture was moved to make space, increasing use was made of sturdier items for support, such as worktop areas in the kitchen for support with balance, turning and reaching. Unable to maintain an upright stance on the commencement of walking, an individual experiencing dyskinesia reported using a well-planned series of hand holds – door-frames and shelves – as he reached and stumbled for support to assist with balance. The husband of one late stage individual was having great difficulty opening his wife's hand after she had reached out to grasp a piece of furniture to save herself from falling. Doors of wardrobes were left open to use as support and walking aids positioned to assist on getting out of bed. A forward stooped posture provided a compensatory mechanism to avoid a tendency to fall backwards when

walking upright. Increased reference was made to crawling, with individuals reporting that they were more able to co-ordinate their limbs on all fours; found it quicker to move from A to B than with a frame; experienced less anxiety about falling and reduced their number of falls. The physical support of a spouse or homecare assistant was reported to aid walking within the home.

Whilst two individuals in the later stages felt they moved far better on stairs than a flat surface, with one commenting that if only he lived in a staired environment he would be perfectly normal, for many even from the early stages stairs posed a challenge. Use of one banister and a dado rail or additional banister for stability were early strategies. Sticks were increasing used.

Several individuals reported the use of shooting sticks to provide a seat to rest whilst out. As with walking inside where furniture or the fabric of the house was used as props, walking outside necessitated finding walls, lamp-posts or railings to lean against if dizzy or experiencing a feeling of legs giving way. Shopping trolleys, children's pushchairs and golf trolleys all provided support. Several individuals would only travel on public transport if accompanied. Someone standing behind could reduce the fear of falling backwards.

10.4 Reduction strategies

Reduction strategies related to changes in the nature of the complexity of the mobility activity, the frequency and amount of the activity performed and the 'standards' that would be applied to the activity.

10.4.1 Complexity

Breaking mobility activities down into sequences enabling each part to be performed separately and gradually built up into a whole formed the basis of complexity reducing strategies (6.3, p. 143). From the earliest stages there was evidence of sequencing of sit to

stand into the following actions: shuffle forwards in chair; place feet under knees; use arms to push to standing; occasionally add rocking motion for momentum; take time to balance; use furniture to straighten and for support if necessary. One early stage individual reported always attempting to set off to walk immediately on standing when in company so as not to draw attention to his initial balance difficulties, however he was not always successful. Another described his sit to stand technique as sliding himself forward to the front edge of this seat, positioning his feet and pushing up using the arms of the chair. However on initial standing he had a tendency to fall backwards.

The most common technique employed to turn in bed from the earliest stages onwards involved raising the upper trunk with abdominal effort into elbow support; hitching the hips in the opposite direction to the turn; turning the upper trunk in the direction of the turn; and lowering into the side lying position. Modifications of this technique involved the addition of semi-flexing the knees and coming up into sitting supported on the hands (Jones et al. 1999b).

In a similar way to crossing roads, being in crowded places meant being subject to a variety of stimuli. Individuals described the experience as “too much happening”, “a lot going on”, and needing to “reassemble things in the brain”. Unable to change direction, individuals tended to simplify the situation by standing still and letting people walk round them; one individual described it as “becoming a mini roundabout”. Escalators posed particular challenges related to stepping on, balancing and stepping off. One individual sequenced the movement as follow: “stand, take light grip, let hand rail slip through hand, conscious ‘go’ and step on”. His wife stood in front going down to prevent falls and behind going up to help him step off. They both felt that lifts were now preferable.

Power assisted steering and automatic gear change reduced the complexity of driving.

10.4.2 Frequency and/or amount of activity

As the amount of an individual’s own movement activity decreased so the use of **SUPPORT** strategies (Chapter 8) increased. There were increasing reports of carers providing physical prompts such as facilitating weight transference side to side and

guiding individuals during walking inside the house. High chairs and cushions aided sit to stand transfers but carer support through the provision of physical and verbal prompts and physical assistance increased with stage. Likewise even in the early stages partner help with bed mobility was required (Jones et al. 1999b). Higher and firmer beds, modifications to linen and bed wear, special equipment and bedroom furniture were all employed to help getting in and out of bed and turning as the amount of movement activity available for the turn decreased. Fitted bed sheets, the tightness of bed covers, the mattress or headboard were used as fixed points to facilitate a turn in bed, often as a long lever without hip or knee flexion. One late stage individual reported getting sore knees as a result of freeing the intentionally tight blankets with flexed knees to turn. The increasing need for carer assistance in terms of the use of verbal and physical prompts and direct assistance resulted in disturbed nights. Specific parts of bed mobility manoeuvres might require assistance. In the later stages individuals could experience difficult releasing the supporting elbow when elbow support had been used to facilitate a turn. This needed carer intervention in a number of cases. Failed attempts to turn could result in marked stiffness as a consequence of lying in the same position all night. One individual who needed to be propped up with pillows at night was unable to correct his position if he slid off, compromising his breathing.

From the earliest stages of the condition there was recognition that individuals were limiting the amount of walking outside the home. Loss of confidence walking outside meant that individuals did not get out as much or go as far on their own. Uneven or wet ground posed particular problems. Going outside alone could become restricted to days when individuals felt well and the weather was fine. Increasingly however the backyard or garden became the only place individuals were prepared or allowed to be outside alone. There was recognition that being accompanied when out lessened stress. Carers could provide support and prompts. Local driving was maintained while longer distances were reduced.

10.4.3 Social 'standards'

As with toileting and bathing activities (9.5.3, p. 228), individuals were aware that the way some mobility activities were being accomplished often fell below the social

requirements of 'acceptable' performance. Whilst crawling offered greater stability and lessened the fear and occurrence of falls (10.3.5), marked distress was caused by the loss of dignity surrounding the need to crawl. One spouse had purchased padded sports knee-pads for her husband to try to prevent injury to the knees.

Stairs were often problematic. Placing one hand on a banister and the other on a stair above for support was described. If only one banister was available, the technique of placing both hands on this banister and side stepping up and down could be employed. Placing one hand progressively over the other and pulling up the stairs was also reported. From early stages a tendency to fall back on the stairs was reported and some individuals preferred to crawl up with hands forward onto the stairs above or walk upstairs using two banisters and leaning well forward. Coming downstairs over-stretching forward and holding with both hands on one banister was also described. If dystonia or dyskinesia were present individuals reported needing to go up and downstairs on their bottom, a technique also used when individuals felt extremely unsafe in standing. An individual with dyskinesia reported holding his hands behind his back to increase his stability on the stairs. Walking downstairs backwards was reported in the later stages, as was increasing reliance on supervision from others, who often provided prompting to step or move hands on the banister. An interesting tension arose when formal home carers were not allowed to supervise individuals on the stairs due to health and safety issues but infirm spouses were.

The need to constantly readjust position due to slipping down the chair was reported in the later stages. Increasing difficulty was reported initiating the sit to stand manoeuvre and in attaining initial balance on standing. Individuals reported reaching behind to push on the back of the chair to ease themselves forwards; sitting on the edge of chairs only to aid transfers; and needing to fling themselves forward out of chairs at particular times in their medication cycle. In the later stages difficulty with sit to stand transfer could necessitate individuals rolling out of chairs onto the floor and crawling to furniture in order to pull themselves up to standing. When 'off' falling off sofas onto hands and knees to crawl could provide optimal mobility. Poor stand to sit technique was evident with the use of descriptors such as dropping, diving and slumping into chairs. Pulling up to standing was a feature of carer technique in the control group.

Severe dyskinesia could cause individuals to slide out of their seats and attempting to attain stability (6.2, p. 138) could necessitate anchoring themselves by gripping the chair arm and wrapping lower limbs around the chair legs; sitting with one leg crossed over the other; sitting with legs over the arm of the chair; and using the lotus yoga position on the floor. One individual described sitting on the floor at night with his back against the settee with arms outstretched along the seat to control dyskinesia.

In common with chair transfers, bed mobility was characterised by increased effort and decreased efficiency of movement with increasing disease stage (Jones et al. 1999b). A variety of techniques were described in relation to getting into bed even at the earliest stages. Techniques included: sitting on the bed edge and swinging one leg then the other onto the bed as the trunk reclined; swinging both legs in and turning in one movement; crawling into bed, grabbing the side of the mattress to pull in. Descriptors such as climbing, stepping, jumping, running, diving or throwing on to the bed were used in relation to techniques of getting into bed as stage increased. Individuals described missing the bed when sitting down on the bed edge and landing on the floor. One individual in the later stages who crawled into his bedroom kept the drawers of his divan bed open to pull himself up into standing to enable him to get into bed. Another late stage individual reported difficulty relaxing down onto the pillow.

Moving across the bed was accomplished by raising the upper trunk with elbow support and alternately shuffling hips and upper trunk; crawling across the bed in four point kneeling; and using elbow support side lying to move shoulder and then hip girdles. Difficulty was experienced working ones way up and down the bed. Pulling on head boards, pressure through heels and attempting to bounce were described. One individual in the earlier stages was only able to turn in bed by getting out of bed and crawling in again and repositioning. Others required the duvet or blankets off to turn. Even in the earliest stages rocking up from lying to standing in one movement, involving springing out of bed, was reported. Pulling on the mattress side to roll and sit up, using a heel on the side of the mattress for leverage was also described, as was swinging legs out to use as a counterbalance to the trunk to sit up. Individuals described orientating themselves sitting on the bed edge prior to standing up. The reports of rolling and falling out of bed onto

hands and knees, or turning onto the stomach and sliding out backwards increased with disease stage, as did partner help.

For some from the later stages using a wheelchair was necessary if any distance needed to be covered outside the home. An individual's attitude to wheelchair use was likely to make a major difference to getting out socially. One late stage individual was reluctant to use a wheelchair due to pride, perceived stigma and fear of the disabled label. He acknowledged increasing social isolation because wheelchair use was not socially acceptable to him. However for another a wheelchair had "opened up the outside world again". Instead of getting hot and flustered she could enjoy shopping, visits to garden centres and "walks". Substituting support to reduce the amount of outside walking was perceived as positive rather than negative.

One individual described having to be dragged across roads by their partner. For others crossing roads was only possible in a wheelchair. References to being pushed and shoved to get in and out of vehicles were common. Sitting in and then swivelling to lift both legs in, and swinging legs out and holding on the door frame to pull up to standing were common techniques employed. Running the seat back, opening the door wide and avoiding parking on an uphill slope helped. Parking on a downhill slope could be useful. Walking sticks could act as a lever to assist getting out of cars. Plastic bags on seats helped the swivel and swivel seats were contemplated.

Individuals were aware that their driving skills were sub-optimal. In addition to reduced reaction times, difficulty judging distances, and slowness in changing gear, individuals reported veering towards the far edge of the road when overtaking, drifting to the affected side and slowing down to a near stop to let cars go passed. Parking, giving way and reversing were cited as problem areas, largely due to loss of trunk rotation.

10.5 Avoidance strategies

Individuals attempted to avoid situations where their mobility difficulties would be exacerbated. Drawing attention to difficulties such as struggling to get out of soft or low chairs or negotiating crowded environments was avoided. One late stage individual found that she needed to avoid pointing her feet down and touching her calf muscles as she slid her legs out of cars to avoid eliciting dystonia. Avoidance strategies were also used to minimise physical stress. For example, an individual reported that when his carer was unable to help him move at night, she made him comfortable and assisted when he was less immobile. Risk was also avoided. Sometimes homes had downstairs toilets but they were difficult to access, for example through garages, which made it easier to use a toilet upstairs. Individuals reported starting to avoid driving due to perceived slow reaction times and a general lack of confidence in driving ability. Despite having access to a car some individuals substituted public transport if possible. One individual commented that he would only drive in an emergency.

10.6 Stopping strategies

Few strategies involving the complete cessation of mobility were recorded. Individuals were unable to stand or walk during dystonic episodes and either sat until the dystonia wore off or crawled, although they dreaded being seen in this condition (10.4.3).

Stopping driving had immediate knock on effects on lifestyle and activity choices. Often it had the effect of shrinking the accessible outside world to the immediate locality that could be reached by public transport or on foot.

10.7 MOBILITY section – Nature of physiotherapy

Strategy mapping enabled the nature of physiotherapy intervention in relation to mobility within the active group to be investigated. Following the initial mapping, subsequent maps for active group participants recorded **MOBILITY** strategies negotiated with the therapist, which had the potential to be incorporated into everyday life. The following section will comment on a series of tables which detail physiotherapist/individual negotiated strategies (as opposed to the individual's own strategies) which appeared in strategy maps during the course of intervention. Strategies negotiated with early stage individuals are listed first within each strategy type.

The main strategy types employed in physiotherapist/individual negotiated **MOBILITY** strategies can be related to the involvement strategy model (Figure 9.2, p. 211), which reflects the work individuals themselves undertake. One aim of strategy mapping was to ground physiotherapy intervention in existing work to address challenges as a result of Parkinson's disease (5.4, p. 131), and this congruence between negotiated and individual strategies would suggest that this was achieved. Compensation, a modification strategy within the model, included prompts, termed cueing in the rehabilitation literature (6.5.2, p. 155). Tables 10.1 – 10.5 show that the full range of cues was employed extensively as a negotiated strategy. Compensation within the model also included a less functional strategy of moving in a block rather than segmentally as a result of loss of rotation. Physiotherapist/individual negotiated strategies addressed loss of rotation through exercises designed to promote and maintain range of movement, and a continuation of the use of rotation.

Table 10.1 Physiotherapist/individual negotiated walking strategies

Strategy type	Specific strategies and aim
Cueing and sequencing	<p>Use of cognitive cues to improve posture (sitting and standing), step initiation, step height, step length, stance width, arm swing, especially when likely to be distracted or during dual activities</p> <p>Use of proprioceptive cues to overcoming freezing</p> <p>Use of movement sequence and cueing - stopping, standing tall, starting with heel led strike and counting – to correct propulsion and reduce shuffling</p> <p>Use of visual cues such as masking tape strips on carpets to improve initiation, stride length and turning</p>
Pacing	<p>Slowing pace of step for quality and balance</p> <p>Taking the rhythm of walking from a carer to maintain gait</p> <p>Allowing time to adjust to position change from sit to stand prior to walking</p>
Balance	<p>Wearing shoes in the house</p> <p>Increasing conscious awareness/anticipation of balance problems</p> <p>Reducing speed of direction change and make semicircular turns through doors and round furniture</p> <p>Practising techniques to get onto and up from floor, ensuring carer instruction to avoid injury</p>
Environmental factors	<p>Removing furniture to avoid obstacles</p>
Aids and equipment	<p>Use of walking aids in the house</p> <p>Use of variety of walking aids depending on level of confidence</p> <p>Use of wheelchair when appropriate</p> <p>Use of perching stool for activities needing balance</p>
Education of carers	<p>Teaching carers to cue walking, turning, overcoming freezing</p> <p>Instructing carers to assist from floor to chair, avoiding risk of injury</p>
Active movements	<p>Stretches to maintain range of movement</p>
Education	<p>Instilling awareness of environmental risk factors</p>
Skill practice	<p>Practising walking in space (garage)</p>

Another aim of strategy mapping was to support successful strategies and challenge less functional ones (5.4, p. 133). Again it would appear that strategy mapping offered the potential to do this. Pacing and stability were further modification strategies within the model that could be identified within negotiated strategies, with stability being addressed in the balance strategy type within Tables 10.1 and 10.2. However stability within the model was often achieved at a physical and psychological cost, associated with staggering for handholds, stooped posture and crawling. Physiotherapist/individual negotiated strategies aimed to achieve stability at a reduced cost through enhanced movement strategies, aids and equipment and carer support.

The model acknowledged that support contributed largely to reduction strategies and physiotherapist/individual negotiated strategies included attention to carer support and aids and equipment (see Tables 10.1 – 10.5). Risk avoidance strategies within the model were addressed within the education elements of negotiated strategies. A key theme for the therapist working with later stage individuals and their carers was respect for the **MOBILITY** strategies that had been established over many years. Modifications were only suggested if they would improve safety.

Table 10.2 Physiotherapist/individual negotiated stair strategies

Strategy type	Specific strategy and aim
Cueing	Increasing conscious awareness of stair height and consequent step height
Balance	Promoting use of handrails
Education of carers	Promoting safe supervision
Aids and equipment	Multi-professional and multi-agency liaison to install additional handrail

Strategy mapping demonstrated that individuals themselves were reducing the complexity of movement through sequencing. However the sequences put in place were often biomechanically unsound, inefficient in terms of neuro-musculoskeletal performance (Durward et al. 1999), and resulted in levels of performance which were physically and socially sub-optimal. Negotiated physiotherapist/individual strategies were designed to

increase the quality of movement and movement efficiency, and minimise carer stress when assistance is required. Tables 10.3 and 10.4 contain examples of optimal cueing and sequencing strategies for sit to stand and bed mobility manoeuvres. The interventions also incorporate attention to environmental factors, aids and equipment, education and maintenance exercise.

Table 10.3 Physiotherapist/individual negotiated sit to stand strategies

Strategy type	Specific strategy and aim
Cueing and sequencing	Cueing and mentally rehearsing sequence of movement – move to edge of seat, place hands, lead with head forward and up over knees, push with hands, take time to straighten and adjust to standing
Aids and equipment	Raising height of chairs Using lumbar roll
Active movement	Encouraging regular changes in position
Education of carers	Instructing carer in prompts and handling
Environmental factors	Considering sit to stand in range of environments – dining table, bedroom, toilet

Mobility strategies underpin activities in all other sections of the **INVOLVEMENT** area of the strategy map (Chapter 9), and Table 10.3 illustrates the practise of sit to stand strategies to ensure carry over of skills to a range of environments, for example the bedroom and bathroom.

Table 10.4 Physiotherapist/individual negotiated bed mobility strategies

Strategy type	Specific strategy and aim
Cueing and sequencing	Cueing and mentally rehearsing sequences to get into, turn and get out of bed: Getting in to bed – push back bedding, sit on side of bed, lower trunk by elbow support on to bed to place head on pillow, lift knees on to bed, reach for bedding and pull up, roll on to back with flexed knees, move shoulders and hips alternately until correctly positioned Turning – bend knees, move shoulders and hips alternately in the opposite direction to turn, turn head, lead with arm in direction of turn to rotate shoulders and hips Getting out of bed – move bedding back, turn to lie along bed edge, push up with upper arm parallel with chest to raise trunk, let legs swing down, take time to orientate Developing individual techniques for problem manoeuvres
Environmental factors	Getting in to bed from different side Reducing pillows to allow head to lead turn
Ordinary items	Purchasing new bed Keeping a torch or light near the bed
Aids and equipment	Use of a bed board Trying glide sheet (unsuccessfully)
Carer education	Instructing carer in prompts and handling
Active movement	Advising on exercise routine to mobilise prior to movement

Physiotherapy involvement in relation to car transport can be directed towards being a passenger and being a driver (Table 10.5). A network of Department of Transport Mobility Centres is aimed at helping with both aspects of car use. Early modifications were made to driving habits to address reducing the complexity and amount of driving, but avoiding driving if possible followed by cessation of driving was a clear trend. This is an example of a stopping strategy that is functional rather than dysfunctional. Cognitive rather than physical problems may preclude driving (Lincoln and Radford 1999), and motor fluctuations as a result of medication can be problematic (Lings and Dupont 1991). Dubinsky et al. (1991) conclude that although individuals with Parkinson's disease may have no more lifetime accidents than controls, with increasing disability there is a smaller

percentage of individuals still driving, fewer miles travelled but proportionately more accidents occurring. If stopping driving is not to stop social interaction outside the home professionals must ensure good information about alternative forms of transport both for individuals and their carers, individually and together.

Table 10.5 Physiotherapist/individual negotiated car transfer and driving strategies

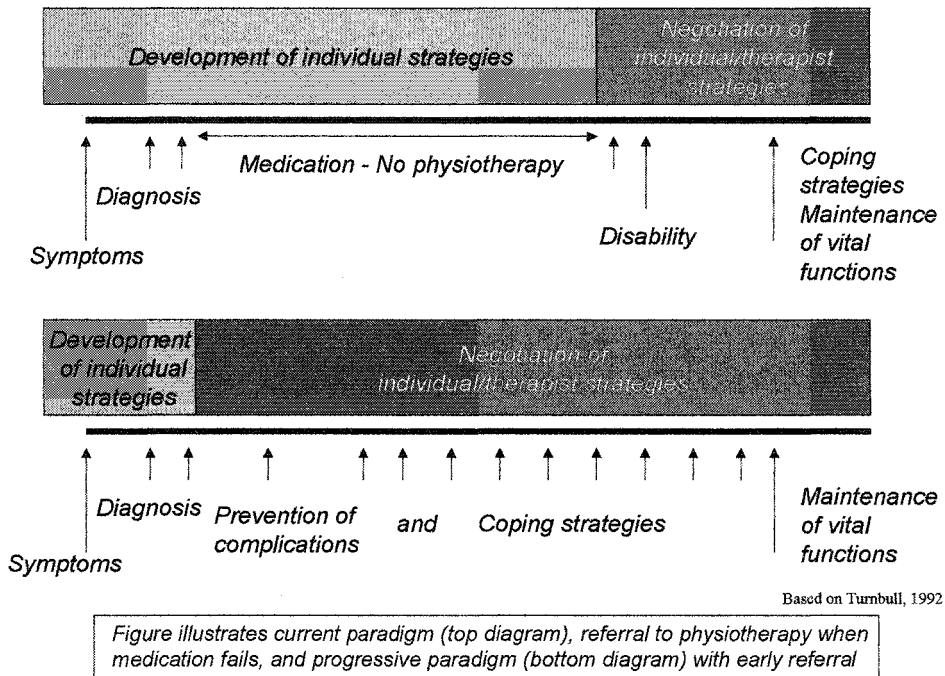
Strategy type	Specific strategy and aim
Pacing	Taking more time to be independent
Environmental factors	Opening door wide
Cueing and sequencing	Moving to edge of seat, leading with head, using appropriate hand holds, taking time to adjust to standing
Active movement	Exercises to maintain trunk and cervical rotation
Education of carers	Instructing family and care staff in safe transfers
Education	Advising on access to the Mobility Centre

10.8 INVOLVEMENT area - Implications for physiotherapy practice and research

The involvement strategy model presented in Chapters 9 and 10 suggests a trend towards sub-optimal performance and progressive withdrawal from involvement in all aspects of everyday life, despite major efforts by individuals to adjust performance to maintain participation, from the early stages of the condition. Physiotherapy involvement with the active group demonstrated that sensitivity to the model could identify the tendency to poor performance and withdrawal and put in place negotiated action to readdress the trend. Within the current Parkinson's disease paradigm (Turnbull 1992) late referral is the norm, meaning that when intervention is commenced involvement may be operating at the lower levels of the involvement strategy model proposed in Figure 9.2, p. 211. Figure

10.1 illustrates the potential that earlier referral offers in relation to strategies in all areas of the map.

Figure 10.1 Strategy development within the current and progressive physical therapy Parkinson's disease paradigms



Under the current paradigm represented at the top of Figure 10.1 the long period of time with no access to physiotherapy or the other paramedical professions means that individuals develop their own strategies. Late referral means that the opportunity for negotiated individual and therapist strategies is limited to the end stage of the condition when impoverished performance leading to withdrawal behaviour is likely to be established. Under the progressive paradigm represented at the base of Figure 10.1 the whole of the disease trajectory can be undertaken in negotiated partnership with professionals in joint commitment to maintaining the highest possible levels of involvement in all aspects of everyday life.

The involvement strategy model has identified that each domain of the model can have within it both effective and ineffective components. For example in relation to **MOBILITY** reducing the complexity of movement through sequencing is an effective strategy. However many of the movement sequences put in place were ineffective, for

example, the tendency to bring the trunk insufficiently far forward over the feet in sit to stand transfers leading to a fall back in the chair. The identification of dysfunctional mobility strategies in Parkinson's disease should allow the mapping of their evolution with disease progression. This work is a precursor to the development and evaluation of potential prevention strategies and the testing of current and future rehabilitation strategies. To date the area of gait deficits in Parkinson's disease and potential rehabilitation strategies has been most widely researched (Morris 2000). In the laboratory setting gait hypokinesia leading to reduction in step length and height can be remediated by external and attentional cues and unitask performance but evidence of carry over into everyday life is lacking.

Work has also been done on strategies used by individuals with Parkinson's disease when undertaking balance related activities (Ashburn et al. 2001a), sit to stand transfers (Kamsma et al. 1994) and turning in bed (Kamsma et al. 1994; Ashburn et al. 2001b). Each research team has also proposed a method of evaluation of respective strategies. In relation to turning activity individuals report slowing down, concentrating, holding on, turning to a preferred direction, taking small steps and making the turn in stages (Ashburn et al. 2001a). These strategies are congruent with the involvement strategy model, illustrating modification strategies of compensation (concentrating), pacing (slowing down), stability (holding on) and reduction strategies of complexity reduction (making the turn in stages) and reduction in amount (taking small steps). Rehabilitation strategies for facilitating stability through widening the base area, training balance control and strengthening and mobilising the pelvic girdle are recommended. Kamsma et al. (1994) demonstrated that compared to controls individuals with Parkinson's disease assume a flexed seated posture, and show inadequate displacement of the limbs, avoidance of simultaneous movement, more pronounced arm activity, premature knee extension, reduced forward flexion of the trunk, fragmented execution and extended rise time. Cognitively directed strategies were subsequently successfully evaluated over a one year period (Kamsma et al. 1995). The sit to stand strategy outlined is congruent with the dominant complexity reduction strategy identified through strategy mapping (10.4.1), as is the description of turning in bed outlined by Ashburn et al. (2001b). The majority of their participants exhibited multiple hip hitching in order to turn, but sitting up and pulling on a support were also employed. When individuals were asked what strategies

they used when turning, pulling on a support was most commonly reported, together with sitting up, getting out of bed, turning prone, having satin sheets, counting or turning in stages. Evaluation of movement strategies, cueing, strengthening and equipment are recommended as rehabilitation approaches (Ashburn et al. 2001b).

A framework for use by health care professionals to promote **INVOLVEMENT** (Figure 10.4) can be proposed based on the involvement strategy model. **INVOLVEMENT** is concerned with identifying the complex inter-relationships between the performance of the activity itself, the context within which it is undertaken and the meaning that involvement in that activity has for individuals. Different people will place differing emphases on the importance of involvement in the various aspects of everyday life. For some nothing less than continuing an activity as before, prior to the diagnosis of Parkinson's disease, will be satisfactory, for example in relation to employment. Therapy may involve negotiating modification in order to maintain involvement. For others avoiding an activity may have caused unnecessary losses, for example in relation to eating out, and negotiating a reduction strategy to maintain an acceptable level of involvement may be attempted. For some individuals it will be appropriate to be operating in the stop domain of the model, as illustrated in relation to driving (10.7). However it is important that the professionals involved explore the meaning of stopping strategies and identify effective strategies to mitigate against the potential effects of giving up the activity.

Figure 10.2 INVOLVEMENT strategy promotion

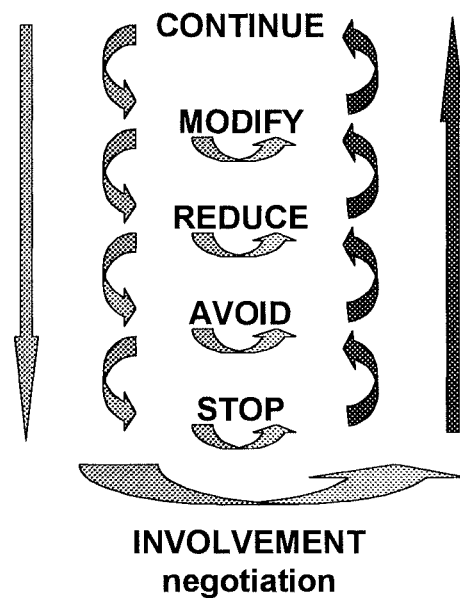


Figure illustrates the tendency to progressive withdrawal from activity (left hand down arrow), and the potential for negotiated change to promote continued involvement at all levels (arrows bridging across to right hand up arrow).

By exploring the meaning and utility of strategies for individuals, the individual themselves, the physiotherapist and team colleagues can come to a shared understanding of whether strategies of importance to the individual should be left unchanged or challenged and monitored for effectiveness at increasing involvement in the chosen activity. The identification of current strategies means that proposed new strategies can be made congruent with existing strategies. The agenda for change is set within the context of an individual's lived experience and primacy is given to an individual's goals and values.

10.9 Summary

The core areas of physiotherapy in Parkinson's disease centre on mobility strategies (Plant et al. 2000), which underpin and act as precursors for the physical performance of other everyday activities (Chan et al. 1999). Strategy mapping, by capturing self-management strategies in relation to everyday activities, provides physiotherapists with the opportunity to explore the contexts in which these core mobility areas are employed in the daily lives of the individuals with whom they are working. This understanding can promote bridging between core movement skills and participation in activity, ideally in the context of joint working with multidisciplinary team colleagues (Plant et al. 2000).

By changing the relationship between the physiotherapist and individual with Parkinson's disease (epistemology), strategy mapping offers a different way of knowing (methodology) which generates different knowledge (ontology) about the condition. The range of different knowledge and the implications for practice and research have been reviewed in relation to each area of the strategy map (Chapters 6-8 and 10). Chapter 11 will provide an overview of these implications and assess the potential impact of the study in relation to practice and research.

11 Strategy mapping and physiotherapy: a discussion

11.1 Overview of chapter

Four perspectives will be examined in this final chapter, in relation to the aims of the research, in an attempt to identify what the current project has been able to contribute to the knowledge base in each area. Three research aims related explicitly to finding out about Parkinson's disease and applying that knowledge to physiotherapy, whilst the fourth was concerned with a personal exploration of the interface between physiotherapy practice and research in the context of the study (1.2, p.2). The perspectives to be discussed here are:

- the ontological perspective - knowledge bases in relation to life with Parkinson's disease
- the methodological perspective - how the nature of the reality of living with the condition can be captured
- the epistemological perspective - the relationship between those who would know (i.e. professionals) and what can be known about life with Parkinson's disease
- the practitioner/researcher perspective – what the familiarity of practitioners with the research process has to offer both practice and research.

The specific implications for practice and research, identified and discussed in previous chapters in relation to each area of the strategy map in turn, will be developed, and conclusions regarding the impact of the overall work presented. The limitations of the project will be examined. Future directions for practice and research will be highlighted.

11.2 Potential mismatches of understanding and action

An illustrative account of potential ontological, methodological and epistemological mismatches (Donald 1998) within the traditional physiotherapy practice relationship in Parkinson's disease, which this study has challenged, provides both a starting point and a reference point for discussion of the developing perspectives within this chapter.

The biomedical knowledge base is essential for accurate diagnosis and optimal medical and surgical treatment of Parkinson's disease. However the reductionist influence within that knowledge base has been allowed to pervade relationships between professionals and individuals and the methodologies employed to evaluate interventions. At the level of the professional, this means a focus on evaluation of the particular parts of the problem complex that the individual presents with which fall within their domain, and the design of an intervention geared to address those specific areas. At the level of the individual reductionism is experienced as isolated interventions that may not contribute to attaining their overall personal goals, which themselves may not have been explored during assessment.

From this work then, what has been revealed about the potential mismatches between understanding and action in the physiotherapy process?

The *first* mismatch relates to ontological questions, which address the nature of the 'knowable' or of 'reality'. Within the traditional therapy model there is a potential for early **ontological mismatch** between a physiotherapist and an individual with Parkinson's disease as the physiotherapist, listening to a narrative about the experience of illness, attempts to reformulate it as a disease. The individual may talk about needing more time and effort to get up in the morning and about not feeling steady or confident enough to manage being out and about alone. The physiotherapist may reasonably record physical signs and symptoms such as bradykinesia and postural instability from this account, using their 'knowledge about' the condition to re-frame and make sense of the individual's 'living with' the condition narrative.

The *second* potential **mismatch** is **methodological**, and relates to the methods used to find out about the individual's experience of the condition. Physiotherapy assessment often takes place out of the usual home environment in a hospital context. Here timed tests may be used to measure how quickly activities such as standing up from sitting or doing up buttons are performed, or whether an individual can stand on one leg for a period of time (Franklyn 1986). These would seem appropriate tests for the bradykinesia and postural instability identified by the therapist in our example. However they may not be appropriate from the individual's perspective. For example, the slowness of dressing may be partly associated with the type of clothing that the individual chooses to wear. Cultural perceptions revealed by this thesis mean that reducing the 'standard' of dress may be unacceptable despite the difficulties encountered. Loss of confidence about being out and about alone is likely to result from a complex interplay of poor mobility in addition to sensitivity towards potentially stigmatising factors such as impoverished speech and dexterity, and involuntary movements. Improvement in timed balance tests in the clinical setting of a physiotherapy department may not translate into an improvement in an individual's experience of life with Parkinson's disease.

There is potential for a *third* mismatch - the **epistemological mismatch** – which can occur in the relationship between the 'knower' (physiotherapist) and the 'known' (individual's story) if the disease category narrative of the physiotherapist dominates the individual's experiential narrative. This can result in reductionism in therapy intervention. This occurs when intervention is directed towards the parts of the disease category narrative that are important for the professional, such as bradykinesia and postural imbalance in our example, whilst marginalising the more complex issues present in the experiential narrative. The therapist may work on attempting to increase range of movement, dexterity and balance to improve the morning routine. However failure to explore an individual's attitude to changes in timing of morning tasks, and their feelings about accepting help with specific aspects of tasks, denies the complex choices about the deployment of resources that individuals make in everyday life.

The question raised from this work then becomes:

Can an emphasis on understanding self-management strategies reduce the potential mismatches in the therapeutic interaction?

11.3 A developing methodological perspective on Parkinson's disease

Aim 1

To explore the experience of living with Parkinson's disease from an individual perspective

- To consider how health care professionals currently understand life with Parkinson's disease
- To develop alternative ways of understanding the experience of life with the condition

In health care practice as well as research, information about individuals is collected in terms of both words and numbers. The amount of emphasis placed on words and numbers respectively, and the emphasis given to ascertaining the personal as well as the statistical significance of numbers, can be seen to differentiate between different methodological stances aligned to different ontological and epistemological positions. Within this study, exploring the dilemmas for individuals with Parkinson's disease associated with ascribing a simple descriptor such as 'Sometimes' or 'Often' to difficulties experienced in everyday tasks in a disability scale, or aspects of life in a quality of life scale, contributed to the conceptual genesis of strategy mapping. Careful listening to attempts to ascribe descriptors to scales revealed a personal self-management story behind each decision.

Making physiotherapy, with its focus on movement, personally meaningful in Parkinson's disease was the main motivator for the current project. The occupational therapy profession has addressed the issue of personally meaningful occupational performance through the development of the Canadian Occupational Performance Measure (COPM) (Law et al. 1990). This is a client centred instrument to guide and evaluate therapy input within the context of the model of occupational performance. Whilst standardised outcome measures may be employed within the process, they are not the primary outcome of therapy, which is determined by client ratings of their identified problems and levels of performance and satisfaction with performance before and after therapy.

Early results from the current project suggested that for physiotherapy to be maximally meaningful the therapeutic encounter needed to be precisely grounded in the individual's experience of everyday life and designed to sustain and augment existing self-management. Strategy mapping was the methodological framework designed to first capture self-management work and then promote meaningful intervention. Strategies were captured during individuals' narrative accounts of life with the condition and they allowed meaning to be constructed in relation to that experience (Kielhofner 1995; Kielhofner et al. 1998; Greenhalgh and Hurwitz 1998). Personal, propositional and practical knowledge (Heron 1981; Higgs and Titchen 1995) interacted within that construction. Mapping strategies within the current project involved paying particular attention to personal knowledge because strategies were identified through listening to the words that made up the experiential narrative. The narrative was readily accessible as part of usual practice interaction and assessment. It is characteristically 'lost' because within the dominant methodology there is no commitment or mechanism to record the story it is telling. This study demonstrated that by focusing on the meaning of strategies the individual's hypotheses about relationships between a strategy and its consequences - propositional knowledge - could be explored with them. Practical knowledge or 'knowing how' was in evidence in relation to the details of strategies employed to address challenges.

Capturing and structuring the range of knowledge within the strategy map allows it to link with other frameworks for professional understanding. As with the COPM, this could include the use of appropriate quantitative outcome measures in relation to physiotherapy intervention, for example to monitor change in turning in bed strategies (Ashburn et al. 2001b) or activity levels (Jones et al. 1998b). What it is unlikely to include is timed tests to measure how quickly activities such as standing up from sitting or doing up buttons are performed, or whether an individual can stand on one leg for a period of time, as used in the methodological example in 11.2. Work to develop strategy mapping as a tool is discussed in 11.4.3.

As discussed in Chapter 3, physiotherapy as a profession is tolerant of combining research traditions (Parry 1997), largely because of the perceived congruence with the recording of objective and subjective information during practice encounters (Schmoll

1987; Shepard 1987). The caveat however must be that it is essential to have a good understanding of the respective ontological, methodological and epistemological bases of the different paradigms (Higgs and Tichen 1998). Not all health and social care professions find the complementary use of research paradigms acceptable. Wright (1998) is also concerned with the resonance between research methodologies and the practice and philosophy of a profession, in her case occupational therapy. However, for her the parallels between qualitative research and practice – person-centredness, use of language, reflection, holism – point to a single paradigm more than the combined designs favoured in physiotherapy. In addition the proper relationship between practice and research has been questioned. For Erlandson et al. (1993) the dominant conceptualizations of science embodied in preferred forms of research design and methodology in social work determine the nature of practice rather than vice versa. This mirrors the debate between evidence based and client centred practice in physiotherapy, presented in Chapter 2, with concerns about the results of statistical meta-analysis of randomised control trials being seen as the gold standard on which to base patient-orientated therapy (Parry 1991; Bithell 2000).

Just as this study has espoused and benefited from a mixed qualitative/quantitative methodology, so physiotherapy practice in Parkinson's disease can benefit from the thoughtful use of both words and numbers. Similarly, used judiciously, the full range of research methodologies from randomised controlled trials to small-scale qualitative studies has something to add to the evidence base (Guidelines Group 2001), the former to evaluate interventions to improve health care and the latter to improve understanding of health issues (Gray 1997). The key point in every case is to place the emphasis on the intervention or the study having potential impact on, or offering insight into, the everyday lives of individuals with Parkinson's disease. Central to this end is the maximal practicable involvement of individuals in their therapy, in service development and in research. This should help to ensure that the questions asked at each level and the methods chosen to answer those questions have meaning for people with Parkinson's disease and the people who support them.

11.4 A developing ontological perspective on Parkinson's disease

Aim 2

To explore the implications of new knowledge generated as a result of alternative ways of understanding Parkinson's disease

- for physiotherapy practice
- for physiotherapy research

11.4.1 Implications for practice

The implications for practice in relation to each area of the strategy map were identified and discussed within the respective chapters, 6-8 and 10. This section will highlight the central issues for practice, and also potential areas for practice development.

Listening to the experiential narrative of individuals with Parkinson's disease in the early phase of this project lead to hearing a story that differed from the traditional disease narrative. At the heart of the story was the work that individuals undertook in an attempt to maintain existing roles and activities in the face of the challenges imposed by the condition. A physiotherapist working within an ontological framework based on self-management work to promote involvement is likely to hear a different story, ask different questions, negotiate different action and assess outcome in a different way to the traditional model (11.2). For example, traditionally listening for, asking about and supporting control and disguise strategies has not formed part of the physiotherapy remit. However strategy mapping has highlighted the extent of self-management work in this area, which despite benefiting from further research (11.4.3.2) could usefully become a focus for physiotherapy input. Sensitivity to the involvement strategy model (Figure 9.2, p. 211) will allow listening for and enquiry about the full range of involvement strategies (continuing, modifying, reducing, avoiding and stopping) in relation to everyday activities. Using that new knowledge opens up the opportunity for discussion about the relative effectiveness of strategies for achieving outcomes that are important for individuals. Negotiated action to promote involvement (Figure 10.2, p. 259) in areas of importance to individuals is then possible.

The earlier example of ontological mismatch within the traditional therapy model will be used to examine the differences when using a strategy mapping approach. Hearing an individual talking about needing more time and effort to get up in the morning and about not feeling steady or confident enough to manage being out and about alone, a physiotherapist would be made aware of the modification strategy of pacing to accommodate bradykinesia, and an avoidance strategy in relation to mobility outside the home. Instead of converting the experiential narrative into a disease narrative, the physiotherapist has situated the account within the reality of the individual's own self-management. Instead of recording bradykinesia and postural instability, pacing and avoidance are recorded. Pacing may very well be an effective, albeit personally frustrating, strategy in the face of slowness of movement, however avoidance of activity outside the home is likely to be ineffective, promoting social withdrawal and isolation. If that perspective is shared by the individual, there is potential for the therapist to negotiate changed strategies to promote outside involvement. Addressing postural instability is likely to be only one part of negotiated action.

Coupling a knowledge base centred on an appreciation of self-management with an understanding of the involvement strategy model and a commitment to involvement strategy promotion points to a focus in physiotherapy management on building on existing integrated solutions rather than the traditional focus on reduction to isolated problems. In this context strategy mapping may benefit from exploration in relation to solution focused brief therapy (Iveson 1994, 1995; Wales 1998). Its founder, Steve de Shazer, and his team found their clients were more responsive when talking about the future or about their achievements than when talking about their problems. More 'future work' (establishing where the client wants to get to), and 'achievement talk' (finding out about what the client has already done to get there) were included in their counselling. Tollinton and Tollinton (1995) describe their personal experience of the use of solution focused brief therapy following stroke in one partner. They found that taking part in ordinary activities as far as was possible, focusing on possibilities without denying the reality of the damage, providing purpose and noting achievements were invaluable strategies as they "coped with the demoralizing effects of the usual rehabilitation approaches". The progressive physical therapy Parkinson's disease paradigm (Figure 10.1, p. 256) is characterised by multiple ongoing contacts between professionals and

individuals over time. It is possible to envisage strategy mapping forming a focus for a variant of solution focused brief therapy during such ongoing contacts, monitoring and supporting solutions as opposed to problems.

Strong links exist between solution focused brief therapy and appreciative inquiry, a theory of change that centres and builds on existing solutions, although appreciative inquiry is largely used in the context of organisations rather than individual lives (Hall and Hammond 2001). The approach was used by Reed et al. (2000) following a whole system event that looked at the experience of older people going home from hospital. A collaborative research group formed after the event approached addressing the gaps in service identified through: appreciating and valuing the best of ‘what is’; envisioning ‘what might be’; dialoguing ‘what should be’; and innovating ‘what will be’. The traditional approach would have been for the professionals to define the problems and attempt to redress them. Appreciative inquiry looked for the solutions that already existed and aimed to amplify what was working. This methodology would offer an innovative way forward for Parkinson’s disease service development (11.7). Strategy mapping could be viewed as appreciative inquiry at the level of individual lives: valuing the self-management work that is being undertaken; thinking about how it could be optimised to achieve greater involvement; and trying out new strategies to see if they enhance the experience of living with Parkinson’s disease.

11.4.2 Implications for education

Beliefs about the nature of Parkinson’s disease are embodied in informal and formal educational initiatives. Through strategy mapping this project has uncovered a great deal that is working well for people with Parkinson’s disease, from a range of attitudes to life (Table 6.1, p. 150) to decisions on living space (8.6, p.198). This needs to be further developed and shared with individuals with the condition. The quarterly magazine *The Parkinson* features articles containing a wealth of strategies that are congruent with those recorded during strategy mapping, and provides an example of individuals sharing successful strategies between themselves. Similarly one of the advantages individuals cite for group work is the ability to share information about what has worked for themselves and others (Plant et al. 2000). Publicising successful self-management work offers the

chance for individual self-help, as opposed to professional management, to be made visible, to be valued, and also provide positive images of 'living' with Parkinson's disease. This is particularly important in a condition that can suffer from ageist attitudes - pervasive, low expectations of the life experience of older people - despite 1 in 20 individuals being diagnosed under the age of 40 (Coene and Griffiths 2000).

The sections within the **INVOLVEMENT** area of the strategy map could provide a useful framework for gathering successful self-management strategies within. For example, the **PERSONAL** section could contain information about the ordinary items that individuals have found helpful to promote independence in personal hygiene (8.4.2, p. 190), and types of clothing which avoid difficulties with poor dexterity (8.4.4, p. 190). The **HOME** section could include nutritious but easily prepared and eaten recipes to avoid fatigue in preparation and drawing attention to difficulty when eating (7.3, p. 167 and 8.4.3, p. 190). Information about supporting successful communication from speaking face to face to using the telephone and computers could be collated (8.4.5, p. 191). Ways to continue a previous hobby such as gardening or DIY could be explored (8.4.8, p. 192). The **COMMUNITY** section could share information about maintaining involvement outside the home, for example by actively making the condition known to significant individuals, such as shop keepers, restaurant owners and taxi drivers, who could make concessions for potential difficulties (8.3, p. 187). Collecting and disseminating strategies in booklet form could form a focus of collaborative activity within a local Parkinson's disease service, a regional Parkinson's Disease Society branch structure or through a national project. It is envisaged that the Institute of Rehabilitation at Newcastle upon Tyne will be proactive in pursuing this activity, using the strategies collected during this project as the starting point. Initial work on purchasing strategies in Parkinson's disease was presented at the First Therapy Weekly Rehabilitation Conference (Jones et al. 1999c) and generated interest from the patient groups in the audience.

The Disability and Rehabilitation Open Learning Project was initiated in 1994 as a result of concern amongst the neurological charities that their members were experiencing reduced quality of life because of poor services exacerbated by inappropriate professional attitudes (Baker et al. 1997). The project recommends greater collaboration between service users, carers and professionals to develop care and education within a common

philosophical framework. The philosophy that new ways of learning could lead to better ways of caring has underpinned the development of the course entitled Practice Development in Parkinson's Disease and Parkinsonism, incorporating the English National Board A43 course, Meeting the Special Needs of People with Parkinson's Disease and their Carers (Suddes et al. 2000). The extended teaching team includes a range of professionals and individuals with Parkinson's disease and their carers, who also participate in module development and course management.

As a result of knowledge gained within the current project, acknowledging the psychosocial reality of biomedical knowledge about neurological conditions has been built into the neuroscience teaching of undergraduate physiotherapists at the University of Northumbria. Seminar groups engage students in discussion about life with a neurological condition from the perspective of individuals with the condition, including case studies based on the current project, and specific links are made through their voices to the pathophysiology of the condition. There is potential for far greater collaborative work between individuals or organisations representing individuals with neurological conditions and course teams at both undergraduate and post graduate level on course development and delivery. The Education Committee of the Association of Physiotherapists in Parkinson's Disease (Europe) (APPDE 2000) is currently engaged in the development of international post-graduate education. As membership of this organisation includes individuals with Parkinson's disease and their carers, there is potential for international collaborative post-registration learning involving both practitioners and people with Parkinson's disease. Strategy mapping could provide a framework for such collaboration.

11.4.3 Implications for research

The implications for research in relation to each area of the strategy map were identified and discussed within the respective chapters, 6-8 and 10. This section will draw together the main themes in the agenda of proposed research.

11.4.3.1 Tools

Ambulatory monitoring, providing objective data in relation to activity, was piloted within the individual case study phase in Cycle 2 (4.7, p. 103). This equipment has the potential to be a powerful tool to link home and clinic to inform decision-making at the level of individuals, particularly in relation to pharmacological manipulation (Jones et al. 1998b). Its contribution to evaluating the effectiveness of response to levodopa, monitoring the effects of initiating and changing drug therapy, and assessing stability of drug management over time has yet to be fully explored. This study has also highlighted the potential of the equipment, in combination with the recording of qualitative data, to demonstrate the links between drug therapy, dietary intake, mobility and wellbeing (Figure 7.4, p. 169), and to identify areas of risk for potential falls within the home by exposing poor step patterns (Appendix 15, Figure 1). Further developmental work using ambulatory monitoring equipment at the level of individual decision making is to be undertaken within the Professorial Clinical Unit, a specialist unit focusing on the multidisciplinary physical management of Parkinson's disease, at the Institute of Rehabilitation in Newcastle upon Tyne.

Two self-report Parkinson's disease specific scales, one relating to disability (SAPDDS) and the other to quality of life (PDQ-39), were also used in Cycle 2 (4.6, p. 101), and difficulties experienced with their use were discussed (4.8.3, p. 111). These included difficulty with the wording of questions, with distinguishing symptoms due to Parkinson's disease, and with answering satisfactorily due to the variability of the condition. In correspondence with the author (Brown 1996) the range of activities that would need to be undertaken to develop the psychometric properties of the SAPDDS were identified, to include revising the item pool and assessing the validity against another accepted measure of disability. Unlike ambulatory monitoring and strategy mapping, the benefit of developing these tools as an aid to physiotherapy specific decision making within the clinical and the research setting would appear to be limited.

Strategy mapping as a tool was both developed and evaluated within the current project. This project was a predominantly qualitative study, demonstrating the possibility of capturing self-management work, illustrating the range of that work, and showing how

uni-professional physiotherapy input could be guided by and linked to existing work. Strategy mapping as a tool could benefit from a range of developmental work to evaluate its use in a multi-professional context (11.4.3.3) and to explore the possibility of incorporating outcome measurement properties into strategy mapping. The five steps in the COPM process (Law et al. 1990) - problem definition, problem weighting, scoring, re-assessment and follow-up - could potentially be used as a template for the development of a personally meaningful quantitative component to strategy mapping. A similarly staged process for the strategy mapping process could potentially involve: strategy identification within the **INVOLVEMENT** area (in which other strategies coalesce to make involvement more or less likely); strategy weighting in relation to the impact making strategies more effective would potentially have on everyday life; scoring current satisfaction with the top five weighted strategies on a satisfaction scale and devising a satisfaction score by multiplying by impact weighting; comparing satisfaction scores at assessment and reassessment; and negotiating strategy review. There is potential for development of strategy mapping as a tool within the remit of the Professorial Clinical Unit at the Institute of Rehabilitation in Newcastle upon Tyne.

11.4.3.2 Physiotherapy management

The core areas of physiotherapy – gait, balance, posture (including range of movement) and transfers (Plant et al. 2000) – site practice at the activity/impairment end of the ICDH-2 (WHO 1997) continuum. This is underlined by the foci of treatment techniques and linked outcome measures identified in a review of intervention studies (2.7, p. 38) (Jones and Plant, in press). The developing ontological perspective on Parkinson's disease proposed by this study seeks to move physiotherapy management towards the participation end of the ICDH-2 continuum, focusing on the understanding of movement performance within the specific contexts in which it is undertaken, and taking cognisance of the meaning of involvement for individuals. This perspective has generated a range of research areas linking movement and meaning.

The physical management of stigmatising symptoms such as involuntary movement (6.5.1, p.152) could form a focus of research. With tremor often unsatisfactorily managed at medication levels that address other cardinal symptoms such as akinesia and rigidity

(Pogarell et al. 1997); 50% of individuals likely to develop dyskinesia within five years of levodopa initiation (Quinn 1995); a lack of formal physical management strategies; and the potential for social stigmatisation, individuals have needed to develop a battery of self-management approaches for control and disguise of involuntary movements.

Correspondence has been initiated between the Institute of Rehabilitation, centres of excellence in the management of Parkinson's disease in North America (Mount Sinai Medical Centre, New York) and Australia (Kingston Centre, Cheltenham) and a company manufacturing lycra splints (Second Skin) on the potential for the use of unobstrusive splinting for the short term control of involuntary movement.

This study has also identified the extent to which individuals with Parkinson's disease are engaged on an on-going basis with the use of a variety of prompts to initiate and maintain movement in everyday life (6.5.2, p. 155). Similar cues form part of physiotherapy management of the condition (Morris 2000). Basic research using positron emission tomography (Brooks 1999) is providing insight into the mechanism by which these prompts are effective. Based on work undertaken within this study, the recognition of the need to understand the pre-existing prompting work individuals are undertaking has been built into an international research study to investigate cueing as a rehabilitation strategy. The Newcastle upon Tyne arm of the study, based at the Institute of Rehabilitation, will develop individual cueing profiles and investigate the potential links between different types of cues and fatigue. Ambulatory monitoring will contribute data to the study. Fatigue, like involuntary movements, has been poorly addressed in terms of preventative physical management.

Three possible research areas are based on the need for physiotherapists to have a better understanding of the psychosocial factors that make participation in an activity more or less likely:

1. Support for movement

The incorporation of physical activity, exercises and movement strategies in everyday life is a major part of physiotherapy intervention in Parkinson's disease (Plant et al. 2000). However increased or alternative movement activity is being suggested within the context of progressively decreasing movement potential and decreasing windows of opportunity

for quality movement, e.g. in the form of ‘on/off’ fluctuations. This study has highlighted that an individual’s exercise history and current routines play an important part in sensitising them to exercise advice and information (7.5.3, p. 177). Further collaborative work is needed to understand how best to structure professional input to support continued optimal movement over the course of the condition.

2. Carer involvement

Similarly carer involvement in physiotherapy must be set within the psychosocial context of the dyadic relationship in the case of a spouse and familial or friendship roles in the case of other relationships. Physiotherapists need a better understanding of the meaning of being supported in the area of physical management from an individual’s perspective, and supporting physical management over time from a carer’s perspective. The responsibility professionals place on carers to ensure carryover of their professional agendas and provide information on effect needs to be explored in greater detail. Mechanisms are needed to ensure that the individual’s voice and the carer’s voice are heard individually and jointly to enable negotiated solutions, and avoid the ad hoc nature of carer involvement which currently prevails (Plant et al. 2000).

3. Information

The third area of research identified from the study in which psychosocial factors are of central importance is the dissemination of information within the physiotherapy role. Helping physiotherapists to identify whether the individuals and carers they are working with are seekers, weavers or avoiders (Pinder 1990) of information, and promoting work on preparing a range of information approaches dependent on where individuals are situated on the information continuum would enhance person-centred care.

By identifying self-management strategies within the strategy map this study has been able to propose an involvement strategy model, awareness of which enables therapists to promote involvement through negotiated change. Discussing the level at which strategies are operating within the model, from continuing through modification, reduction and avoidance to stopping, allows negotiation of strategies to promote effective involvement at the optimum level. Important follow-up work will involve testing of the model to see if satisfaction in participation increases as a result of therapy involvement. The development

of strategy mapping as a tool (11.4.3.1) would enable both quantitative and qualitative data to be collected during evaluation. On-going work will be undertaken under the auspices of the Professorial Clinical Unit at the Institute of Rehabilitation.

11.4.3.3 Physiotherapy and teamwork

This study has developed and piloted strategy mapping within a uni-professional context. However, physiotherapy in Parkinson's disease is best undertaken in the context of a multi-professional team (Plant et al. 2000). If strategy mapping is to have a wider application it will be necessary to undertake a detailed evaluation of the method as a tool to aid multi-professional decision making in Parkinson's disease or a related long term health condition. Teamwork can be addressed through the use of a number of models. The models most commonly referred to are multidisciplinary teams, involving many professionals, and interdisciplinary teams, where the many professionals involved combine individual elements of their professional input in relation to specific goals of intervention with the patient or client. Trans-disciplinary teams (Mackey and McQueen 1998) seek to share and transfer each professional's skills with and to each other to ensure a more stream-lined, comprehensive and co-ordinated approach. However the fact that each of these models have 'disciplinary' in their titles indicates that they are from a tradition that gives primacy to professional knowledge, both propositional and practical, despite the rhetoric that individuals and carers, the prime holders of personal knowledge about the condition, are key members of the team (De Souza 1990). Although each type of knowledge – propositional, practical and personal (Heron 1981; Higgs and Titchen 1995) - will be possessed in different ways by all those involved in the management of Parkinson's disease, truly espousing a partnership or collaborative model would involve particular commitment to the experiential knowledge base held by individuals with Parkinson's disease. Strategy mapping is based on that commitment, and this would provide a major strength as a decision-making tool. The concept facilitates a move from problem solving within a professionally set agenda to problem setting within a person centred agenda (Schon 1983). Use could be made of the proposed scoring system (11.4.3.1) to ascertain the impact of trans-disciplinary input on promoting satisfaction with involvement in everyday life.

In addition, a number of separate areas of the strategy map have highlighted potential future studies with implications for teamwork. For example, the relationship of physiotherapy to medication in Parkinson's disease has long been debated, with questions raised about whether it can delay or potentiate drug therapy, and precisely how it functions in an adjunctive capacity (7.5.1, p. 174). The role of the physiotherapist working collaboratively with individuals to evaluate symptom management related to pharmacology in assessment and review contexts, using meaningful outcome measures including ambulatory monitoring, has yet to be explored. Similarly evaluation of trans-disciplinary working to enhance dietary management (7.5.2, p.176) has the potential to enhance involvement strategies. Using multidisciplinary guidelines to optimise medication effect and nutritional wellbeing through dietary management, the physiotherapist can potentially contribute at the levels of seating, posture, balance, dexterity and mobility to aid safety, enjoyment and efficacy of dietary intake.

The roles of occupational therapists and physiotherapists in the management of Parkinson's disease have multiple overlaps (Chesson et al. 1996). Strategy mapping has identified two specific areas where joint research between the two professions in collaboration with individuals with Parkinson's disease would be beneficial. The first area relates to the use and usefulness of commonly supplied aids and equipment (8.7.4, p. 205). Relating current theories of movement control to equipment options would enable the generation of advice on optimal solutions for difficult issues such as turning in bed, getting in and out of a chair or car, and managing stairs. The second area identified for joint working relates to optimal living space design in Parkinson's disease. This project has identified two considerations which are difficult to reconcile, one is the need for unimpeded space to avoid freezing episodes (9.6, p. 231) and the second is the need for stability (10.3.5, p. 242), which individuals often look to nearby items in their environment to provide. Professor Tom Kirkwood in his final Reith Lecture (2001) bemoaned the fact that our society has been slow to apply design technology knowledge to the issues facing older people. Developing a 'smart' environment to address the challenges of Parkinson's disease could provide major benefits to other constituencies of individuals facing similar challenges.

This study identified that support from local businesses and facilities such as corner shops and libraries could be important in promoting participation in activity outside the home (8.7.2, p. 201). Studying the effect of raising awareness in a local community, including the business community, in relation to Parkinson's disease offers the potential for collaborative working between statutory and non-statutory agencies and the higher education sector. For shared solutions to be reached (Disability Rights Task Force 1999) opportunities have to exist for sharing of issues. Success with a local project of this nature could prompt wider take up of issues nationally and internationally. Like the 'smart' living environment, a 'smart' local environment for people with Parkinson's disease is likely to benefit others in the community.

11.5 A developing epistemological perspective on Parkinson's disease

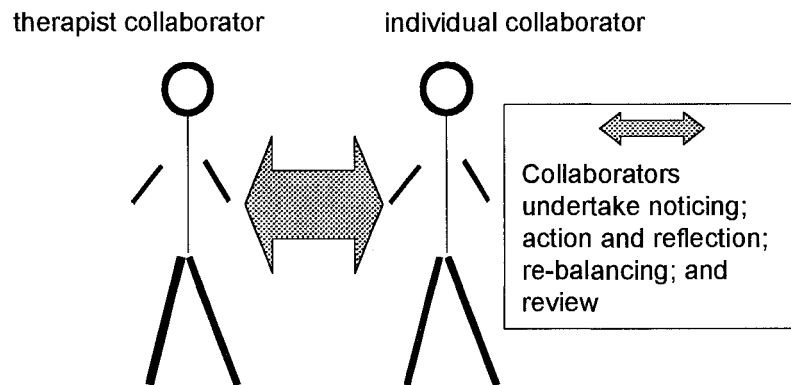
Aim 3

To investigate how physiotherapy practice can be structured to take account of both new ways of understanding and new knowledge in Parkinson's disease

Within the traditional therapy model (Heron 1981) there is a power differential in favour of the therapist's knowledge base which forms a barrier restricting the flow of information from individual to therapist. A recent study exploring the power balance between physiotherapists and their patients (Harrison and Williams 2000) supports the continued existence of this model in practice, reporting that patients felt overwhelmed and disempowered by their perception of the power imbalance. Whilst therapists perceived there was an imbalance, they felt that it was only slightly in their favour. Strategy mapping is designed to reduce the power differential between individuals and professionals. The concept is based on an experiential practice model (Figure 11.1), developed within this study from Heron's (1981) experiential research model. In this model each person, both therapist and individual, is involved as a collaborator. This is especially appropriate in the management of long-term illness when self-management by

the individual will be on-going, and the therapist needs to appreciate the intricate interaction between pathology and everyday life.

Figure 11.1 Experiential therapy model



Based on Heron 1981

As with experiential research (Heron 1981), there are two complementary aspects to experiential practice – noticing and categorising what is going on (phenomenological mapping), and trying out some developmental procedure (intentional interaction). Within the experiential practice model therapist and individual collaborate to notice and to try out. The strategy map forms the focus for the exchange of ideas in relation to noticing (Stage 1). Discussion centres on endorsing successful strategies, identifying less successful ones and exploring new options. What each collaborator needs to do in relation to strategy change is agreed. Collaborators undertake the agreed action, perhaps during a course of therapy, and also reflect on the experience of the action within themselves and between themselves (Stage 2). A period of time is allowed to elapse during which a re-balancing is sought following change in strategies for the individual and knowledge for the professional (Stage 3). For the individual the re-balancing is within their everyday life and for the professional it is within their professional life as a result of the combined

action with the individual. Review of the process is sought, with evaluation of the modifications made to strategies in relation to the work of self-management for the individual and future practice for the therapist (Stage 4).

Once again personal, propositional and practical knowledge bases (Heron 1981; Higgs and Titchen 1995) are seen to interact. Propositional knowledge (or 'knowing that') is encompassed in facts or truths stated as propositions. Stages 1 and 4 of the experiential practice interaction centred on strategy mapping, take place at the level of propositional knowledge. Hypotheses about the effect of modifying strategies are voiced and refined at Stage 1 and reviewed at Stage 4. Practical (or professional) knowledge relates to 'knowing how'. The therapist needs to know how to influence strategy change and the individual to incorporate it, and each needs to know how to interrelate action and experience with ideas (Stage 2). The third form of knowledge is personal (or experiential) and relates in the model to the experience of changing strategies and changing knowledge (Stage 3).

Although age, social class and ethnicity can affect the ability and willingness of individuals to participate, siting decision making at the level of everyday activity and participation is likely to make the collaboration more accessible (Errser and Atkins 2000). Traditional models of training and practice can however make it difficult for physiotherapists to situate their intervention within the complex fabric of individual lived experience. This was highlighted by Dawson (2000) in a study of a new domiciliary physiotherapy service. In an interpretive account of domiciliary physiotherapy practice, transitional and settling in phases, characterised by a move away from the biomedical knowledge base to a focus on client centred problems respectively, had to be worked through before the emergent phase allowed therapy to be situated firmly within the context of individual client and carers needs.

The experiential practice model is congruent with the reciprocal learning model of domiciliary physiotherapy (Dawson 2000). Within that model decision-making is accomplished within a framework of mutual sharing of knowledge. However during reflection on the project Sheila Harrison expressed concerns about the potential expectations of 'patients' for 'treatment' and the expectations of physiotherapists to

'treat', an area which would have benefited from further investigation (11.7). Insights into collaborative therapy relationships gained through strategy mapping within the context of Parkinson's disease management have the potential to allow more focused articulation of physiotherapy/individual relationships in a range of areas of practice. This would be particularly pertinent in relation to other long term health conditions with an acknowledged emphasis on self-management, such as rheumatoid arthritis (Sandles 1998).

11.6 A developing practitioner/researcher perspective in physiotherapy

Aim 4

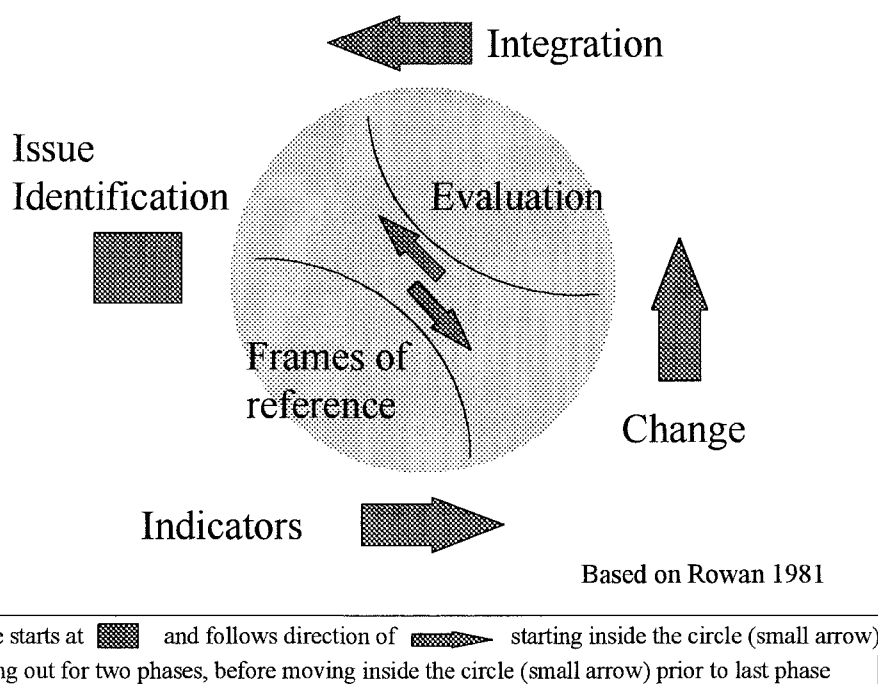
To explore the interface between physiotherapy practice and research through personal exposure to the research process

One of the drivers for the start of my journey in research was the realisation that research awareness and confidence was a prerequisite for practice in the current health service. However barriers are still in place which make research seem something that is done outside rather than as a fundamental part of practice (Pollock et al. 2000). The emphasis on gold standard evidence can have the unfortunate effect of devaluing the evidence base of practice, and the mystique of the research process can disempower practising therapists. It also disempowers the users of health services.

Hierarchies of evidence or appropriateness of health care research design do not include the views of patients (Bury 1998), and patient advocacy groups were ranked lowest in relation to providing health-related information in a survey of GPs (Illman 2000). However, within the current health service agenda driven by quality through evidence based practice (NHSE 1998), there is also a focus on user/client/patient involvement, including their involvement at all stages in randomised control trial methodology (Consumers in NHS Research Support Unit 2001).

Through the use of the research cycle model (1.3, p. 3) I became aware of its potential to bridge the research-practice gap (Jones et al. 1999a) by growing research awareness and skills in both clinicians and service users. The first step in the process is to highlight the similarities between the research cycle model and practice. A practice cycle model relating the research cycle stages to a typical encounter between a therapist and an individual was devised (Figure 11.2). Recognising that the process is familiar may help make the research cycle more accessible to practising clinicians. The practice cycle model is congruent with the type of collaborative practice necessary for strategy mapping in long term health conditions such as Parkinson's disease. A clinician working with an individual will identify and verify issues important to them both (commensurate with BEING in Figure 1.1, p. 3). With an inward movement they will both apply their particular frames of reference to those issues (THINKING). The results of this thinking will guide the goals they set together and the indicators of success they identify (PROJECT). During the therapy intervention (ENCOUNTER) changes are made which are evaluated (MAKING SENSE) in terms of reaching the desired goals. Sharing perceptions of the success of the changes that were made (COMMUNICATION) will influence subsequent cycles as the long-term therapeutic relationship forms a spiral of review, negotiated change and review.

Figure 11.2 The practice cycle model



Many of the areas of further research highlighted in the course of this study (11.4.3) could be undertaken in practice as collaborative exercises between therapists and individuals with Parkinson's disease. Having become familiar with the cycle related to practice, its research cycle equivalent could be used to provide a bridge to collaborative practice development and research. This will be illustrated here using the example of the investigation of walking aids in Parkinson's disease (8.7.4, p. 206).

In the context of continuing professional development, a therapist might identify, with an individual with whom she/he is working (BEING), that a walking stick, which was meant to aid gait, is in fact causing additional problems for the user. Interested to know whether this has been recognised as an issue for other professionals and individuals, they agree to enter a period of THINKING, during which formal and informal information seeking and appraisal skills are required. Armed with the literature and experiences of both therapists and individuals, the question of how to study the issue in practice and in real lives arises (PROJECT). This could just involve the original therapist and individual, or extend to other therapists and individuals in the same or other locations. Methodology and methods – observation of performance, survey, diary - will need to be chosen, and data collected (ENCOUNTER). It will then be necessary to ask, “How can we interpret what we've found?” (using analytical skills at MAKING SENSE), and “How can we explain the implications?” (using writing and/or presentation skills at COMMUNICATION).

The research cycle model has been used within this project as an aid to conceptualising and communicating about the research process. It has been possible to model its theoretical application to practice with the aim of making the research process familiar by aligning it with the practice process. Making research and development possible in practice settings helps this context to become a rich environment to explore practice-based issues systematically, within a culture of inquiry that grows research awareness, capacity and involvement in both clinicians and individuals. Further development work is required to evaluate the practice cycle's use as a bridge between practice and research.

11.7 Limitations of the study

There are a number of limitations of the present study. Although the research spiral allowed for correction in later cycles to achieve increased levels of collaboration (Table 1.2, p. 11), the study would have benefited from a greater degree of user involvement at all stages of the research cycle. My personal commitment to collaborative research has grown over the course of the project. Planning the same project now from a collaborative base would mean involving individuals with Parkinson's disease not just largely as informants, as in the original design, but as collaborators at all points in the research cycle. An example of the difference this might have made is in the choice of methods used to explore life with Parkinson's disease in order to inform physiotherapy practice. The current project chose group and individual interviews, scales and ambulatory monitoring. It is possible to conceive of methods that would have been less influenced by a research or professional agenda, such as the use of creative methods such as art, poetry or drama to convey the meaning of movement in Parkinson's disease to professionals. Groups of individuals with Parkinson's disease could be invited to work individually or collectively, with or without professional involvement, on the theme of movement in everyday life. Similar sessions could be envisaged for carers who facilitate movement in their partners, family or friends with Parkinson's disease. Feedback and consensus on the messages from the work could be via exhibitions, performance and collaborative workshops involving individuals and professionals.

Although maximum opportunities were taken to present ongoing work on the project to both lay and professional audiences, this was always done by either Sheila Harrison or myself in formal circumstances at conferences, presentations, lectures or in-service training sessions (Table 3.4, p. 82). Had collaboration between individuals with Parkinson's disease and researchers occurred at all phases of the research cycle, including COMMUNICATION, individuals would have had the choice of taking part in presentation of results. This is likely to have extended the range of settings for dissemination and the nature of dissemination to take increased account of lay audiences. It is likely that increased collaboration would have placed the production of accessible information about the strategies collected within the study higher up the dissemination agenda.

Only one therapist was involved in strategy mapping development within the context of a new service. Future studies could involve several physiotherapists in established services in the introduction of strategy mapping to test its transferability to on-going practice. The project focused heavily on the collection and interpretation of strategies for use in physiotherapy intervention. It would have been helpful to place more emphasis in data collection on the perceptions of individuals working in a collaborative way with therapists. Extending the use of strategy mapping by different therapists and monitoring perception of its use by both collaborating professionals and individuals offer further opportunities for development.

Strategy mapping has been developed and piloted within this study in a uni-professional context but physiotherapy is best undertaken within a multi-professional team and the need for development of the tool in this setting has been identified (11.4.3.3). If a team of professionals working with people with Parkinson's disease were to espouse practice based on positive self-management there would be a need to develop a service structure which was congruent with that philosophy. Appreciative inquiry (11.4.1), building on aspects of a service that were perceived by participants to be working successfully, could offer a collaborative way to engage key players in person-centred service development incorporating strategy mapping.

11.8 Future Directions

This chapter has argued that an emphasis on understanding self-management strategies offers the possibility of reducing the potential for mismatches to occur in therapeutic encounters in long term health conditions such as Parkinson's disease. This section will summarise in point form what needs to be done in the future to take an emphasis on self-management work forward:

to develop the methodological perspective there is a need for –

- a commitment to listening to the experiential narrative and hearing the story of self-management
- the use of strategy mapping to capture, structure and use the story as a basis for negotiated action
- thoughtful links with other frameworks to aid understanding of specific areas of the map e.g. relevant outcome measures
- potential collaborative developmental work to add a quantitative component to strategy mapping to evaluate change

to develop the ontological perspective there is a need for –

- knowledge about self-management to influence practice to ensure intervention is congruent with personal reality
- a focus on building on existing integrated solutions
- the dissemination of information on self-management strategies to provide a positive image of living with a long term condition
- the involvement of individuals with long term conditions in the development and delivery of education at all levels, for both professional and lay audiences
- the development of tools, such as ambulatory monitoring and strategy mapping, which allow knowledge to flow between home and health care settings
- self-management to provide a foci for research studies which will further support personal work
- collaboration within the health care team and the wider community to enable robust and creative solutions to support self-management

to develop the epistemological perspective there is a need for –

- the power differential between the respective knowledge bases in the therapeutic relationship to be addressed
- an explicit exploration of the expectations of both parties in relation to the therapeutic encounter
- a commitment to collaborative therapy relationships to allow mutual sharing of knowledge, learning and change

11.9 Conclusion

Paradigm development within a profession takes place when solutions to practice problems generate and develop theory, which challenges epistemological thinking within a discipline. This thesis has charted the ways in which the current study has contributed to the paradigm debate in relation to physiotherapy practice and Parkinson's disease at all three levels - practice, theory and epistemology. This study started at the level of lives of individuals with Parkinson's disease, into which physiotherapy may enter. Strategy mapping was developed to provide a solution to the practice problem of locating an individual's self-management work as they undertake their journey with a long-term health condition. The involvement strategy model, centred on the identification of continuation, modification, reduction, avoiding and stopping strategies, provided a theory about the potential lived experience of the individual with whom the therapist may be working. In order to work successfully in the context of that experience, the experiential practice model proposed that epistemological issues centred on collaborative change be addressed.

This thesis placed the voice and experience of people with Parkinson's disease at the centre of physiotherapy practice. This focus enabled the development of a person centred methodological tool, strategy mapping, and a revised therapy relationship based on collaboration, the experiential practice relationship. The different knowledge gained as a result of strategy mapping enabled changed priorities for practice, education and research to be articulated. In addition the model used to describe the research process itself was seen to provide a bridge between practice and research. This work has attempted to increase the degree of alignment between the everyday lives of individuals with Parkinson's disease and physiotherapy practice, education and research. Future work should seek to align those spheres with even greater congruence.

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APPENDIX 1 – Publications arising from (a) research project and (b) related activity

(a) Project-based publications

Published conference abstracts and letter

Chandler, C., Jones, D., Plant, R. and Walker, D. (1996) Activity analysis by ambulatory monitoring (NUMACT) in patients with Parkinson's disease. Movement Disorders, 11(Supplement 1), p. 93.

Jones, D., Chandler, C. and Plant, R. (1996) Developing a taxonomy of indexing categories to identify need in Parkinson's disease. Physiotherapy, 82(7), p. 413.

Jones, D. (1997) Looking through different spectacles (Letter). Physiotherapy, 83(2), p. 104.

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Jones, D., Plant, R., Chandler, C. and Whittaker, C. (1999) Physiotherapy and Parkinson's disease: implications of changing cultures of care. Journal of Neurologic Rehabilitation and Neural Repair, 13(1), p. 73.

Conference proceedings abstracts

Jones, D., Chandler, C., Plant, R. and Whittaker, C. (1996) But is it due to Parkinson's?: individuals' perceptions of causal relationships within their own symptomatology. 2nd European Parkinson's Disease Conference, Stockholm.

Jones, D., Harrison, S., Chandler, C., Plant RD and Whittaker, C. A. (1997) Mapping self-management strategies: a client-centred approach to therapeutic intervention in

Parkinson's disease. The Challenge of Motor Disability in Parkinson's Disease: From Science to Practice, London, British Geriatric Society, p. 16-17.

Jones, D. and Harrison, S. (1997) User strategies as a guide to physiotherapy practice. Towards the Millennium - the Challenges of Developing Health Care Practice, Newcastle upon Tyne, University of Northumbria.

Jones, D., Chandler, C., Plant, R.D., Harrison, S. and Whittaker, C. (1998) Strategy mapping in Parkinson's disease. 6th European Congress on Research in Rehabilitation, Berlin, p. 370-371.

Jones, D., Chandler, C., Walker, R., Suddes, M. and Heslop, P. (1998) The use of activity analysis in Parkinson's disease management. From Science to Practice, Multidisciplinary Care in Parkinson's Disease and Parkinsonism, London, British Geriatric Society, p. 21-22.

Jones, D., Harrison, S., Plant, R., Chandler, C. and Whittaker, C. (1999) Research spirals as a paradigm to link research and practice. 13th International Congress of World Confederation for Physical Therapy, Yokohama, Japan, p. 265.

Jones, D., Harrison, S., Plant, R., Chandler, C. and Whittaker, C. (1999) The self-management of bed mobility by people with Parkinson's disease. From Science to Practice, Multidisciplinary Care in Parkinson's Disease and Parkinsonism, London, British Geriatric Society, p. 20. (Awarded The Winning Poster Presenter Prize)

Jones, D., Plant, R., Chandler, C. and Harrison, S. (1999) Purchasing strategies to make life easier in Parkinson's disease. 1st National Therapy Weekly Rehabilitation Conference, London, p. 21.

Jones, D. (2000) Strategy mapping: narrowing the user-professional gap. Dutch Association of Physiotherapy in Geriatrics Conference, The Hague, p. 4-5.

(b) Related publications

Book chapters, published abstracts and reports

Jones, D. (1997) Research into Physiotherapy and Parkinson's in 'Parkinson's: the Physiotherapist'. Parkinson's Disease Society, London.

Jones, D. (1997) Rehabilitation in early onset Parkinson's disease in 'Parkinson's : the Physiotherapist'. Parkinson's Disease Society, London.

Jones, D. and Godwin-Austen, R. B. (1998) Parkinson's Disease. In Stokes, M. (ed.) Neurology for Physiotherapists, Mosby, London.

Jones, D., Plant, R., Lovgreen, B., Ashburn, A., Handford, F. and Kinnear, E. (1999) Best practice physiotherapy in Parkinson's disease. Journal of Neurologic Rehabilitation and Neural Repair, 13(1), p. 73.

Ashburn, A., Jones, D., Lovgreen, B. and Plant, R. (2000) Physiotherapy and Parkinson's disease: evaluating best practice, Physiotherapy, 86(1), p. 32.

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Plant, R. D., Loader, S., Jones, D., Hutchinson, A., Thomson, J., Ashburn, A., Lovgreen, B., Kinnear, E. and Handford, F. (2000) Physiotherapy in Parkinson's disease - referral, contact and discharge patterns. Movement Disorders, 15(3), p. 171.

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**APPENDIX 2 – Letter entitled ‘Looking through different spectacles’
published in *Physiotherapy* (1997), Volume 83, Issue 2, p 104**

MADAM – In her article ‘Epistemology, private knowledge, and the *real* problems in physiotherapy’ (*Physiotherapy*, September 1996), Robertson likens the claim that physiotherapists should know about the nature of knowledge (epistemology) in order to generate knowledge to the claim that someone who needs glasses should know about the laws of optics. She asserts that all one needs to know is that glasses ‘can provide suitable correction’.

Physiotherapists do need to know about different theories of knowledge precisely because specific inquiry paradigms, with their associated epistemologies, provide a variety of lenses through which the world can be viewed. Part of ‘research awareness’ (Newham 1997) is an appreciation of the importance of the epistemological question – the nature of the relationship between the would-be knower and what can be known (Guba 1990). French and Swain (1997) challenge physiotherapists to consider participatory and emancipatory research approaches, based in the critical theory paradigm, which question the objectivist epistemology of the positivist paradigm that dominates disability research. In her article entitled ‘Constructing realities: An art of lenses’, Hoffman (1990) explores the implications for her own practice as a family therapist of moving from a dualist epistemology influenced by the circular feedback loops of cybernetic theory to the transactional epistemology of social construction theory where meanings evolve as part of human interaction. A practice based on a search for shared understandings and ideas for action replaced ‘the visiting expert’ (Hoffman 1990).

Physiotherapists could usefully consider trying on different epistemological glasses to see how their professional worlds and the worlds of their clients change with different lenses.

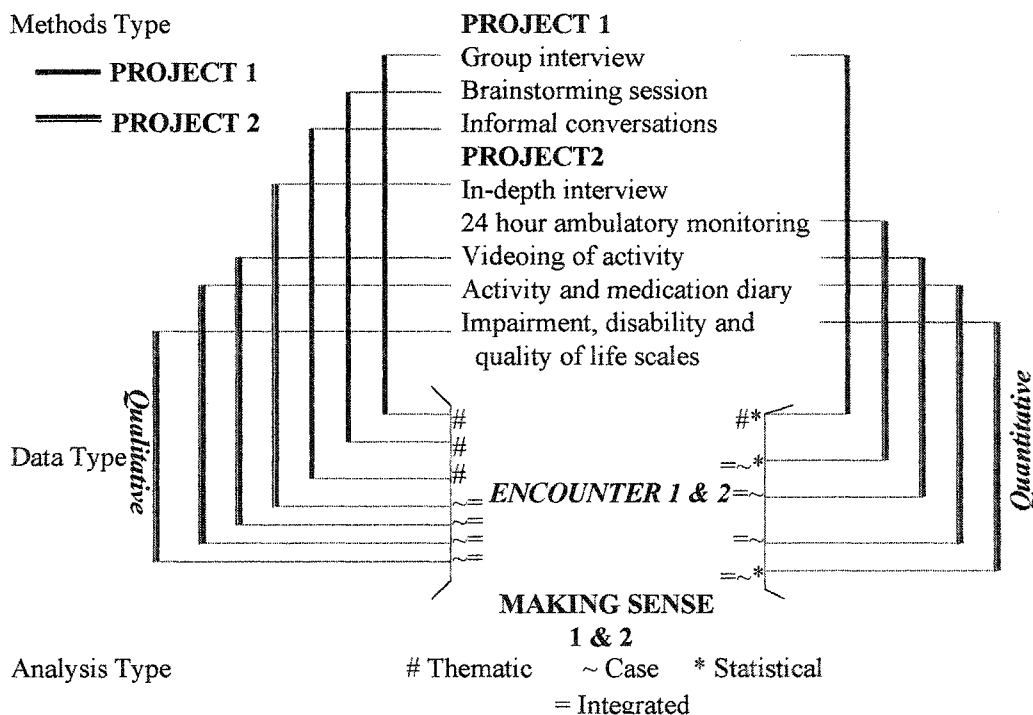
APPENDIX 3 – Technological support for analysing words and numbers

Note – Table sets out types of technological support used to support the analysis of words and numbers collected during ENCOUNTER (data collection) phases of the project, with numbers (in bold) indicating sequence of analytical strategies within the chronology of the project

DATA COLLECTION PHASE →	Words from ENCOUNTER 1, Fig 1.3. p. 6	Words and numbers from ENCOUNTER 2, Fig 1.4, p. 12	Words and numbers from ENCOUNTER 3, Fig 1.5, p. 16
TECHNOLOGICAL SUPPORT FOR ANALYSIS ↓			
PEN AND PAPER		4 Coding and memos	
SCISSORS AND SORT		11 Cut and sort of Strategy node in 7 & 10	
MICROSOFT WORD	1 Themes 6 Data entry for NUD*IST	2 Transcription 9 Data entry for NUD*IST 13 Integrated analysis coding sheet	16 Recategorising strategies as map developed
MICROSOFT EXCEL		5 Sort of coding 8 CSV files from NUMACT to Excel for graphs	
MICROSOFT POWERPOINT		17 Integrating NUMACT and diary data graphically	15 Development of strategy map
NUD*IST	7 Analysis using fixed indexing tree 12 Re-analysis using hierarchical theory	3 Fixed indexing tree off-line 10 Tracking trajectories tree 14 Integrated analysis	19 Analysis of strategy maps
SPSS (Statistical Package for the Social Sciences)		18 Exploration of NUMACT and scale data relationships	

APPENDIX 4 – Triangulation strategies related to methods, data and analysis type

Note – Figure summarises the qualitative-quantitative linkages and the triangulation strategies related to methods of data collection, qualitative/quantitative data types and analysis type (see below) employed in Cycles 1 (Figure 1.3, p. 6) and 2 (Figure 1.4, p. 12).*



** Analysis type: #Thematic – identification of themes; ~Case – within and across case analysis; *Statistical – manipulation of numerical data; =Integrated – synthesis of within case data*

APPENDIX 5 – Information sheet for ENCOUNTER 2



Institute of Health Sciences

Head: Professor D W Watson

Newcastle upon Tyne NE7 7XA

Telephone (0191) 227 4266

Fax (0191) 227 4419

Direct Telephone Line

A STUDY OF MOVEMENT PROBLEMS IN PEOPLE WITH PARKINSON'S DISEASE

Thank you for agreeing to take part in this study, the aim of which is to investigate how Parkinson's disease affects the performance of activities involved in everyday life.

A research physiotherapist will spend some time with you over a number of weeks, at home and in the community if applicable, observing and interviewing you about carrying out everyday activities. You will also be requested to have your mobility recorded for a 24 hour period, and to have a number of activities video recorded at the end of the monitoring period. The recording system comprises a pocket-sized computer and small junction box secured in a waist belt, and two leads with silicone rubber pads attached with tape to the chest and thigh. Diary records of medication and activity levels will be requested during mobility monitoring. The equipment is inconspicuous, and assessment will not involve any risk or harm to you. All information will be treated as confidential and you may withdraw from the study at any time.

The results of this initial part of the study will inform an interview survey to be carried out with a larger number of people with Parkinson's disease. Subsequently physiotherapy intervention with people with Parkinson's disease will be evaluated.

This study will provide information about how movement problems associated with Parkinson's disease affect everyday life and will inform future physiotherapy service provision.

If you need further information please contact Anna Jones, Research Physiotherapist, on 091 227 3025, or Dr T Walls on 091 273 8811.

APPENDIX 6 – Consent form for ENCOUNTER 2

UNIVERSITY of  at NEWCASTLE
NORTHUMBRIA

Institute of Health Sciences

Head: Professor D W Watson

Newcastle upon Tyne NE7 7XA

Telephone (0191) 227 4266

Fax (0191) 227 4419

Direct Telephone Line

A STUDY OF MOVEMENT PROBLEMS IN PEOPLE WITH PARKINSON'S DISEASE

The aim of this study is to investigate the effect of Parkinson's disease on activities involved in everyday life. If you agree to take part in the study a research physiotherapist will spend some time observing and interviewing you at home over a period of several months. You will also be requested to have your mobility recorded for a 24 hour period. The recording system comprises a pocket-sized computer and small junction box secured in a waist belt, and two leads with silicone rubber pads attached with tape to the chest and thigh. Diary records of medication and activity levels will be requested during mobility monitoring. The equipment is inconspicuous, and assessment will not involve any risk or harm to you. All information will be treated as confidential and you may withdraw from the study at any time.

The results of this initial part of the study will inform an interview survey to be carried out with a larger number of people with Parkinson's disease. Subsequently physiotherapy intervention with people with Parkinson's disease will be evaluated.

This study will provide information about how movement problems associated with Parkinson's disease affect everyday life and will inform future physiotherapy service provision.

If you need further information please contact Anna Jones, Research Physiotherapist, on 091 227 3025, or Dr T Walls on 091 273 8811.

I have read the details of the project to be undertaken by Anna Jones

who explained the study to me on(date).

I understand what is involved in the study and agree to participate in the project.

Signed:

Witness:

APPENDIX 7 – Self-Assessment Parkinson’s Disease Disability Scale

SECONDLY, PLEASE COMPLETE THE SELF-ASSESSMENT PARKINSON’S DISEASE DISABILITY SCALE:

Please read the questions below. For each item circle the number which describes best how easy or difficult it is for you to perform that activity. If you are more able at some times than others, indicate how you are **in general** at the times of day you would normally perform these activities. If you use a frame or walking stick or any special aids to help you, please answer according to how well you would manage **without** the aid.

- 1 Able to do alone without difficulty
- 2 Able to do alone with a little effort
- 3 Able to do alone with a lot of effort or with a little help
- 4 Able to do but only with a lot of help
- 5 Unable to do at all

1. Get out of bed	1	2	3	4	5
2. Get up from an armchair	1	2	3	4	5
3. Walk around the house/flat	1	2	3	4	5
4. Walk outside - for example, to the local shops	1	2	3	4	5
5. Travel by public transport	1	2	3	4	5
6. Walk up stairs	1	2	3	4	5
7. Walk down stairs	1	2	3	4	5
8. Wash face and hands	1	2	3	4	5
9. Get into a bath	1	2	3	4	5
10. Get out of a bath	1	2	3	4	5
11. Get dressed	1	2	3	4	5
12. Get undressed	1	2	3	4	5
13. Brush your teeth/manage dentures	1	2	3	4	5

SELF-ASSESSMENT PARKINSON'S DISABILITY SCALE CONTINUED:

Here is a reminder of the scoring system:

- 1 Able to do alone without difficulty
 - 2 Able to do alone with a little effort
 - 3 Able to do alone with a lot of effort or with a little help
 - 4 Able to do but only with a lot of help
 - 5 Unable to do at all
-

14. Open tins (not using an electric opener)	1	2	3	4	5
15. Pour milk from a bottle or carton	1	2	3	4	5
16. Make a cup of tea or coffee	1	2	3	4	5
17. Hold a cup and saucer	1	2	3	4	5
18. Wash and dry dishes	1	2	3	4	5
19. Cut food with a knife and fork	1	2	3	4	5
20. Pick up an object from the floor	1	2	3	4	5
21. Insert and remove an electric plug	1	2	3	4	5
22. Make a telephone call	1	2	3	4	5
23. Hold and read a newspaper	1	2	3	4	5
24. Write a letter	1	2	3	4	5
25. Turn over in bed	1	2	3	4	5

HEALTH SERVICES RESEARCH UNIT
DEPARTMENT OF PUBLIC HEALTH AND PRIMARY CARE
UNIVERSITY OF OXFORD

PDQ-39

**Parkinson's disease
quality of life questionnaire**

and

scoring system

August 1995

DUE TO HAVING PARKINSON'S DISEASE, how often have you experienced the following, during the last month?

Due to having Parkinson's disease, how often during the last month have you

Please tick one box for each question

	Never	Occasionally	Sometimes	Often	Always or cannot do at all
1. Had difficulty doing the leisure activities which you would like to do?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Had difficulty looking after your home, e.g. DIY, housework, cooking?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Had difficulty carrying bags of shopping?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Had problems walking half a mile?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Had problems walking 100 yards?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Had problems getting around the house as easily as you would like?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Had difficulty getting around in public?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Needed someone else to accompany you when you went out?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Felt frightened or worried about falling over in public?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please check that you have ticked one box for each question before going on to the next page

Due to having Parkinson's disease, how often during the last month have you

Please tick one box for each question

	Never	Occasionally	Sometimes	Often	Always
10. Been confined to the house more than you would like?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. Had difficulty washing yourself?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. Had difficulty dressing yourself?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. Had problems doing up buttons or shoe laces?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. Had problems writing clearly?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. Had difficulty cutting up your food?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. Had difficulty holding a drink without spilling it?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. Felt depressed?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. Felt isolated and lonely?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. Felt weepy or tearful?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please check that you have ticked one box for each question before going on to the next page

Due to having Parkinson's disease, how often during the last month have you

Please tick one box for each question

	Never	Occasionally	Sometimes	Often	Always
20. Felt angry or bitter?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21. Felt anxious?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22. Felt worried about your future?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23. Felt you had to conceal your Parkinson's from people?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24. Avoided situations which involve eating or drinking in public?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25. Felt embarrassed in public due to having Parkinson's disease?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
26. Felt worried by other people's reaction to you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
27. Had problems with your personal relationships?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
28. Not had support in the ways you need from your spouse or partner?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
29. Not had support in the ways you need from your family or close friends?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please check that you have ticked one box for each question before going on to the next page

Due to having Parkinson's disease, how often during the last month have you

Please tick one box for each question

	Never	Occasionally	Sometimes	Often	Always
30. Unexpectedly fallen asleep during the day?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
31. Had problems with your concentration, e.g. when reading or watching TV?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
32. Felt your memory was bad?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
33. Had distressing dreams or hallucinations?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
34. Had difficulty with your speech?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
35. Felt unable to communicate with people properly?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
36. Felt ignored by people?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
37. Had painful muscle cramps or spasms?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
38. Had aches and pains in your joints or body?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
39. Felt unpleasantly hot or cold?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please check that you have ticked one box for each question before going on to the next page

The following questions are about your symptoms of Parkinson's disease, during the last month.

40. TREMOR:

	Never	Rarely	Sometimes	Often	Always
a) How often have you had a tremor or shaking of your hands or limbs?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	No problem	Quite mild	Moderate	Severe	Very severe
b) How bad was this?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

41. STIFFNESS:

	Never	Rarely	Sometimes	Often	Always
a) How often have you had stiffness of movement?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	No problem	Quite mild	Moderate	Severe	Very severe
b) How bad was this?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

42. SLOWNESS:

	Never	Rarely	Sometimes	Often	Always
a) How often have you had difficulty "getting going" or been slow moving about?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	No problem	Quite mild	Moderate	Severe	Very severe
b) How bad was this?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

43. FREEZING:

	Never	Rarely	Sometimes	Often	Always
a) How often have you suddenly been unable to move, ie frozen to the spot?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	No problem	Quite mild	Moderate	Severe	Very severe
b) How bad was this?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

44. JERKING:

	Never	Rarely	Sometimes	Often	Always
a) How often have you had uncontrolled jerking or large movements of your limbs?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	No problem	Quite mild	Moderate	Severe	Very severe
b) How bad was this?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

PDQ-39 SCORING SYSTEM

Coding system for questions

All questions on the PDQ-39 are coded in the same way.

We recommend that data is entered using the following codes:

0 = Never

1 = Occasionally

2 = Sometimes

3 = Often

4 = Always (or cannot do at all, if applicable)

Dimensions and their questions

Mobility

10 questions, nos. 1 to 10

Activities of daily living (ADL)

6 questions, nos. 11 to 16

Emotional well being

6 questions, nos. 17 to 22

Stigma

6 questions, nos. 23 to 26

Social support

3 questions, nos. 27 to 29

Cognitive impairment (Cognitions)

4 questions, nos. 30 to 33

Communication

3 questions, nos. 34 to 36

Bodily discomfort

3 questions, nos. 37 to 39

Scoring for each dimension

Each dimension is calculated as a scale from 0 to 100
0 = no problem at all; 100 = maximum level of problem

If the response to a question is missing, no scale score is calculated for that individual for that dimension.

Formula for scoring each dimension

$$\frac{\text{sum of scores of each question in dimension}}{4 (\text{max. score per question}) \times \text{nos. questions in dimension}} \times 100$$

Mobility

$$(\text{scores of questions } 1+2+3+4+5+6+7+8+9+10) / (4 \times 10) \times 100$$

Activities of daily living

$$(\text{scores of questions } 11+12+13+14+15+16) / (4 \times 6) \times 100$$

Emotional well being

$$(\text{scores of questions } 17+18+19+20+21+22) / (4 \times 6) \times 100$$

Stigma

$$(\text{scores of questions } 23+24+25+26) / (4 \times 4) \times 100$$

Social support

$$(\text{scores of questions } 27+28+29) / (4 \times 3) \times 100$$

Cognitions

$$(\text{scores of questions } 30+31+32+33) / (4 \times 4) \times 100$$

Communication

$$(\text{scores of questions } 34+35+36) / (4 \times 3) \times 100$$

Bodily discomfort

$$(\text{scores of questions } 37+38+39) / (4 \times 3) \times 100$$

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The Parkinson's Disease Society of Great Britain

This questionnaire is made available free of charge, with the permission of the authors, to all those undertaking non-profit making research. The questionnaire is also available, with the permission of the authors, to profit making organisations, provided a full copy of the research protocol is deposited with the authors. No changes may be made to the questionnaire without written permission.

The Health Services Research Unit is a non-profit making organisation which is part of the University of Oxford. The Parkinson's Disease Society of Great Britain is a charitable organisation.

For further information, please contact

Viv Peto, Crispin Jenkinson or Ray Fitzpatrick

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URL: <http://hsru.dphpc.ox.ac.uk>

Fax: (01865) 228414

APPENDIX 9 – NUMACT information sheet

NUMACT MOBILITY RECORDER

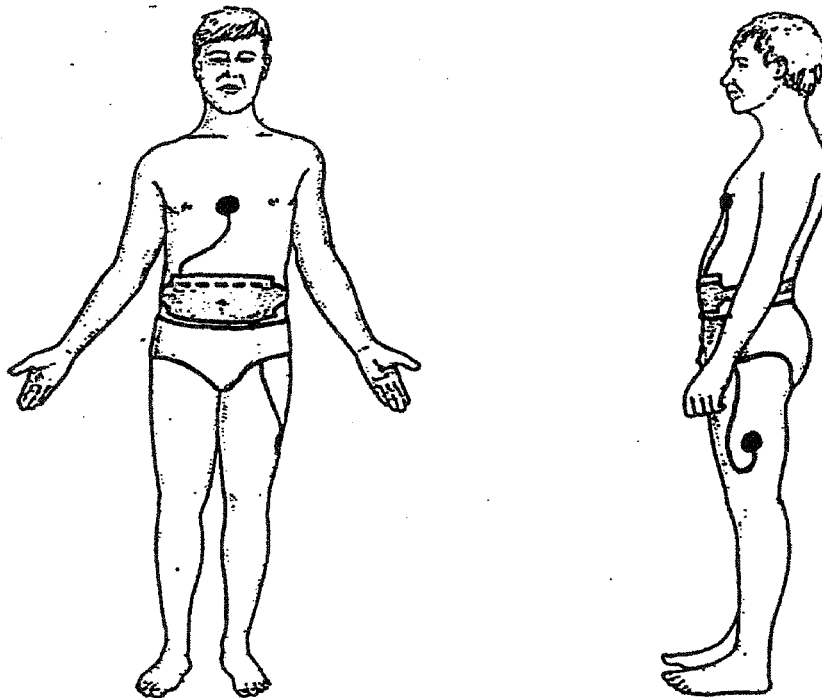
INFORMATION SHEET

The aim of the NUMACT mobility recorder is to monitor and record the activity of an individual whilst lying down, sitting up, standing and walking over a selected period of time (usually 24 hours).

The recording system includes a pocket-sized computer, a small junction box and two leads with silicone rubber pads. It is secured in a waist belt which may be worn inside or outside the clothing as preferred. The two leads are attached to the body by a microporous adhesive sheet, one to the chest and one to either thigh (as illustrated below).

Please note that during the period of monitoring it is of paramount importance to our research that you *do not* alter your normal daily routines, ie specifically organising activities to fit in with the recorder. You should behave exactly as you would have without the monitor. The one limitation the recorder will present however is that bathing and showering will not be possible.

If special family/social events get planned for the day of monitoring, perhaps you could let us know so we can organise an alternative date.



If you have any queries or experience any problems with the NUMACT recorder, please do not hesitate to contact:

ANNA JONES, RESEARCH PHYSIOTHERAPIST, INSTITUTE OF HEALTH SCIENCES,
UNIVERSITY OF NORTHUMBRIA AT NEWCASTLE, COACH LANE CAMPUS,
NEWCASTLE UPON TYNE, NE7 7XA.

Telephone number 091 227 3025.

APPENDIX 10 – Medication, activity and well-being diary

NUMACT DIARY

Participant no

Name

Date and time monitoring commenced

Date and time monitoring finished

Date and time video recording commenced

Date and time video recording finished

MEDICATION RECORD DURING MONITORING

Name of drug	Dosage (if known)	Time taken
For example: Kemadrin	5 mg	midday

Please record the main activities carried out in each of the 4 time periods - before breakfast, before lunch, before dinner, before bed. For example:

BEFORE LUNCH Sat and read the paper until mid-morning.
 Was picked up in the car by a neighbour and went
 to the garden centre.

DAY 1 BEFORE LUNCH

BEFORE DINNER

BEFORE BED

DAY 2 BEFORE BREAKFAST

BEFORE LUNCH

BEFORE DINNER

BEFORE BED

Thank you for your co-operation.

Section to be completed with Research Physiotherapist on removal of monitoring equipment:

Day of the week Mon Tues Wednes Thurs Fri Sat Sun

Season of the Year Spring Summer Autumn Winter

Would you describe the weather on the monitored day as being:

snow/ice very wet/ wet/ damp/ perfect
storms cold hot humid conditions

Would you describe your mood on the monitored day as being:

very miserable/ fine/ happy/ euphoric
depressed unhappy OK contented

Considering all the ways Parkinson's disease affects you, how were you feeling on the monitored day?

very poor poor fair good very good

On the day of monitoring did you feel you were:

as independent as usual requiring more help requiring less help

Would you describe the period over which you were monitored to have been:

very busy very quiet average

Were the activities undertaken during monitoring done by:

choice necessity both

Did anything unusual happen during the monitored day which would have increased or decreased your activity? Yes/No

If Yes, please supply details:

APPENDIX 11 – Example of an Initial Strategy Map

Note – Table illustrates a strategy map constructed after an initial assessment visit to a 63 year old female in the active group, who had been diagnosed under 2 years, and was on a minimal Parkinson’s disease medication regime (Table 7.1, p. 163). Strategy map areas and associated sections are indicated in the left hand column of the table, with strategies identified in the right hand column.

Strategy Map	Strategies
SELF	
PHYSICAL	None
THINKING	Aware of need to increase step height as tends to trip up stairs Aware of reduced arm swing and tendency to propulsion so conscious effort to improve this Increased care when walking on uneven surfaces
FEELINGS	Knowledgeable about PD through books and neighbour in Ireland, ex-footballer, devastating effect Doesn’t want to be cosseted by family Takes everyday as it comes Neighbours aware of PD – younger, very sociable, often out for meals – she avoids invitations, ‘self-conscious’ though they are encouraging
ROUTINES	
MEDICATION	Sinemet LS x 2 per day Keeps records of PD medication effect, symptoms, information all together Asked for 4 months after diagnosis of PD to come to terms with diagnosis and start medication then if necessary
DIET	Eating smaller portions Increased cholesterol, aware of dietary manipulation Increased fruit intake
EXERCISE	Previously very fit – badminton, all Ireland champion cyclist Enjoys walking, makes effort to continue regular local walks, half to one mile maximum, and aware of tiredness and dragging left leg with distance Goes to T’ai chi classes
SUPPORT	
INSIDER	Husband does cooking Husband cuts up meat May have to ask husband’s assistance with zips
OUTSIDER	GP Movement Disorder Specialist

ORDINARY ITEMS	<p>Uses fork for eating</p> <p>Often prefers easier type of earrings (clip ons)</p> <p>Uses extra (triangular) cushion on chair to improve posture and assist in/out low settee (for replacement of cushions in future)</p> <p>Husband bought word processor to assist with writing letters</p> <p>Shoes with buckles – tying laces difficult, crepe soles stick</p> <p>Avoids clothes with small buttons</p> <p>Uses own shopping bag, plastic bags too difficult</p> <p>Changed glasses, previous bifocals difficult walking</p>
SPECIAL EQUIPMENT	None
STRUCTURAL	<p>Hangs on to door to get off toilet</p> <p>Using pedestrian crossing now</p>
INVOLVEMENT	
PERSONAL	<p>Often no earrings due to difficulty</p> <p>Removed rings from fingers secondary to swelling, pins and needles</p> <p>Some difficulty applying makeup with left hand, uses right or both together</p> <p>Fastens bra at front, swivels around</p> <p>Puts left arm in jacket first</p> <p>Tends to stoop forward when eating, mouth to food</p> <p>Insomnia – to bed late, often gets up to make cup of tea, usually 5 hours sleep</p>
COMMUNITY	<p>Shops within walking distance</p> <p>Prefers to go out for meals with family only</p> <p>Making effort to continue local walks</p> <p>T'ai chi classes</p> <p>Runs errands 2 x daily to avoid tiring self</p> <p>20p in pocket for bus fare before getting on bus</p> <p>Holds purse in right hand</p>
WORK	<p>While working in delicatessen (now retired) other assistants often took over certain jobs involving hand dexterity e.g. grinding coffee, because it took so long</p>
MOBILITY	<p>Tends to hang on to door handle to assist on-off toilet in en suite so leaves door open</p> <p>Into bath, on to knees then rocks back into sitting position with maximum assistance of bath handles</p> <p>Turning in bed, sits up, shuffles onto elbow, hips through and down</p> <p>Uses banister to pull herself up stairs</p> <p>Difficulty in car parked on a slope, getting out tends to swivel then get out</p> <p>Stopped driving the car because of bradykinesia, slow reactions (also car large family type)</p> <p>Sits in front outside seat in bus, presses button and doesn't get up until bus stops</p>

APPENDIX 12 – SUPPORT area: ORDINARY ITEMS Tables

Note – Tables 1-8 identify the use of ordinary items to minimise difficulty experienced in everyday life as a result of Parkinson’s disease. Within each Table strategies identified in the earliest stages are reported first. These are often identifiable in the later stages with minor modifications.

Table 1 Seating, Beds and Bedding, and Furniture

Seating	Beds and Bedding	Furniture
cushion support for neck/back	changed position of bed to aid transfers	furniture used for balance support
high backed chair	triangular pillow for positioning and lumbar support when sleeping	pouffe used to spread newspaper out on to read
high stool in kitchen	twin beds in summer (husband’s restlessness), double in winter	moving of furniture for space
high chairs	single beds	uses table to eat if in lounge
suite with high seats/arm support	additional pillows for neck pain	low stool
extra cushions for posture and transfers	new bed	Ottoman in bathroom to sit on dry/change stool in bathroom
triangular cushion to help transfers	fitted bed sheets	bath stool with towel as step into bath
hard board under cushion to firm up seat	mattress used for turning	uses bedside cabinet to turn in bed
carver type chair	pillow to support leg in bed	table to read newspaper on fridge on top of unit for easier reach
Parker Knoll recliner chair	satin sheeting	table set out with all needed - TV controller, radio, books, telephone, intercom, snack, drink
swim ring to relieve pressure	duvet	opens doors of wardrobes to use as support to get out of bed
	towel in bed for increased salivation	opens drawers of bed to use as support to get into bed
	orthopaedic bed, hard mattress for transfers	footstool for circulation and relaxation
	no duvet cover as legs tend to tangle up in bed covers	bed moved downstairs
	cotton sheets with shiny surfaces	
	old pillow case and hankies due to increased salivation	

Table 2 Bathing and Showering, Toileting, and Personal Hygiene

Bathing and Showering	Toileting	Personal Hygiene
bath mat use container to pour water on hair installing shower uses towel with holes in to hold on to loofa long handled brush uses old clean paint brush to clean between toes towelling bathrobe smaller towel shower chair stool by sink uses hair shower head to spray self down double sized shower tray with curtain to assist carer support	sanitary towels/panty liner in case of accidents pot at night bucket in bedroom for morning higher toilet in en suite towel on chair in case of accidents	electric shaver electric toothbrush mirror with magnifying side to help with makeup special shampoo for increased dandruff and sweatiness liquid soap hankies for salivation face cloths for salivation towels for salivation

Table 3 Eating and Drinking, Cooking, and Household

Eating and Drinking	Cooking	Household
use fork more uses spoon more uses mug rather than cup and saucer sharper knife for meat straw to drink through high cereal bowl to scoop food out bowl for toast in the morning to avoid slippage steak knife for meat pinafore for mealtimes uses big supper cup special hot plate (child's type) to keep food warm as slow eater ice tongs for salad	tends to cook with frozen vegetables rather than fresh more prepared food ready made meals but add vegetables and gravy tinned snacks ready washed potatoes pastry mix frozen foods	jar opener pasty cutter dishwasher jug to fill kettle garden kneeler for accessing cupboards automatic washing machine reorganisation of kitchen for ease of use using grill and microwave more than oven electric tin opener especially for soups tray trolley new vacuum cleaner talking clock bottle top opener automatic kettle thermos flask so don't have to go into kitchen for hot drink electric carving knife TV in bedroom igniter for cooker teasmaid screwdriver for opening jars microwave to reheat meals fans for sweating episodes

Table 4 Clothing, Footwear, and Dressing/Make up/Jewellery/Accessories

Clothing	Footwear	Dressing/Make up/Jewellery/ Accessories
<p>leisure wear - T-shirts, track suits, polo shirts more trousers trousers with elasticated waists big fitting jumpers cardigans pockets to disguise reduced arm swing long sleeved blouses to hide tremor tops without buttons extended thread on top button on shirts larger buttons stretchable socks stay up stockings instead of tights or stockings pop socks no tights, no socks bed socks for cold feet at night boxer shorts silk pyjamas extra nightwear as changes clothing during the night due to excess sweating drip dry, non iron fabric looser, front fastening clothing all in one corset to support posture all in one bra camisole not bra layers garments - light, wide hat and gloves as feels cold polo neck sweaters stretch leggings trousers to stop bruising from dyskinesia knee length socks T-shirt in bed to turn more easily keeps knot in tie or slip on tie/clip on tie zip cardigan cotton clothing for sweating dark clothing to disguise perspiration braces shorter tops to aid toileting</p>	<p>flat, lace up shoes slip on shoes wearing shoes more in house resoling and reheeling more supportive outdoor footwear sandals in house pull on boots rubber soles velcro fastening shoes trainers outside Slipper socks slippers during the day with no socks wiggly stay up laces moccasin type slippers with soles insoles for shoes to cushion heels and reduce jarring previously slip ons but feet swell so laced shoes but keep laces done up wider fitting shoes ankle boots to give increased support metal tips on shoes for sound</p>	<p>Dressing long-handled shoe horn coathanger to bring clothes down back hook end of long handled shoe horn to pull up trousers</p> <p>Make up pale nail varnish to get away with mistakes pale lipstick</p> <p>Jewellery/ Accessories Clip on earrings Velcro on handbag</p>

Table 5 Writing, Reading, and Telephones

Writing	Telephones	Reading
typewriter as writing deteriorated lined paper word processor to write letters personal computer electric typewriter cartridge type ink pen lead pencil thicker pen typewriter even for cheques	extension of telephone to dining room/bedroom relocating telephone to reduce distraction telephone rather than write answer phone portable cordless telephone various types of telephone in house to encourage continued use speaker telephone by bed last caller recall mechanism if unable to answer phone immediately memory function on phone	smaller papers larger tabloid hard board support for book bulldog clip to hold newspaper sheets together along folded edge book rest book stand on legs

Table 6 Walking and Shopping, and Driving

Walking and Shopping	Driving
Walking - granddaughter's push chair for balance high hiking stick metronome shooting type stick folding chair for rests Shopping - tray purse uses own shopping bag as plastic bags too difficult four-wheeled shopper uses shopping trolley as wheeled frame uses notes to pay purse with zip round three sides draw string bag for coins	new car with power assisted steering bought car with Mobility Allowance automatic car people carrier type vehicle for ease of access plastic bag for car transfers jeep type car rubber soled shoes for driving

Table 7 Health, Medication, and Remembering

Health	Medication	Remembering
changed glasses as bifocals difficult walking corks wrapped in old nylons to prevent cramps Walkman for exercise tape exercise videos dark glasses reduces effect of sunlight bar in garage for back stretch inflatable head/neck support lip salve to prevent lip dryness elastic support for glasses uses masking tape to try to stop tremor at night sports knee pads for crawling hearing aid dentures	filing trays for medication alarm clock for timing big plate for setting our medication	notice board for messages diary calendar

Table 8 Hobbies, Lighting/Security, and Work

Hobbies	Lighting/Security	Work
Gardening garden kneeler long handled gardening equipment pesticide for weeds DIY electric screw driver invests in scaffolding rather than use ladder for house maintenance at higher level overalls with press studs cordless electric drill Needlework tapestry stand	Lighting torch under pillow additional lighting top of stairs has front and back of house well lit socket lights for landing at night due to decreased balance timer on landing light night light Security burglar alarm system fitted bell in bathroom hammer in bedroom	Meals on Wheels small tray with dividing ridge to stabilise foil containers using carrier bags to place meals in to deliver using trolley to load up van Music teacher pointer to point to music

APPENDIX 13 – SUPPORT area: SPECIAL EQUIPMENT Tables

Note – Tables 1-8 identify the use of special equipment to minimise difficulty experienced in everyday life as a result of Parkinson’s disease. Tables indicate at what stage of the disease the item was recorded in use and how many times the item was identified in the strategy maps of both the active and control group.

Table 1 Seating, Beds and Furniture

Item	Stage 1 n=21	Stage 2 n=11	Stage 3 n=14	Stage 4 n=21
Seating -				
Chair raisers	2	3	3	4
Electric recliner/riser chair		1	1	4
Spring loaded high chair			2	
Perching stool	1	1	1	4
Seat board		1	1	
Beds -				
Bed board	2	1		1
Bed lever	1	1		2
Back rest	1		1	1
Bed raisers		1		2
Rope ladder		1	1	
Monkey pole			2	1
Multiglide				1
Mattress raiser			1	2
Electronically operated bed			1	
Spenco mattress				1*
Sheepskin				1
Furniture -				
Cantilever table	1	1	1	2
Etwell trolley			1	2

* used on the floor to fall out of bed onto

Table 2 Bathing and Showering, and Toileting and Continnence

Item	Stage 1 n=21	Stage 2 n=11	Stage 3 n=14	Stage 4 n=21
Bathing and Showering -				
Bath/shower board	5	2	3	3
Bath seat	2		3	3
Bath lifter	3	4	4	8
Shower chair/seat	1	2		3
Sit in type bath				1
Toileting and Continnence -				
Raised toilet seat and surround	1	3	4	3
Plastic sheet	1			1
Commode		1	2	6
Urinary bottle		2	3	6
Incontinence pads		1		4
Absorbent pants				2
Waterproof mattress cover		1		
Convener at night		1		
Cantilever toilet rail			1	2
Kanga sheet			1	
Kylie sheets				1

Table 3 Eating and Drinking, Dressing, and Household

Item	Stage 1 n=21	Stage 2 n=11	Stage 3 n=14	Stage 4 n=21
Eating and Drinking -				
Dycem mat	1	1		
Plate guard	1	1		
Large handled knife and fork		2		3
Lidded cup with straw hole		1		1
2 handled cup with spout			1	2
Dressing -				
Tights aid	2			
Hook to pull up zips	1			
Sock aid	1			
Button hook			1	1
Household -				
Lever taps	1	1	1	
Plug grip	1		1	
Helping hand	2	1	1	2
Kettle tipper	2	1		1
Teapot tipper			1	

Table 4 Support/Braces, Pain Relief, Symptom and Medication Management

Item	Stage 1 n=21	Stage 2 n=11	Stage 3 n=14	Stage 4 n=21
Support/Braces -				
Tubigrip		1		1
Support stockings		1		2
Cervical collar			1	
Lumbar support	1	1	1	1
Ankle support		1		
Wrist splints			1	
Knee brace				1
Caliper/orthotic shoes				2
Pain Relief -				
TNS	2		2	1
Hand held massager	1			
Vibrating cushion	1	1		
Electric hot pack/pad	1			1
Symptom Management -				
Ice packs for nodules				1
Vibrator for nodules				1
Medication -				
Pillmeter			4	1
Medidozette			3	1

Table 5 Walking Aids, Wheelchairs and Cars

Item	Stage 1 n=21	Stage 2 n=11	Stage 3 n=14	Stage 4 n=21
Walking aids -				
Walking stick	4	4	5	7
Tripod			1	
Elbow crutch				1
Fischer sticks (for rheumatoid arthritis)				1
Walking frame		1	2	5
Wheeled walking frame			2	2
Delta walking frame			1	
Combined perching wheeled walking frame				1
Wheelchairs -				
wheelchair for outside use	3	2	5	12
Outdoor electric wheelchair			1	
Electric buggy				1
Cars -				
Hand controls				1
Extension on accelerator pedal				1
Swivel seat		2		2
Swivel board		1		1

Table 6 Reading, Writing and Speaking

Item	Stage 1 n=21	Stage 2 n=11	Stage 3 n=14	Stage 4 n=21
Reading -				
Line guide	1			
Large print books	1			1
Talking books			1	1
Large magnifying glass on swivel		1		1
Writing -				
Dycem mat		1		
Speaking -				
Speech amplifier				1

Table 7 Security

Item	Stage 1 n=21	Stage 2 n=11	Stage 3 n=14	Stage 4 n=21
Security -				
Personal/telephone alarm system	1	3	2	4
Intercom to front door		1	2	3
Emergency pull cords		1		1
Entry key pad				1

Table 8 Rails and Stairlifts

Item	Stage 1 n=21	Stage 2 n=11	Stage 3 n=14	Stage 4 n=21
Stair rails -				
Additional handrail for stairs	4	2	2	8
Grab rails:				
Front door	1		1	1
Back door		1		4
Bath/shower	5	4	3	5
Toilet	1	3	2	6
Bedroom			1	1
Kitchen				1
Corridor/lounge			3	1
No specific location	2		1	1
Stairlift		1	3	1

APPENDIX 14 – Chapter 9, INVOLVEMENT area, illustrative case study example of daytime and night-time macro and micro activity levels using ambulatory monitoring

Ambulatory monitoring offers the potential to study activity levels over a full 24 hour period, and to analyse both brief snapshots of activity and longitudinal changes over time with repeated monitoring (4.8.4, p. 115). Figure 1 illustrates levels of individual steps for two 24 hour traces recorded 16 months apart for Participant 1, aged 70, in the early stages of Parkinson's disease. There is less evidence of continuous walking as indicated by black areas (short walks and occasional steps being represented by green and red areas respectively) and a markedly reduced step amplitude indicated by the overall height of the groupings of steps in the lower diagram. A similar overall pattern of daily activity is evident (the display is from 12.00 noon on day 0 to 12.00 noon on day 1) and corroborated in the concurrent activity diary kept by the Participant. A consistent pattern of night-time disturbance is demonstrated, with a first 'breakfast' prepared between 3.00 a.m. and 4.00 am on both monitored occasions. Never a good sleeper, this participant felt that Eldepryl had contributed to his sleep disturbance.

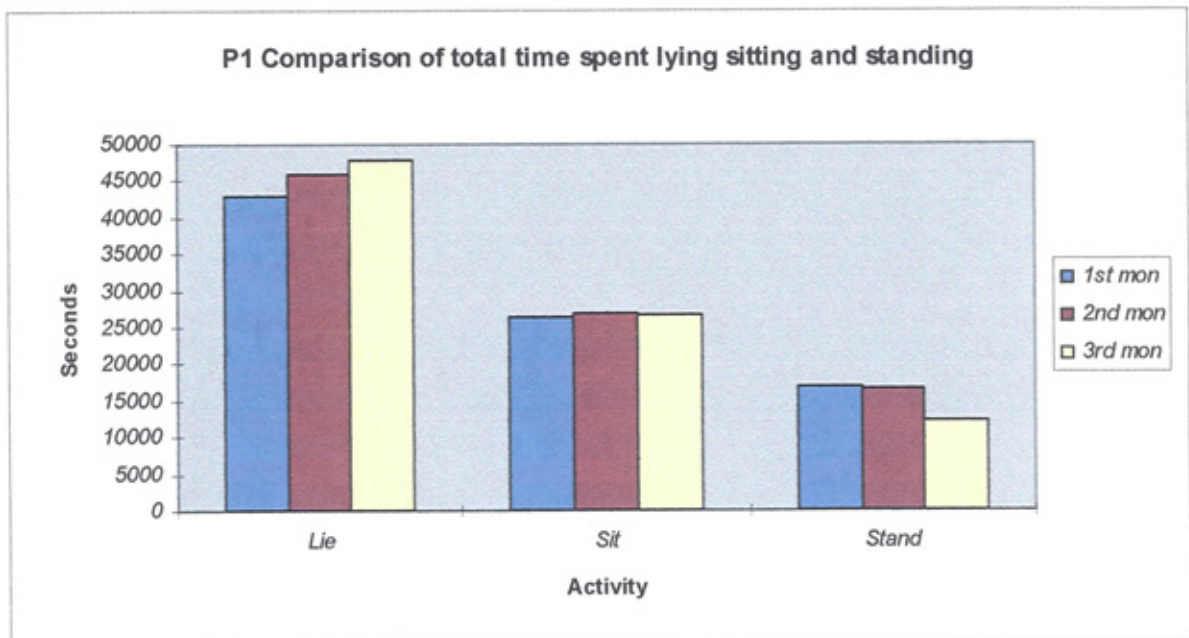
Figure 1 Longitudinal comparison of 24 hour activity

P1 24 hour activity compared 16 months apart



Figure 2 compares time spent lying, sitting and standing for three monitored periods separated by sixteen months and seven months respectively for the same Participant. Levodopa therapy had been initiated prior to the final monitored period. Increasing time was spent lying over the monitored periods, with a decrease in the time spent standing and similar times spent sitting. The Participant had waited to commence therapy and was disappointed that at the level of dose he was taking he was not feeling any benefit. Ambulatory monitoring data collected as part of routine review offers the opportunity, in conjunction with subjective accounts, to monitor the effect of medication changes on activity (Jones et al. 1998b).

Figure 2 Comparing time spent lying, sitting and standing

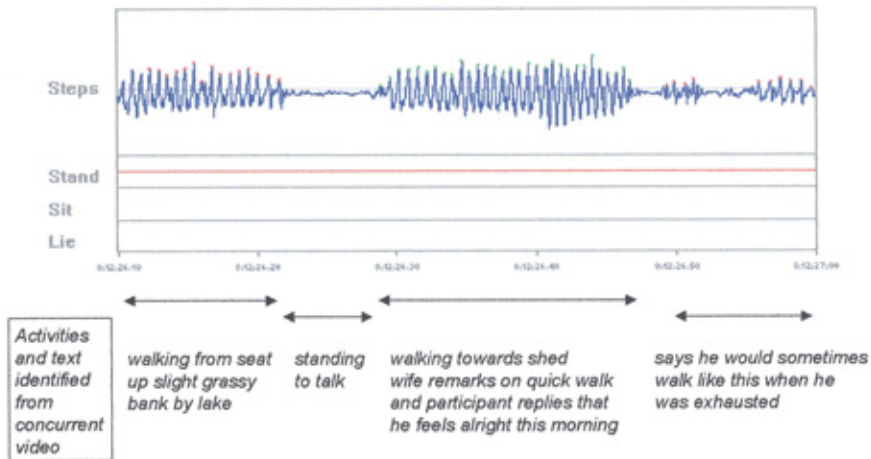


Note: mon – monitoring. Figure shows time in seconds on the y axis and amounts of time spent lying, sitting and standing for three monitored periods along the x axis.

On the final monitored session for Participant 1 ambulatory monitoring coupled with video and accompanying speech provided both objective and subjective evidence of changes in gait as a result of fatigue. Figure 3 illustrates a 50 second trace of Participant 1 walking in his garden. His wife commented on how well he was walking and he replied that he was feeling well but when he was fatigued his walking was not so good. As he illustrates this for the video, his step amplitude peaks drop, indicating reduced vigour of step, and the video shows him adopting a stooped posture.

Figure 3 Objective and subjective descriptions of changes in gait

P1 Occasional steps and continuous walking outside



Ambulatory monitoring in the home environment coupled with narrative accounts offers individuals and health care professionals the opportunity to explore the nature and meaning of activity, how interventions are experienced in everyday life, and provides a platform for shared decision making about management.

**APPENDIX 15 – Chapter 10, INVOLVEMENT area, case study material
illustrative of lived experience of mobility issues in Parkinson's disease**

<p>Participant 6, male, aged 49, diagnosed 3 years</p>
<p><i>Insights into self-management strategies in relation to mobility issues gained from in depth interviews</i></p>
<p><i>Walking outside –</i> “... when I'm walking out like the road up there, I'm alright, I tend to be walking in straight lines ... But when I go into a shop I sometimes, the same thing happens when I go through a door, when I get into a narrow aisle ... I start getting stuck.”</p> <p>“I have a slight tendency to flaming waltz across the road at the minute without looking ... I sort of come to the conclusion cars have got brakes and they can use them when I walk across the road.”</p> <p>“I tend to go [out maybe once or twice a week] ... have a walk around to the Library which is about 100 yards down the road.” <i>Participant's wife comments that someone has got to with him because he can't carry the bag of books (dual activity of walking and carrying).</i></p> <p>Wife: “He once went across to the shop ... and I was standing at the gate watching him, because I like to watch what he's doing, you know and some kids were standing over there ... It didn't bother him, I think it did actually, deep down.”</p> <p>Participant: “I find if you take no notice of them they get bored. Before I went into hospital I used to walk all over the place and I was gradually slowing down without noticing it ... Then, especially walking [gives location] there used to be a group of lads shouting, calling us poof ... Things like that and I used to just ignore them, and walk through the middle of them ... they just got bored.”</p>
<p><i>Stairs –</i> “I'm alright if I can go upstairs in one go. If I actually stop half way up I have difficulty starting to move again ... At one time coming downstairs [was] what might be called a controlled fall ... I just started walking and I couldn't stop [until] I hit the bottom ... Once I got going I couldn't stop ... And it's like when I'm going upstairs. If I, if somebody is coming down, they have got to get out of my road.”</p>
<p><i>Bed mobility –</i> Participant: “I'm generally up about half four, five o'clock and then sometimes I'm up again about half six ... It's not discomfort, it's hard to explain, it's just a dire need to move ... to actually know that I can move, that I know I'm not going to be stuck there ... when it first happened ... I was on the edge of the bed and I rolled out of bed and I'd, like I say, all I ready know is that I was actually walking around the bedroom saying, “Christ, I've been paralysed”. And the second time it happened ... [wife] woke up and I was sweating, panting, couldn't breathe, and I was having like a panic attack because I couldn't move my right hand side. I was in bed.”</p> <p>Wife: “You rolled over onto your back, and he was telling me that he couldn't get up or anything.”</p> <p>Participant: “It freaked us out is about the best way to put it.”</p> <p>Wife: “ It frightens you. His eyes were like big saucers, I got a fright when I saw him ... I was just rubbing his back, trying to calm him down. I brought him downstairs, I made him a cup of tea, and then my son came in.”</p>

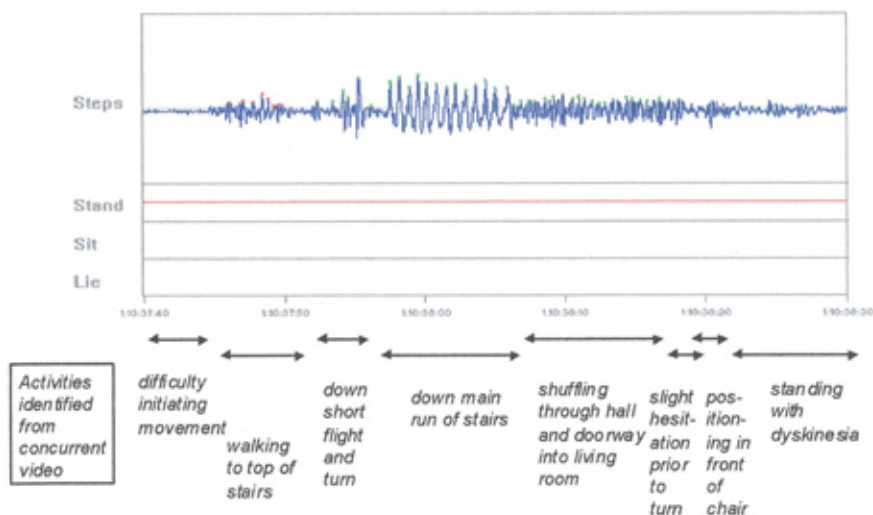
Public transport –

“We went to see my daughter last Sunday. We were coming home about 8 p.m. and I could feel my right hand side getting a bit ... Then I was terrified I was never going to be able to get off the bus ... I was worried in case I couldn’t pull myself off the bus seat ... I have trouble opening my hand ... I was worried in case I might not be able to let go of the bus, once I got hold I couldn’t let go.”

Figure 1 illustrates the difficulty experienced by Participant 6 in initiating movement, his shuffling gait pattern and turn in a narrow hallway after completing a set of stairs, and his hesitancy when turning to prepare to sit in a chair, corroborated with concurrent video.

Figure 1 Negotiating stairs, narrow spaces and turns

P6 Negotiating stairs, narrow spaces and preparing to sit



Narrative accounts and ambulatory monitoring in the home setting can combine to provide powerful insights into the lived experience of mobility issues in Parkinson’s disease both in the home and the wider community.