

**CHAPTER SIX**

**PERSONAL BARRIERS TO OCCUPATIONAL  
ROLE PERFORMANCE**

**AND**

**PERSONAL STRATEGIES EMPLOYED TO  
ENHANCE OCCUPATIONAL ROLE  
PERFORMANCE**

## 6.1 Introduction

The naturalistic methodology employed, as described in Chapter Five, produced data that was analysed at a number of levels. The findings that resulted from this analysis address the overall purpose of the study which was to:

1. Describe the manner in which people with a chronic illness such as Parkinson's disease and their partners continued to actively maintain the roles required to participate as members of their social environment.
2. Investigate if and how such people maintained an acceptable sense of perceived control in their everyday occupational role performance.

The chapter describes personal barriers to occupational role performance identified by participants that related to Pd, and personal strategies that they employed to try and counteract the impact of these barriers and regain their sense of personal control.

Participants identified a wide range of barriers to occupational roles and occupational performance and discussed how this impacted upon their everyday lives. Participants did not, of course, discuss every barrier they were experiencing. However, the form of the interview encouraged them to discuss the issues that they perceived were most important to them at the time.

Analysis produced four major themes that described the nature of the personal barriers encountered by participants with Pd and their partners and the strategies they employed to regain control. They were:

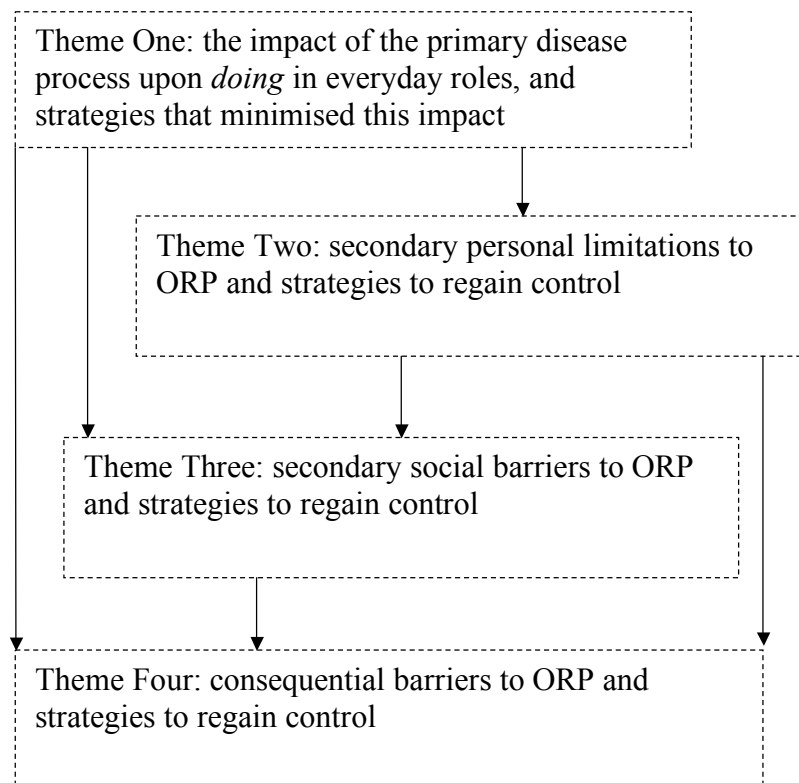
1. The impact of the primary disease process upon *doing* in everyday roles and strategies to minimise this impact.
2. Secondary personal limitations to occupational role performance and strategies to regain control.
3. Secondary social limitations to occupational role performance and strategies to regain control.
4. Occupational role performance limitations in valued roles and strategies to regain control.

There were up to three levels of description within each theme. Each theme had a number of sub-themes, and some of these sub-themes had strands. The first theme described the impact the symptoms of Pd had upon participants' occupational performance, limiting valued occupational role performance. Participants with Pd and their partners described movement problems, difficulties in managing medication, issues of reduced energy, difficulty with cognition and other factors. This first theme provides information about specific losses in function that led to occupational role performance changes. Strategies described how participants worked to overcome their limitations to *doing*. The second theme related to the impact these initial barriers had upon how participants felt. Participants described having to find resources within themselves to deal with the disease as it impacted upon their ORP, and identified psychological difficulties in dealing with the negative impact Pd had upon their sense of who they were in relation to their roles. In this way they described secondary barriers to maintaining an acceptable sense of self. The strategies participants took to try and deal with their reactions to the disease itself and maintain a positive view of themselves are described. The third theme described the impact these psychological changes had upon their social interactions, and how the expectations of others sometimes reinforced their sense of insecurity. Strategies in this theme related to participants' attempts to cope with the attitudes of others and restore the balance of their relationships. The fourth and final theme described the cumulative effect the barriers had upon participants' occupational role performance. The strategies in theme four described how participants worked to recover a sense of control over their most important roles by attempting to minimise role losses. The sequence of these four themes was significant, as each theme impacted upon the next (See Figure 6.1).

Each section provided a description of the perceptions of participants with Pd, and a description of the perceptions of their partners. Partners often discussed barriers and strategies in two ways. First, in relation to how they perceived the effect upon their partner with Pd, and second, perceptions of the impact upon themselves. The same themes emerged for partners as for participants with Pd, but some sub-themes assumed greater importance and others disappeared completely. For example, only four partners identified barriers related to the expectations of others, while ten participants with Pd did so. A number of the less visible secondary symptoms, such as pain, reported as significant by participants with

Pd, were not identified by their partners at all. Detailed tables of the findings for participants with Pd and their partners can be found in Appendix 5.18.

**Figure 6.1. Diagram of themes showing how each theme built upon the preceding one(s)**



Participants identified personal strategies that they used to try and overcome perceived personal barriers. Couples did this singly and as a team. Participants with Pd discussed a wide range of personal strategies used to deal with the problems or barriers they perceived. They actively changed their occupational performance to help them overcome barriers. Their partners assisted them in developing and carrying out some of these strategies, as well as developing strategies of their own. The partners' interest in developing and utilising strategies was to help their partner with Pd, to help themselves in the task of caring, and to deal with the barriers their partners' illness imposed upon their own lives.

Team work between couples was an important strategy that was evident through all levels of all four major themes. In the early phase of Pd, couples described patterns of interaction and cooperation that had probably developed over the course of their marriage. In middle phase, couples talked of working together to overcome the barriers that Pd presented.

By late phase this team work was falling apart. It seemed much more difficult for the person with Pd to make the type of contribution that allowed the two of them to work together in the same way as before.

Personal barriers and personal strategies are described as they were placed into each theme during analysis. Barriers affecting participants with Pd are discussed first, with information from both participants with Pd and their partners being presented. Following that, the personal barriers experienced by partners that related to their own lives are presented. Then personal strategies to overcome these personal barriers are described in a similar fashion. Because of the complexity and inter-twining of the data, some barriers and some strategies should perhaps appear in several places. For the sake of simplicity they have been placed in the section that appears most pertinent.

In the descriptions, an indication is given of the number of participants who mentioned a particular topic. This number is not intended to be exhaustive, or for use in weighting the data, but to give some indication of how widespread each factor was across all the participants of the study. A summary is provided for each of the major themes, as well as a chapter summary. Quotes are used throughout the findings chapter to provide validation, to illustrate a point, or to provide a memory hook for the reader. Contrary to APA style (American Psychological Association, 2001) lengthy quotes are presented indented, in italics, and single spaced for ease of reading. Participants were, of course, allocated pseudonyms from the outset of data analysis, and no real names have been used. The themes are represented in more detail in Appendix 5.18, where, for each sub-theme, there is a list of the personal barriers described by participants and the personal strategies that were identified.

## **6.2 Theme One: The Impact of the Primary Disease Process Upon ‘Doing’ in Everyday Roles, and Strategies to Minimise the Impact**

This theme addressed the functional changes imposed by the symptoms of Pd and how they impacted upon the routines and tasks that made up occupational role performance. Participants as a group defined problems in everyday ‘doing’ as they affected valued occupational role performance. Four major areas of function were mentioned by the majority

of participants with Pd. They were movement, medication management, reduced energy and cognition. Five other areas were identified by a minority of participants. The personal barriers identified by participants were all perceived to interfere in some way with the performance of routines and tasks that were part of the roles they identified. Participants with Pd mainly discussed strategies to deal with movement, reduced energy and ‘other’ personal barriers as they impacted upon their everyday occupational role performance. In addition, some more general strategies that supported ‘doing’ were identified from analysis of the data.

Partners did not identify specific strategies for dealing with reduced energy, although more global strategies discussed in theme four were inclusive of reduced energy issues. Partners showed an increasing trend to assist their partner as the Pd became more severe. The two partners of participants in phase one did not discuss any strategies to help their partner with daily *doing*. Those whose partners were in the middle phase did discuss helping their partner, while by late phase partners were overwhelmed by the amount of assistance their partner needed on a daily basis. Arthur (late phase husband of Jenny) described a typical start to his day:

*“I wake at five and I get up at a quarter to six, and I make the morning tea and the breakfast and bring it to bed, and she takes the first day's tablets about half past six, and she doesn't become mobile until about half past eight ... At the present moment I'm picking my grand-daughter up at a quarter past seven ... and taking her to day care, and so I get home from that at eight o'clock and [Jenny] is still in bed. And then I do the washing up and make the bed and do the washing and do various chores that are involved in running the house ...”*

Two sub-themes emerged within Theme One:

- The impact of specific symptoms upon role related routines and tasks
- General strategies that supported ‘doing’ in relation to everyday roles

### **6.2.1 The Impact of Specific Symptoms upon Role Related Routines and Tasks**

Participants discussed a range of barriers that could be related to the symptoms of Pd they were experiencing. There were five strands to this sub-theme:

- Movement: personal barriers and strategies to regain control
- Medication Management: personal barriers and strategies to regain control
- Reduced Energy: personal barriers and strategies to regain control
- Cognition: personal barriers and strategies to regain control
- Other factors that limited occupational role performance: personal barriers and strategies to regain control

***Movement: Personal barriers and Strategies to Regain Control***

Personal barriers to role related routines and tasks incorporating movement as perceived by participants with Parkinson's disease.

The movement problems described by participants were typical of the patterns described in Chapter Three. Twelve out of the fourteen participants with Pd mentioned movement control difficulties that limited mobility and fine motor task performance. Balance, poor voice control, slowness of movement, tremor, rigidity, and limitation of the dominant limb were the difficulties most commonly identified by participants with Pd. Eight participants reported difficulty doing things that required good motor control in the upper limbs. Favourite pastimes became more difficult. Writing became a problem for five participants. Adele (Phase two) was a prodigious letter writer and found she could no longer keep in touch with friends. Five participants from all phases reported difficulties in communication due to a soft, receding voice. Jenny (late phase) said, "*I speak very softly, ... but it doesn't seem soft to me, you see*". This made conversation difficult and the telephone hard to use. Jenny found it limited her valued role as a member of her church.

Strategies reported by participants with Parkinson's disease to regain control of occupational role performance related to movement.

All the participants with Pd identified *medication* as a very important factor in assisting them to manage their symptoms. Michelle (middle phase) described how she had no symptoms at all for the first five years following her diagnosis. She just took the medication and got on with her life. She still took her medication religiously and could feel a great benefit each time she did. Helen (late phase) said, "*Your body soon tells you that it's time for a tablet*".

Seven participants with Pd said *exercise* was helpful, both as a preventative measure and to minimise symptoms of tenseness and tremor. Peter (early phase) played tennis regularly. Others walked, went to gentle stretching and exercise groups, or practiced yoga. Frank (middle phase) found going for a walk very helpful if his tremor was becoming troublesome. Some *anchored* their tremor with another body part or furniture. Some talked of practicing *conscious control*. Bruce (middle phase) said:

*“I’ve been caught ... I forgot to take the medications with me and I really tightened up ... I had to ... just concentrate on walking technique. ... you realise how complicated a task like walking is when your basal ganglia aren’t there to ... organise the details for you.”*

Two participants identified *therapy* as a useful strategy for overcoming motor control problems. Five participants were aware that other people found them difficult to understand. Three were consulting a speech *therapist*. Jenny (late phase) was consulting a speech therapist for her communication problems. She did not appear to avoid social situations, as long as her husband was there, and it seemed he often provided the link. Three participants said they *avoided* telephone contact because they found it too difficult, although others relied heavily on the telephone to keep in touch with friends and family. These strategies were all developed in response to losses in function that were perceived to limit occupational role performance in valued roles.

Personal barriers to role related tasks incorporating movement as perceived by participants who were partners, both for their partners and for themselves.

Seven of the eleven partners of participants with Pd discussed their partners’ movement problems. The most commonly identified problem was dressing, followed by general safety, affecting the role of self maintainer. All four partners of people in the late phase of the disease identified movement problems as a major barrier. Half the partners of those in middle phase discussed it. Neither partner of the early phase participants was concerned. Phillip (late phase partner of Helen) said that she was often unable to transfer on her own and needed a lot of help from him. Her bed mobility was poor and she had a tendency to get tangled in the bed clothes. This meant that Phillip needed to be with her at all times, limiting his opportunities to participate in his other roles. Arthur (late phase partner of

Jenny) felt that home modifications made to help her had increased her independence to a dangerous degree, paradoxically making her at greater risk of a fall.

Some partners had mobility problems of their own. Two, Vince (middle phase partner of Gwen) and Una (middle phase partner of Frank) had low back pain which limited their endurance and flexibility. A number of partners perceived that occupational role performance in a range of roles had been adversely impacted by mobility problems for each of them individually and for the two of them as a couple.

Strategies reported by participants who were partners to help them both to regain control of occupational role performance related to movement.

In relation to role-related everyday routines and tasks that had to be done, partners spoke in more detail than participants with Pd about specific strategies to assist with specific tasks. A major strategy for partners was to pick up whatever needed to be done to enable them both to survive at home together. All of the partners discussed strategies they felt helped to lessen their partner's occupational performance problems as they related to movement control. Their descriptions showed how they worked together as a functional team to address movement difficulties that represented barriers to occupational performance for both of them.

Personal care routines were difficult for some participants who were in the middle phase, and all participants in the late phase. *Physical assistance* was regularly provided by partners. Dressing was a common issue. Six participants with Pd and five partners reported that the partner provided assistance with dressing. Two used equipment such as velcro fastenings. Three partners provided toileting assistance (transfers and managing clothing).

Using *teamwork*, couples developed routines that worked for them. For example, with bathing, Rex (late phase partner of Enid) ensured the water temperature was safe. Enid showered herself, with the help of equipment, and then he helped her to dry herself. Frank (middle phase) had swallowing problems, and his wife provided soft food such as stews or cut his food up small. Participants in late phase Pd used built-up cutlery and non-slip mats. Their partners provided considerable assistance with preparations for eating, such as spreading bread and cutting up food.

Partners provided *guidance* of routines. They made sure that their partners took their medication on time, reminding them if they felt it was necessary. Some said they actively pushed their partner to get exercise. For example, Rex made sure he and Enid (late phase) went for a walk together for at least 20 minutes every day.

A number identified purposeful strategies to enable their partner to *continue* with specific routines and hence maintain participation. For example, Arthur and Jenny (late phase) prepared meals together, and he followed her orders. Other partners used the strategy of *taking over* some tasks previously performed by their partner with Pd. Ken always hung out the wet washing for Michelle (middle phase). Steve lifted hot, heavy casseroles out the oven for Adele (middle phase).

Almost all partners identified strategies that were about making life easier for themselves rather than for their partner with Pd. For example, Olive (late phase widow) worked out solutions to her husband's showering problems, organised showering equipment and showed her husband how to shower using the equipment so that she would not have to physically help him, and avoided the arguments they tended to have over this task. In this way she tried to maintain their marital relationship.

### ***Medication Management: Personal Barriers and Strategies to Regain Control***

#### Personal barriers to managing medication perceived by participants with Parkinson's disease.

The previous section indicated how important medication was to assist in controlling movement, but participants identified it is as a major strategy for dealing with other symptoms of Pd as well. A reduction in symptoms had a major effect upon participants' abilities to perform effectively in role related routines and tasks. However, nine participants with Pd discussed the problems they experienced as a result of having to take medication. The issues most commonly mentioned were: medication that needed finer adjustment than was possible through the medical management available, side effects that were difficult to manage, and a perceived decline in the effectiveness of medication.

Side effects from medication were problematic. Caroline (early phase) had only recently been diagnosed with Pd. She described some of the issues related to developing optimal medication management:

*“I get a lot of leg movements with the Sinemet ... the pay-off is that I can move very well while I am [on it]. So we've just reduced the dosage a bit and I've found that my left arm is dragging more and my hand turns in ... but I'm enjoying the fact that my legs are much stiller than they were. ... I had been on an anti-depressant for some years which had worked very well for me, but it was not compatible with Sinemet. So I had to come off that and that was tricky.”*

Strategies reported to overcome barriers to effective medication management by participants with Parkinson's disease.

Only one participant said she worked with her doctor on achieving optimal medication effects. Most participants saw their doctors regularly, but had developed an independent attitude to managing their medication. Bruce (middle phase) had this reinforced by a disastrous hospital admission. He was admitted for elective surgery on his nose. His Pd drugs were taken away from him and only dispensed at the ward drug round. His symptoms went haywire. He said: *“So I've learnt two lessons about hospital. Take your own private drug supply and medicate yourself”*. Other participants experimented and adjusted what they took according to what they perceived they needed. Medication was independently adjusted in terms of the *frequency* with which it was taken, the *amount* taken and the *timing* in relation to daily routines. Michelle (middle phase) said:

*“Some days I don't feel real good of a morning, but [this time] I took an extra tablet through the night. I said to [Ken], ‘It's the best day I've had for months’. I felt good all day. So I've been taking that extra tablet and it seems to work”*.

Some participants reported having stopped medication altogether without consulting their doctor. Lynne (early phase) was taking an anti-coagulant. She experienced months of nausea. She said, *“One day when I was violently ill, I thought Cartia was [involved]. It's this little orange thing and it was all so orangey ... I immediately suspected Cartia and ... I stopped taking it”*.

Peter (early phase) and Bruce (middle phase) had symptoms that were limiting desired levels of performance in roles they valued highly. They perceived problems with medication that led them to develop important roles as health managers. They kept themselves extremely well *informed* about medication, via their support group, the media, and conferences on Pd that they attended. They used this knowledge to discuss their medication with their prescribing doctors and request changes, and they made changes without consulting their doctors. Peter was very concerned that if he took too much medication now, its period of usefulness would be shortened. He had searched for a cure to his Pd in alternative medicine. He ceased medication altogether for some time on the advice of a naturopath, enduring disabling symptomatology. At the time of the interviews, he was back on medication, but he kept himself on a tight regime, choosing to accept a bit of rigidity and tremor rather than ‘squander’ the medication’s ability to be effective. Participants in late phase did find their medication’s effectiveness was waning. Their strategy was to *take as much as possible*. Nancy (late phase) said: “... *see I take eight a day, so ... I get through the 100 in quick smart time. And my doctor said to me – ‘You can’t get an increase’ ...*”

#### Barriers to effective medication management perceived by participants who were partners, for their partners.

Four partners discussed their partners’ medication but none of them were early phase partners. Two partners felt that the effectiveness of the drugs was unsatisfactory. Two were concerned that their partners might forget to take their medication. Steve (middle phase partner of Adele) described it in this way: “[*At*] *about half past eleven: ‘Have you taken your eleven o’clock yet?’ ‘Oh no, I forgot’. I can tell by the look of her that she hasn’t had it*”. Phillip (late phase partner of Helen) felt alarmed that his wife was taking alternative medicines and worried that these would interfere with her Pd and anti-depressant medications.

#### Strategies to promote more effective medication management reported by participants who were partners.

Four partners described *watching* – both time and their partner. They could tell when a pill was needed. Rex (late phase partner of Enid) felt routine was important to successful medication management. He had conditioned himself to wake at midnight and at four a.m. to

give Enid her medication. He juggled it in frequency, amount and timing, to try to give her the best outcome. Phillip (late phase partner of Helen) found out as much as he could about Helen's medication so that he could understand and discuss issues with her doctor.

### ***Reduced Energy: Personal Barriers and Strategies to Regain Control***

#### Personal barriers to role related routines and tasks that are due to low or fluctuating energy levels as perceived by participants with Parkinson's disease.

Seven participants with Pd reported low energy levels. Seven associated this with *feeling bad*, described vividly by some as: "*Feeling bugged*" or "*old, feeble and shaky*". Five felt this limited their ability to engage in their most important roles in a major way. They reported these feelings were exacerbated by other problems which may or may not be related to their Pd, such as insomnia.

Participants in each of the three phases described a loss of energy. The debilitating feeling was identified as very important. Dorothy (early phase) said "... *it's just your body is heavier and it can't cope the same ... like a tiredness. You want to do it, ... and then you just can't manage as much as you thought you could*".

#### Strategies to address low or fluctuating energy levels reported by participants with Parkinson's disease.

The strategy most commonly identified (nine participants) to deal with sudden drops in energy levels was taking *medication* and managing medication for optimum effect. *Avoidance* was a major strategy for dealing with problematic roles and routines. Peter (early phase) was forced to give up his greenhouse business because he just couldn't find the energy to keep it going. Sharing routines with partners was helpful. Some routines, such as cleaning the bath or doing the vacuuming, were being done entirely by someone else. Dorothy (early phase) said: "*I'm not fulfilling everything like I was, because [husband] does quite a bit for me now. He helps with the washing and sometimes he does his own ironing ... and vacuuming, which is heavy ... and quite difficult*". Adele (middle phase) and Steve and the Gwen (middle phase) and Vince hired cleaners to do the heavy housework, leaving them free to participate in more highly valued routines and tasks. Eight participants reported that

driving had become an issue. All but one had dealt with this by reducing or eliminating the task, relying on someone else to drive.

*Planning ahead, priority setting and eliminating* tasks was reported by seven participants. They thought carefully about their daily commitments and distilled them down by a process of prioritisation to those they considered essential. Nancy (late phase) went to the Parkinson's support group because she thought it was worthwhile, even though she had to give herself the next day off because she knew she would be completely exhausted. She used the community bus and said: "*He [the bus driver] does go on other trips but I don't go ... I've been, and I've got home so tired I can hardly move and I don't think it's worth it*".

Seven participants reported *modifying the environment* in which a task was performed. Michelle had reduced the number of plants growing in their garden, and replaced those needing a lot of care with hardier specimens so that gardening became an easier part of her role as a home maintainer. Others used equipment to help them.

Six participants *timed* specific routines and tasks for the optimum time of day, when they knew their energy levels were generally at their best. Wendy (early phase) generally cooked the evening meal because that was her best time of day. Her husband prepared the other meals. All participants spoke of having 'good' times and 'bad' times. Most had developed a routine that took this into account so that they did more when they were able, and rested when they were not. Dorothy (early phase) said: "*... of an afternoon you can feel more like doing things, and ... particularly in the warmer weather ... you get outside in the afternoons*". Others simply put tasks aside until they felt up to doing them.

Two participants discussed *modifying* tasks and routines, breaking them down so that they did not have to do the whole thing at once. When playing lawn bowls Dorothy said, "*... of a morning I don't converse a lot when I first get there because I'm ... a bit tired*". Seven participants spoke of having *naps* during the day and of *going to bed early*. Gwen (early phase) had two naps during the day. On the other hand, Bruce (middle phase) kept irregular hours, often working on his poetry at night.

Participants made a conscious effort to *slow down* the pace of their life. Lynne (early phase) kept her social arrangements fluid so that if she felt unable to do something she could opt out without letting people down. Helen (late phase) said: “*I sort of find I’m thinking of myself a bit. I think ‘Oh, will I be able to cope?’ And if it’s a late night I get concerned, you know, because I need my sleep*”. Four participants had withdrawn from specific roles altogether because they felt they were doing too much.

Barriers to role related routines and tasks caused by low or fluctuating energy levels as perceived by participants who were partners, both for their partners and for themselves.

None of the partners discussed reduced energy as such. However, they said things like “*she can’t walk far*” or “*sometimes she’s not up to it*” or “*not having a good day*”. The three male partners of participants in the late phase of Pd all described caring for their partners as a twenty-four hour job and that consequently they were tired most of the time. Olive (late phase widow) did not recall it like that, but spoke instead of the exhausting arguments and stress she experienced with her husband.

Strategies reported by participants who were partners to address barriers relating to low or fluctuating energy levels.

Most partners of people in middle and late phases of Pd described being flexible, sharing routines and “*being ready to do whatever needs doing*” at a moment’s notice.

***Cognitive Difficulties: Personal Barriers and Strategies to Regain control***

Personal barriers to role related routine and task performance perceived by participants with Parkinson’s disease to be due to cognitive difficulties.

Eight participants with Pd reported difficulties with cognitive function. Being aware and concerned about the deficiency, loss of focus or concentration, difficulty moving between thoughts, and memory lapses, were the most commonly identified issues. Communication was hampered by cognitive difficulties. Some participants reported difficulty following a conversation, limiting their ability to participate as they would wish in a number of socially orientated roles such as friend and family member.

Bruce (middle phase) talked about his bad memory, and the difficulty he had from time to time in focusing his thoughts. This was obvious to him because in his valued role as a poet it interfered with the intellectual process of writing poetry. This difficulty with memory, focus and concentration was evident in other tasks such as cooking and dressmaking. Cooking had always been second nature to Wendy (early phase). She said: “...and when I make a cake it takes me longer because I've got to keep going back and think what I have put in”.

Strategies reported by participants with Parkinson's disease to regain control of occupational role performance affected by cognitive difficulties.

Participants practiced a wide range of strategies to try to maintain their cognitive ability. Michelle (middle phase) spent a few hours each day doing crosswords and jigsaw puzzles. She felt they helped her to keep thinking, as well as being a way of passing the time. Frank (middle phase) consciously tried to apply his past experience to problems. He *persisted* with problems rather than giving up. He said: “I'll keep it in my mind and I'll fix it eventually”. Lynne (early phase) tried to *keep calm, slow down* and *concentrate* if she was having difficulty, while Bruce (middle phase) found that if he *allocated extra time* to cognitively challenging tasks he could work them out. Three participants reported using *aides memoire* to help them. Bruce had a number of lists pinned to the wall of his unit. He said: “I've got to *compensate for the memory not being so good by becoming better organised*”.

Five participants with Pd reported trying to organise their lives so they could *avoid* situations where they might be put on the spot in ways they felt they couldn't handle. Both Bruce and Peter avoided stressful situations because they found it much harder to think straight. Enid (late phase) used *humour* to soften her embarrassment and frustration when she lost the thread of what she was saying. “I was a busy little girl, and I tell you what ... [pause] Oh! Goodbye again!” A final strategy that was identified was that of *acceptance*. Participants said they were learning to live with their reduced cognitive function.

Barriers to role related routines and tasks arising from cognitive difficulties as perceived by participants who were partners, for their partners.

None of the partners of people in the early phases made any comment about their partner's cognitive status. Four late phase partners felt their partner with Pd had cognitive problems. Arthur said about Jenny: "*She's lost cognitive skills, but she's very on the ball*". Phillip and Rex both felt their wives (Helen and Enid) could not be trusted with safe task performance because of their cognitive deficiencies. Phillip reported Helen had bouts of confusion. Rex had a long list of incidents where Enid had done something bizarre. He believed she could not be trusted to do anything on her own – particularly in the kitchen. His belief meant that he gave up nearly all his time to watching and helping her.

Strategies reported by participants who were partners to counteract the cognitive difficulties they perceived.

Partners of participants who were in late phase were all deeply concerned about cognitive issues. They described a number of strategies they employed to ensure they and their partner were safe. They described *watching* their partner all the time. Rex tried to keep Enid *stimulated*, asking her questions and engaging her in conversation to try to help her to retain as much cognitive function as possible. Phillip encouraged Helen to *substitute* the microwave for the stove when cooking, saying "*we've had a one or two fires*".

***Other Factors that Limited Occupational Role Performance: Personal Barriers and Strategies to Regain Control***

Personal barriers to role-related routines and tasks arising from a number of factors related to Pd, as perceived by participants with Parkinson's disease.

Thirteen participants with Pd identified other problems that interfered with their ability to *do*. These were other symptoms that arose as a consequence of Pd including, pain, sleep disturbance and nausea; and interactions between their Pd and other health problems that occurred at the same time. These symptoms all combined to limit the effective performance of role related routines and tasks.

Five participants reported *pain* that arose from reduced movement on the side of their body affected by Pd. Lynne (early phase) and Michelle (middle phase) both got cramps in their legs and feet. Four participants said that their pain was severe enough to disturb their sleep. *Sleep disturbance* was reported by six participants. Apart from pain, some had insomnia, while others said they were woken by their tremor if their medication wore off.

There were other negative changes participants associated with Pd. *Lability* was a problem for three participants, who found it very embarrassing when performing in valued social roles. Two reported problems with *nausea*, and Michelle (middle phase) found this limited her ability to travel. Two participants were still experiencing the after-effects of past *falls*. Adele (middle phase) had a bad fall four years ago and had permanent damage to her vision as a result. Jenny (late phase) had undergone a series of operations for an injury to her neck resulting from a fall.

Participants reported a range of health problems that were unrelated to their Pd but that nevertheless interacted with it and limited what they were able to do. Three participants reported cardiovascular disease. Other conditions discussed were Dupytren's contracture, osteo-arthritis, pre-existing depression, low back pain, and asthma. Medications taken for these conditions sometimes adversely interacted with Parkinsonian medication. It was hard for participants to distinguish Parkinsonian symptoms from normal ageing processes and from other medical conditions. Lynne said: "*I also have a pacemaker and ... I get puffed very easily. And you don't know if what's happening is because you've got that or because of your Dupytren's on your feet or whether it's the Parkinson's*".

#### Strategies reported by participants with Parkinson's disease to counteract a range of Pd related symptoms and regain control.

Five participants said they had learned to live with *pain*. Three said they worked through their pain. Lynne (early phase) said: "*I ache. Everything seems to ache and they say if it aches stop [what you are doing]. Well I mean, some days I wouldn't start! But afterwards I feel better*". Two participants said they took medication to control their pain, and two used exercise and stretching. Four participants dealt with *sleep disturbance* by going to bed early. Two said they took a nap to compensate for lost sleep.

A number of participants identified the problem of unexpectedly *'feeling bad'* while out in the community. They took steps to ensure they had an escape route if they needed it. This was usually in the form of a partner who was ready to rescue them if necessary. Some participants practiced avoidance to deal with situations they felt unable to deal with because of various symptoms of Pd. Michelle (middle phase) and Enid (late phase) refused to go far on car journeys (to their husbands' disappointment) because they experienced *nausea*. This limited their opportunities to participate in leisure roles. Both couples had enjoyed travelling by bus or car, and this was no longer possible.

Six participants described how they worked to *simplify* their whole living environment. Bruce (middle phase), who had low back pain as well as Pd lived alone in a unit and had everything arranged to suit his personal needs exclusively. For instance, he had one straight backed chair for visitors and no dining table, because his back pain was such that he never sat down, preferring to lie, kneel or stand.

Participants *modified* their *behaviour* to deal with the wide range of symptoms they identified from other health conditions, which, of course, interacted with their Parkinsonian symptoms. Frank took walks to control his rigidity and tremor, and to try and control his blood pressure.

Personal barriers to role related routines and tasks arising from a range of secondary Pd symptoms and other health conditions as perceived by participants who were partners.

Some partners experienced pain from their own health conditions. Partners of participants in the late phase were disturbed by their partner with Pd. Their partner might need to take medication during the night, or have poor bladder control. Phillip (late phase partner of Helen) said, "*She has this restless sleep problem ... by eleven o'clock she'll be out of bed walking around the house*". Some partners experienced discomfort as a result of changes to their *doing* that could be ascribed to their partner's Pd. Arthur described how mealtimes gave him indigestion. He helped his wife extensively to prepare the meal, trying to protect her from injury. Then she needed his help to eat. He said, "*I find that difficult. By the time I get the meal, I don't ever have a really relaxed meal. I miss that, and I get a little bit of stuff in the stomach as a result ...*"

Strategies reported by participants who were partners to counteract the impact of a range of symptoms secondary to Parkinson's disease.

Partners took steps to ensure their general health as a couple was good. Una (middle phase partner of Frank) took care to ensure that she and Frank both ate well. Three partners spoke of taking exercise, and practicing good lifting techniques in order to maintain their own bodies so that they could continue to care for their partner.

## **6.2.2 General Strategies that Supported 'Doing' in Everyday Roles**

Participants demonstrated they had knowledge of their own levels of performance in personally meaningful roles and routines. They appeared to use this knowledge, combined with personal beliefs about behaviour that was effective to help them experience a positive sense of control in relation to their everyday occupational performance. Two strands emerged from this sub-theme:

- Personal beliefs that maintain perceptions of control of everyday role performance
- Personal occupational performance knowledge

### ***Personal Beliefs that Maintain Perceptions of Control of Everyday Role Performance***

Many participants spoke of what they did, particularly in relation to dealing with Pd, as being directed towards achieving greater control. They identified specific *behaviours* that they clearly *believed* would help them to maintain or regain control. These were stated strongly, often in non-negotiable terms. Phillip, talking about Helen and himself, said, "... *we've got to be together ...*" Some used the perceived alternative in order to reinforce the belief. Peter (early phase) said, "*I've got to look after myself or nobody's going to look after me. I've got to look after myself or be in a nursing home*".

Many participants spoke of the need to keep trying in order to maintain or regain control. Nancy (late phase) said, "*I push myself ...*" Bruce (middle phase) said, "... *one of the basic things - you've got to be flexible. ... You've got to be adapting and changing*". The importance of *planning* was identified. Olive said, "*I just feel like you've got to be sensible and work these things out, you know. You can't just sit there and let things happen. You've*

got to try and do something about it”. Some beliefs were about what *not* to do. Bruce said, “*I wouldn’t trust anyone with my brain. ... I see the neurologist for ten minutes every four months. ... I see my own brain for 24 hours every day*”.

Where participants felt unable to change things, they voiced beliefs about how to cope with what they might not like. Bruce said, “*I think you can reach a state of happiness regardless of circumstances, to some extent*”. Stoicism and acceptance were important. Wendy (early phase) said, “*I mean you’re living with it [Pd] from day to day. You have to ... say, ‘Well I’ve got to accept this thing and do the best I can’*”. Most participants used stoicism as a means of dealing with losses of control that they felt unable to reverse. Many stoic strategies contrasted action with inaction, identifying the need to get on with *doing* things in the presence of lost or reduced choice, rather than waiting for things to sort themselves out. Dorothy (early phase) said, “*... you’ve got to be positive ... My mother ... always said ‘Well, you just can’t sit in a heap’. You’ve got to get up and do things, haven’t you?*” Where action was not perceived as useful, participants were stoic about accepting what they could not change. Michelle (middle phase) said, “*You just keep going*” and Frank (middle phase) said, “*You just have to wear it*”. Being *positive* was a common theme. Not complaining was important. Enid (late phase) said, “*I mustn’t whinge and grizzle*”. A different kind of stoicism related to being *satisfied* with doing your best. Adele (middle phase) said, “*If you do your best, then you should be satisfied*”. Some participants spoke of avoiding what they could not control. Unfortunately, that often meant giving up something that was important.

### ***Personal Occupational Performance Knowledge***

All participants showed they had acquired and were still acquiring a body of *knowledge*, about themselves, about Pd, and about how to deal with its impacts. Participants with Pd and participants who were partners both demonstrated their knowledge and experience in discussing how they dealt with strategies.

Participants often referred to what they could or could not *do*. Peter (early phase) said, “*I can run hard*”. Gwen (early phase) said, “*I can’t do very much. I have to rest in the morning and rest in the afternoon, so I really can’t do a great deal*”. Participants’ knowledge of their own occupational performance and that of their partners had undergone

and was undergoing *change* in the presence of Pd. Bruce said, “... *after I got Parkinson’s, little things that wouldn’t have normally upset you, would upset you and, ... I’d react badly*”.

Participants had knowledge of the *resources* they could use to assist them with occupational performance difficulties. They knew what was available to them and how useful particular resources were. Phillip (late phase partner of Helen) discussed assistance from health professionals. He said, “*It leaves a lot to be desired. ... that’s a bit of a disappointment ... I sort of just pass it off and take my own steps*”. Partners expressed knowledge of how they needed to care for their partner with Pd. Olive (late phase widow) said, “*I knew he wanted to do things himself*”.

Participants appeared to have developed beliefs about what constituted effective *doing* from their past experiences, and used their knowledge of past responses, judgements and decisions. Michelle said, “*I don’t like shiny floors. They look slippery*”. They showed they were forming new beliefs that related to knowledge about current occupational performance as the Pd continued to develop. Lynne said, “*I know I have to do things slower. I used to tend to rush into things ... I have to concentrate a bit more on what I do*”.

### **Summary of Theme One**

In summary, participants defined barriers affecting their ability to ‘do’ in role related routines and tasks that went beyond the basic movement control symptoms that are well known to be associated with Pd. They identified low energy, ‘feeling bad’, cognitive problems, and a range of other difficulties, such as pain, and sleep disturbance that were consequent upon their Pd. Some identified problems that were due to other diagnoses, and most made the point that it was hard to tell whether a particular problem with ‘doing’ was due to their Pd, their other diagnoses, or to normal ageing. It is important to note that medication, whilst assisting greatly with symptoms, could present its own barriers to *doing*.

Participants who were partners discussed the barriers to *doing* they perceived their partners faced. They described consequent barriers to their own occupational role performance arising from the need to provide assistance. Partners were very aware of the movement, medication and, where present, cognitive barriers experienced by their partners

with Pd. They seemed less aware of the impact that less clear-cut symptoms such as nausea, 'feeling bad' and sleep disturbance had upon their partners. There appeared to be a clear trend of decline through the three phases for mobility, and communication. The trend was not so clear for reduced energy, and sleep disturbance, although late phase partners identified sleep disturbance as a major problem for themselves. Cognitive problems were identified by early and middle phase participants with Pd, but only late phase partners discussed cognitive issues. Obtaining good results from Pd medication was problematic initially, whilst the correct regime was worked out. In middle phase medication seemed to be satisfactory, but by late phase its efficacy was wearing off.

Participants and their partners discussed strategies related to their symptoms and to the impact of these symptoms upon their everyday, role related *doing*. It is suggested that the purpose of these strategies was to restore a sense of personal control. Medication to control symptoms was very important. Avoidance of particular routines, timing occupational performance to fit fluctuating function, and relying on partners were all commonly employed.

The two partners of participants in the early phase of Pd did not discuss any strategies to assist with 'doing'. Partners of those in the middle and late phases were assisting their partners with their movement problems, but it seemed they did not always understand some of the more intangible secondary symptoms their partners were experiencing. None of the partners discussed strategies for their partners' reduced energy, for example, yet all the participants with Pd discussed reduced energy as a major problem.

Participants spoke in ways that indicated they had firm beliefs (formed in part from the knowledge they had acquired from their past life experiences) about what behaviours would help them to maintain or regain a perception of control. These beliefs were often strongly stated and used to guide behaviour. See Table 6.1 for a summary of Theme One.

**Table 6.1 Theme One. Personal barriers and strategies sub-themes and strands affecting both types of participants**

<b>Theme One: The Impact of the Primary Disease Process Upon ‘Doing’ in Everyday Roles, and Strategies to Minimise the Impact</b>
<p><u>The impact of specific symptoms</u></p> <ul style="list-style-type: none"> <li>• Movement: Personal barriers and strategies to regain control</li> <li>• Medication management: Personal barriers and strategies to regain control</li> <li>• Reduced energy: Personal barriers and strategies to regain control</li> <li>• Cognitive difficulties: Personal barriers and strategies to regain control</li> <li>• Other factors: Personal barriers and strategies to regain control</li> </ul>
<p><u>General strategies that supported ‘doing’</u></p> <ul style="list-style-type: none"> <li>• Personal beliefs that maintain perceptions of control of everyday role performance</li> <li>• Personal occupational performance knowledge</li> </ul>

### **6.3 Theme Two: Secondary Personal Limitations to Occupational Role Performance and Strategies to Regain Control**

This second theme deals with how the problems and deficiencies outlined in theme one affected participants’ sense of themselves. Loss of ability meant that participants with Pd had to adjust to a new image of themselves that was different to how they used to be. These changes evoked a negative response within them towards their sense of themselves. Because of the changes they experienced, their partners found they had to change too, if their partnership was to continue.

Participants with Pd spoke of how they used strategies in two ways. Some strategies were intended to maintain or restore a more positive sense of themselves. Other strategies were used to minimise the impact their symptoms had upon their active engagement with the environment so as to retain or create opportunities for positive self expression. The two sets of strategies were closely intertwined. Data analysis indicated that these tactics utilised *knowledge* acquired from experience and were based around a set of guidelines or *beliefs* that participants stated at various points in their interviews.

Three sub-themes emerged within theme two:

- Sense of self as an occupational being
- The impact of Parkinson's disease upon sense of self
- Occupational role performance and sense of self

### **6.3.1 Sense of Self as an Occupational Being**

A *sense of self* was expressed by participants throughout the interviews. These expressions were not necessarily conscious statements of self identity. Analysis showed that participants tended to provide information about their sense of self in three ways.

Participants defined themselves by the *roles* they held and by making declarations about who they were and who they were not. They described themselves in terms of what they *did*, and *did not do*, and they explained *how* they had developed over time to become the person they were at the time of the interview.

Active engagement with the environment allowed expression of self and appeared to be used by participants to gauge their sense of self as it related to their ORP. While some experiences were negative, others were positive, leading to a reinforcement of their sense of their occupational selves. In seeking strategies to deal with personal barriers related to their sense of their occupational self, participants employed their knowledge of themselves as occupational beings and a set of guidelines or beliefs that were evident in the way they spoke.

There are five strands to the sub-theme 'sense of self as an occupational being':

- Definition of self as it relates to role
- Formation and changes to sense of self as occupational being
- Maintaining a role related sense of self
- Expression of self through active engagement
- Occupational Role Performance as a Source of Self Expression

### *Definition of Self as it Relates to Role*

Overall, participants described who they were, and used contrast to further define themselves by saying who they were not. All participants, whether they had Pd or were the partners of participants with Pd, said something about who they perceived they were at the time of the interview(s). They did this by talking about significant *roles*, and were clear about the roles they held or did not hold. They made *declarations* about the sort of person they were.

A number of participants made statements about who they were using *role* language. For example, Peter (early phase) referred to his valued work role. He said: “*I’m a licensed plumber, drainer and gasfitter ... I’m a developer*”. Nearly all participants indicated that valued roles were a significant part of who they were.

The process of identifying a list of roles as part of the interview appeared to offer insight for some participants. Lynne (early phase) looked at the roles she had sorted as performing most frequently and exclaimed “... *they’re not what I do. That’s what I am, and that’s who I am isn’t it?*” Most participants made succinct statements about what type of person they were and tended to describe personal *characteristics*.

Overall, participants provided contrast to who they were by saying who they were not. Participants were clear about the *roles* they held and those they did not hold. Ken (middle phase partner of Michelle) was asked “Do you think of yourself as a carer, separate to being a husband?” He answered “*No. As a partner. As a husband or partner to my wife.*” Some participants indicated roles that had been acquired by force of circumstance, and were not part of their perceptions of themselves. Lynne said “*A ‘person with health problems’. Well, that’s a role that’s been forced upon me*”. Some participants made firm declarations about what *sort of person* they were not. Bruce (middle phase) said “*I’m not the sort of person that could ever just follow instructions*”. Participants talked in ways that showed this knowledge was not static, but rather was evolving with time and experience, and they used this knowledge to make judgements about themselves.

### ***Formation and Changes to Sense of Self as Occupational Being***

In order to explain their sense of themselves at the time of the interview, participants looked back over time to trace the *changes* to their sense of self, identifying past influences and discussing who they had *become*. They identified *damage* to their sense of themselves as occupational beings by contrasting what they used to do with what they do (or don't do) now, and discussed historical factors that contributed to the development of roles and characteristics that formed part of their role related sense of self.

Most participants spoke of social factors that had developed their picture of themselves. Family was important. Lynne referred to her family several times throughout the three interviews. She rated her role as family member as second in importance to her. She said "*Because of my family I've become a spiritual person*". Michelle (middle phase) said "*My father was a band master ... I love music*".

Some participants spoke of how they had changed over time in terms of roles and role characteristics. Rex (late phase partner of Enid) described how his role as husband had changed as Enid's disabilities had become more severe. He said "*I think carer now takes the place of husband ... because I'm always watching her. ...*". The relationship was no longer a reciprocal one. Enid seemed to suggest that Pd had taught her to be more accepting. She said "*I've become a much more placid person*".

### ***Maintaining a Role Related Sense of Self***

Analysis showed that participants with Pd and their partners appeared to have *beliefs* that they seemed to find useful as guides to help them develop strategies to maintain a sense of self while dealing with ORP losses in the course of everyday life. There were general beliefs linking self to occupational performance. Peter said, "*I love taking a risk*". Michelle said, "*I like to get out*".

Participants described their *knowledge* of how they generally behaved. Their conversation was peppered with maxims that related to how they dealt with life's difficulties. Some of these related to specific *strategies*. Actively trying to make the best of a situation was a common theme. Jenny said, "*I try to do my best*". Lynne added a proviso, "*Do your*

*best with what you have on the day*". Other maxims related to how to live with what you could not change. Enid referred to *acceptance* when she said, "*Patience is a virtue*".

Participants talked in general terms about what made life easier, what they did or did not like, and what they did not *have* to do. Some participants appeared to have general beliefs relating to what they used to help make things easier for them. Peter said, "*I use humour a lot*". Bruce sought to understand his Pd. He said,

*"I find if I can ... have a handle on it and ... know what's going on I can ... rationalise it and deal with the thing ... clinically and more detachedly, rather than have this ... nebulous unknown dreadful thing lurking out there"*.

Participants had beliefs about what made them feel good or bad. Enid Irwin said, "... *I like everything to be nice and easy and everybody talks to everybody*". They excused themselves from doing things they would perhaps normally expect of themselves. Lynne said, "*I don't push myself*". Michelle said, "*I don't go looking for work*". Some absolved themselves of responsibility for other people's reactions to their Pd. Bruce said, "*Oh, God, if I worried about other people's expectations I'd be a nervous wreck*". Lynne said, "*It's [Pd] their problem. That's what I've learned. If people have a problem, that's their problem and I'm not going to wear it*".

These strategies appeared to be about survival of self through modifying, but still meeting personal expectations, in the presence of a chronic illness (Pd). Many quotes that identified this theme came from participants who had Pd, with fewer quotes from partners, perhaps because they did not have to deal with the personal challenge of a chronic illness, but rather, they had to deal with what was happening to their partner.

### ***Expression of Self through Active Engagement***

The term *Active Engagement* is intended to cover the actual performance (doing) aspects of participants' roles (ORP) and the planning that goes into such ORP, leading to opportunities for reaffirmation of self (and of contextual fit).

Through *active engagement* participants appeared to experience themselves as unique, helping to reinforce and further define their sense of self. Participants talked of the things they did or did not do in relation to their sense of self. They discussed their *active engagement* with their social, cultural, physical and sensory environments and described how they felt about it. Participants tended to identify themselves through their occupational performance. They described *what* they did, *how* they did it and *who* they did it with, and what they did not do.

Some participants demonstrated their sense of identity by making statements about what they did and how that related to who they were. Michelle was discussing the place playing the piano had in her life. She said, *“I’m putting tea on and I’ll think – oh, nothing to do, so I’ll go and play”*. Identifying activities done with important role partners provided further contributions to a role related sense of who they were. When asked about her roles, Dorothy said *“Well, we [she and her husband] do a fair bit”*. Participants made judgements about the quality of their interactions, identifying *strengths*. For example, Yvonne, referring to her role as friend and neighbour of Michelle (middle phase) said, *“I’m a good listener”*. Ken (Michelle’s husband) said *“I’m pretty easy going”*. Participants identified what they believed they did not do well, identifying *weaknesses*. Arthur (late phase partner of Helen) regretted his temperament. In relation to his role as her carer he said *“I’m pretty bad tempered. ...For a time I withdraw ... I’m not very proud of myself when I go through those periods”*. Some participants identified what made them *happy*. Peter (early phase) clearly relished a challenge. He said *“I like to take risks”*. Ken emphasised his acceptance of the ORP losses imposed by Michelle’s Pd. He said:

*“I’m quite happy sitting around doing nothing. That’s what I knocked off work for. I mean, I’m not like [a local talk show host] who’s got millions of dollars and still wants to keep working. Not me. Finish work and that’s it.”*

Participants described the things they found *difficult* to do. Lynne (early phase) found it hard to let her friends do things for her. She said *“... it is harder to receive”*. These statements appeared to be used by participants to provide definition of themselves as individuals.

Statements participants made about how they did not actively engage with the world around them, further refined their sense of self. Una (middle phase partner) said *“I’m a bit shy. I don’t talk an awful lot”*, while Frank, her husband, said *“I’m not as active as I used to be ... but that’s not unusual for anybody my age”*.

### ***Occupational Role Performance as a Source of Self Expression***

Participants identified ORP that allowed them to be themselves. Peter said, *“Oh, flying. ... That’s my passion”*. Bruce said, *“I see my self expression ... as related to writing poetry ... or socialising with friends”*. Even the unwanted role of person with a chronic illness, or carer, provided opportunities for self expression. Bruce said his Pd allowed him to express his scientific interests. When talking about his role as a health manager he said, *“But all this sort of thing is not unpleasant. I think it’s quite a fascinating intellectual challenge or stimulus. I’m quite curious about health matters and medicine generally”*. Being a carer had positive aspects for Rex. *“I get a feeling of well-being on Enid’s good days. Looking after her - to see her have a good day”*.

Participants identified specific routines, not necessarily linked to highly valued roles, that offered opportunities for self expression. Enid loved reminiscing with her photographs. She said, *“... you come across something - pictures ... and I think – ‘Oh gee, didn’t we have a good time!’ You know? And I could spend hours doing that”*.

### **6.3.2 The Impact of Parkinson’s Disease upon Sense of Self as an Occupational Being and Strategies to Regain Control**

All the participants in the study had been forced to deal with something that had come into their lives unbidden. The impact of the disease meant that each participant, whether as someone with Pd or as a partner, had to address the issues of personal control this raised. Recognition of the need to accept the disease was a common issue. A number of participants spoke of a fear of the future. The data suggested they asked two questions of themselves – ‘how do I *do* this?’ and ‘What sort of person have I, and will I, become?’

As a consequence of the primary functional problems that participants described, all reported secondary problems with *doing* that related to how they felt about themselves. They

experienced reduced levels of confidence and a perceived loss of control. They expressed feelings of frustration, anxiety, reduced motivation and depression. Participants discussed their responses and how they dealt with them in two ways. First, they discussed how they managed to keep themselves going with *doing* and second, they discussed how they dealt with the responses they had to the impact of the disease.

From the analysis emerged two strands of personal limitation:

- The emotional impact of dealing with the disease
- The emotional impact of Parkinson's disease upon a sense of being

### ***The Emotional Impact of Dealing with the Disease: Personal Barriers and Strategies to Regain Control***

Participants discussed the feeling of personal barriers to coping with the daily impact of the disease.

#### Personal emotional barriers to coping with Pd on an every day basis that were perceived by participants with Parkinson's disease.

All participants discussed the relentless nature of Pd. Their every day occupational role performance informed them of changes they perceived to be negative. They had to find resources within themselves to deal with this perception on a daily basis. When combined with other health problems, the cumulative effects were identified as a further barrier by four participants across all phases of Pd. Participants who were in the early phase identified a dearth of skills and experience they could draw upon for the task. Some expressed a sense of frustration and ineptitude. Caroline (early phase) said:

*“... I don't feel there's an instruction book on how to deal with it. You have to work it out ... because you want life to get better than this ... I'd like to ignore it and pretend it wasn't there but ... I have to accept that it is there.”*

Participants in the middle phase seemed more comfortable and successful in coping with their symptoms. Given that there were many barriers, they seemed to be saying that

they had learned how to live with the disease most of the time. They had developed a wide range of strategies for dealing with the impact of the disease that fitted their preferences and their social situation. The unpredictable nature of Pd seemed the hardest feature for them to deal with.

Participants in the late phase were finding the strategies they had used in the past no longer worked. The unpredictability of the disease was an even greater problem for them. Jenny (late phase) said “*One day you will be walking quite well and the next day you can hardly get along*”. A fear of falling was mentioned by participants in all phases of the disease.

Personal strategies reported by participants with Parkinson’s disease to cope emotionally with the barriers imposed by Parkinson’s disease on a daily basis.

Participants with Pd discussed personal strategies for coping with barriers imposed by the disease. They spoke of a range of specific strategies and beliefs they had developed to help them keep going with their lives and achieve the things that were important to them.

The tactic of *persistence* was discussed repeatedly by the majority of participants as important to their ability to achieve the goals they set themselves. Being persistent meant participants had to boost their own motivation reserves, be prepared to push themselves, be active and creative problem solvers and be prepared to adjust their goals if necessary. When Wendy found she could not do something, she said, “*I will put it down and come back to it later. And then later on it’ll work for me*”. Dorothy regularly played twenty-five ends of lawn bowls in an afternoon. She said rather defiantly “*I get a bit tired after, but I mean, the others do too!*” She said, “*Yes, I push myself ... well, you’ve got to, otherwise you just sit and mope don’t you? I don’t know what will happen if I can’t one day*”.

Being *pro-active* in the management of their own disease was important to a number of participants. In addition to managing their energy levels and their medication as discussed earlier, they generated a range of other tactics that related to their attitude to coping and helped them to deal with of the disease. Peter, Bruce and Lynne were all notably proactive in the way they approached their daily lives. Bruce said “*... it’s one of the basic things. You’ve got to be flexible*”. They were not interested in waiting to see what other people thought. All

three were very independent in their attitudes. Persistence and being pro-active were tactics with the potential to achieve direct control of role related routines and tasks.

Some participants accepted their limitations and chose not to keep active in the same way as they had before. They *slowed down*. They spent a great deal of their time at home. This did not mean they had given up. Michelle passed the time there reading magazines, doing jigsaws and puzzles, playing the piano, and resting. While these activities may not sound dynamic, she spoke of trying hard and being persistent. Such tactics, if successful, offered the reward of a perception of control.

Four participants reported employing the strategy of *avoidance* to deal with their fears of falling. Jenny (late phase) used the strategy of equipment (a walking frame) but still felt the need to go to bed around eight-thirty p.m., “*Cause I'm no good at walking around [after that]*”. Nancy (late phase) said: “*After lunch I can hardly walk ... I've got to be very, very careful ... so I just doss down in the bed and have a sleep for about an hour and then I'm better*”.

The perception of a lack of resources to help them cope with the disease led many participants to *utilise* their personal *resources* by taking steps to control their symptoms in ways described in previous sections. In addition, they all found their support group provided some form of support. For some the support was social. Others found the information the groups provided was useful. Three participants felt the main reason they went was to support others. It is possible that this provided them with a means to support their desire to see themselves as useful members of society.

In relation to health professionals, some took steps to find one that they felt comfortable with. Some described being *assertive* where they believed it to be necessary. Some said they heard the health professional out and then made a decision, using their own *knowledge* of themselves, about whether they would follow his or her advice.

Emotional barriers to coping with Parkinson's disease on an every day basis that were perceived by participants who were partners for their partners and for themselves.

Partners of participants with Pd who were in the early phase reported doing small things for them such as doing up a button or a bra strap. They did not identify a role as carer, and did not appear to feel Pd made much difference to their lives. Those in the middle phase did more things to help their partners. This was not expressed as a problem, but some spoke of the caring aspect of partnership, while others did identify a carer role. The unpredictability of their partner's symptoms was the most commonly identified difficulty. For example, Steven spoke of the need to be ready to pick up the things his wife routinely did at a moment's notice. Most partners in the middle and late phases said they could not plan their daily routines because their partners' needs were so unpredictable.

All male participants with partners in the late phase spoke of the unrelenting 24 hour nature of their partners' needs. Even if friends took their wives out, they felt the need to be on call in case they became ill and needed to be picked up. Phillip said it was hard because he did not want to completely 'take over'. Trying to allow Helen to still have some sense of control in her life was difficult. They all identified themselves firmly as carers, and two were receiving a Carer's Allowance.

At times, their partners' behaviour caused further problems. Rex said Enid's erratic behaviour meant that, "...I'm ... constantly on the alert that she's going to do something ... wrong". He recounted how she had put clean underwear in the refrigerator when sorting the laundry, hot water in the tea caddy when making tea, and so on.

Strategies reported by participants who were partners to deal with coping on an emotional basis with the daily demands of Parkinson's disease, both for their partner and for themselves.

Partners of participants with Pd generally supported their partner's efforts to manage or deal with the impacts of their disease upon their sense of self. Some tried very hard to be *proactive* and prevent things from happening. One partner of a person in the middle phase of Pd and two partners of people in late phase spoke of *watching* all the time to try and prevent stumbles and falls, or anticipate errors in their partner's occupational performance in various

routines and tasks. Rex said, “*I’ve got to watch her like a hawk*”. As described in theme one, a number of partners provided a lot of *physical assistance* to enable their partner to complete personal care and other tasks. A number said they were conscious of *taking over* in order to control the situation, but felt they had to. A typical story was given by Arthur (late phase partner of Jenny), who said:

*“... while she was independent, ... two of my friends walked home with her, and she collapsed on her face and broke a tooth on a plate and I thought she’d fractured her maxilla, and she cut her face and, oh, it was a terrible mess. And so that’s when she was forbidden to travel alone.”*

Several partners spoke of trying not to take over, but rather to share the task, doing the minimum that was needed. Despite the stricture he placed upon Jenny’s community mobility, Arthur said:

*“... this is the balance you’ve got to maintain, because depriving her of her independence is the last thing that you need to do. ... Up to a point she’s got to do what she wants to do, but you’re still anxious about her.”*

It appeared that partners of those in late phase Pd felt able to take advantage of the opportunity their partner’s dependence gave them to take control of their role related occupational performance in specific ways, if they felt it was in their partners’ best interests. At the same time, they tried not to be too overbearing.

Partners spoke about strategies they used to meet their need to maintain their own sense of self. The partners of those in the middle and late phases felt they had to be endlessly flexible about their own needs in order to be constantly on hand and ready to assist. Ken (middle phase partner of Michelle) said “*Like, whatever she wants to do, I’ll do it. There’s no such thing as ‘I want to do this’ ... I run my life according to her*”. Despite putting their partners first, partners of people who needed high levels of care did work out ways to make their own lives a little easier and find a little space for themselves. Three identified that their *Parkinson’s support group* provided opportunities to exchange ideas with other partners and carers and learn more about the disease. This helped them to understand what was happening to their partners more clearly.

Rex and Phillip discussed *respite care* as something that would be potentially very helpful to them. However, both felt that it was not something that was pleasant for their partners, so there was a reluctance to push for it.

### ***The Emotional Impact of Parkinson's Disease upon a Sense of Being: Personal Barriers and Strategies to Regain Control***

The process of confronting Pd on a daily basis produced psychological responses to having Pd which formed a barrier to ORP. A sense of negativity made life difficult for those with Pd and for their partners.

#### Emotional barriers to an acceptable sense of occupational self perceived by participants with Parkinson's disease.

A sense of *lost control* seems to sum up participant descriptions of how they felt when encountering barriers to ORP. They reacted emotionally to the impact of the disease, and had to deal with their reactions. Caroline said:

*"... it's a hell of a shock to me compared to how my life was a year ago. ... What I have to deal with is so minimal as a problem that I don't understand the dramatic response that I've had to it, of such negativity".*

Some participants in the middle phase reported loss of confidence and some felt stressed, but overall, they appeared to have a greater perception of personal control than the other two groups. They seemed to have had time to adjust psychologically. Participants in the late phase described a dramatic loss of personal control.

Six participants said they were *depressed*. Two participants in the early phase reported they had been diagnosed with depression. *Loss of confidence* was reported by six participants. Helen said,

*"I've been alright up till this year. I've been able to sort of manipulate it, you know. But it seems to have got to that stage now that it's not responding. Everything's getting worse and developing ... I feel that whatever I do, I can't get on top of it".*

Participants, from all phases, reported feelings of *anxiety*, *stress* or *panic*. Dorothy said “*You get uptight about silly things. Really ridiculous*”. Some participants, particularly in the middle and late phases were critical of their own performance, while others found it difficult to get things done due to lowered energy levels and of a *loss of motivation*. Wendy Egan (early phase) said “*And I think, I really don't feel like doing any shopping. ... There are days when you just don't want to do anything*”.

Personal strategies reported by participants with Parkinson’s disease to regain an acceptable sense of self as an occupational being.

Participants had to cope psychologically on a daily basis with the emotional barriers they encountered in their everyday lives. They all spoke in various ways of the importance of maintaining a positive attitude. Attitudes displayed by various participants included denial, positivism, stoicism and acceptance. They discussed how these attitudes helped them to cope, and worked hard to achieve and maintain them. They identified a wide repertoire of emotional strategies they found useful in achieving this end. Some participants identified threats to their sense of themselves, and either *denied* or *avoided* them. Peter said “*One [talk] was on incontinence or something, so I figured ... I wouldn't listen to that on principle*”.

Participants considered continuing to *do* an essential factor in minimising the personal effects of Pd. A *positive attitude* was identified as being a very important part of managing to keep active. It seemed a good antidote to feeling depressed or losing confidence. Bruce said:

*“All the books talk about tremoring and bradykinesia... The most important thing is whether you've got a smile on your face or not. Huge numbers of Parkies are either anxious or depressed. If you're depressed, that's terrible and if you're not, well then, who cares if you're twitching and jerking? As long as it doesn't worry you it's not a big problem...”*

Others said their partners really helped to keep them positive. Wendy’s husband Tom expected her to keep up the same pace of life as always, and they had always led busy lives.

Participants discussed a number of strategies that could be summarised as being *stoic*. Positive self-talk, sometimes using family sayings or beliefs from long ago, helped. Dorothy said “*You've got to be positive, haven't you? As my mother always said ... 'Well, you just can't sit in a heap'.*” Some participants consistently expressed the view that they were better off, or at least no worse off, than others with the disease. Wendy’s transcript was sprinkled with remarks such as: “*... it affects everybody like that ... other people have that problem too ... if you talk to others with it, you'll find they're the same ... I'm a lot better than some people*”. This view led participants to express how grateful they were for what they had. Enid said “*And [Rex] is an absolute treasure. Everybody wants to adopt him ... Oh no, he's been wonderful.*” Finally participants spoke of being strong. Peter said “*... nobody's going to look after me*”.

Being stoic and thinking positively involved *acceptance* of losses which could not be restored. The ability to make adjustments that were personally acceptable was very important. Participants showed varying levels of acceptance of the disease process. Jenny said:

*“I started off being very, very angry about it. ... I resented it. I feel more accepting of it now ... When I first had it I wouldn't go to any of the Parkinson support groups ... because I wanted to deny it. The first support group meetings I went to I used to look at the people who'd ... had it for a long time, and I felt sorry for them. That was when I began to accept it, I think. Now I'm one of those bad ones.”*

As part of acceptance, some participants spoke of the need to be patient. They developed activities they found diverting, such as knitting and puzzles, to fill the time they had gained by the process of relinquishment.

#### Emotional barriers to an acceptable sense of occupational self perceived by participants who were partners, both for their partners and for themselves.

Participants in the early phase did not identify barriers for themselves. Participants in the late phase were expressing feelings of stress and concern as all aspects of life were taken over by the need to deal with the consequences of their partners’ illness.

Many participants expressed *concern* for their partner with Pd. They were very aware of how their partner must feel, and wished there was more they could do to help them deal with it. Rex spoke of Enid's cognitive problems. He said: "... *So the thought's gone out of her mind from the middle part of what she was going to say. That must be terrible for her*". Arthur said of Jenny, "*I think she is very resentful of not being able to cook meals, although together we cook casseroles and things like that*". Ken was concerned that friends and family did not understand Michelle's problems. He said "*I think ... why is it her? Because she never smoked, never drank. ... She's lived a good life*".

Personal strategies to regain control of an acceptable occupational sense of self reported by participants who were partners.

Partners used similar strategies to deal with their responses to the impact of the disease as their partners with Pd. The majority of partners practiced *stoicism*, saying similar things to their partners. Ken said, "*you've got to accept what you can't change*". Some partners said they had to *learn new ways of relating* to their partner. Olive said their marriage had always been based on having equal but differing responsibilities. When her husband's Pd became disabling, she had to learn that he needed her help now. At the same time, she found him difficult and demanding at times. She said she told herself, "*I've got to do it ... I've got to put up with it*".

Some partners used *denial*. Una (middle phase partner of Frank) disliked like going to the support group. She said "*Sometimes I've been up there and they're like this and that and I think, I don't want to see that; I don't want to know that*". Some talked of achieving *acceptance*. Phillip said he found Helen's fluctuating levels of function very difficult to deal with, until he came to accept it as a fact of their life together. It seemed the major thing that the partners of those in late phase had learned, was to accept was that their life now consisted largely of one role – that of carer. It seemed Arthur had been through the same process of denial, followed by acceptance, as his wife. He said, "*And I went through a very resentful period. But there are no worries now*".

Some partners used *positive self-talk* to feel better about themselves. Rex said, "*I deserve a carer's pension*". A number of partners were supported by the belief that they

were *doing what was right*. Olive said, “*I realised that if things were different he would be caring for me*”. Three of the men talked of facing up to their responsibilities.

### **6.3.3 The Cumulative Impact of an Altered Sense of Self as an Occupational Being Upon Occupational Role Performance and Strategies To Regain Control**

It was clear that the participants in this study had a strong sense of self which they wished to maintain. It was reinforced by *actively engaging* with their environment in ways which gave them satisfaction. Where such active engagement was unsatisfactory, they identified changes to their sense of themselves that they perceived as damaging.

Two strands emerged from within this sub-theme:

- Who am I? An altered sense of occupational self
- What will I become? Fears for the occupational self

#### ***Who am I? An Altered Sense of Occupational Self***

##### Personal barriers to occupational role performance arising from an altered sense of self as perceived by participants with Parkinson’s disease.

Many participants spoke of experiences of loss leading to *negative changes in their sense of self*. They had to learn about the person they had become and the person they might become in the future. Six participants identified losses in ORP. In order to illustrate how they had changed, participants spoke of what they used to do, contrasting it with what they did at the time of the interview. Wendy’s (early phase) top three roles were wife, mother and grandmother. She was talking about how she used to cook regularly for her family. She said:

*“I haven’t done that for a while because I find it’s a bit too much for me now. I sort of get a bit worried about [it], you know. Yet for years I’ve always had ... seven or eight people in the house in and out, you know, for meals.”*

Peter described his old working style as follows: *“I used to run on adrenalin. I used to really bite off more than you can chew and chew like crazy ... Always used to go. ... I used to like the difficult jobs”*.

Lost opportunities to validate themselves by actively engaging with their environment in meaningful, role-specific ways meant that participants had to adjust their sense of self. Participants variously discussed that they had lost: choice, independence, a sense of purpose, being an active person, and being a risk-taker.

Personal strategies to regain control of altered sense of self as it relates to occupational role performance reported by participants with Parkinson’s disease.

There was a clear interaction between occupation role performance and sense of self. All participants discussed the things they did to feel in control of their disease, and most felt that the impact of Parkinson’s disease had led to the development of a new role as a health maintainer. All participants said they tried to take care of themselves. Many appeared to place an emphasis on doing things that would support their perceptions of themselves as occupational beings. Common strategies were to try to understand the disease, reduce stress and maintain a sense of purpose.

Some participants spoke of the need to be in touch with themselves and to *understand their symptoms* as fully as they could. Bruce had developed a major role as a health manager. He listened to health programs on the radio, and to tapes from conferences about Pd. He read around the subject extensively and went to his Parkinson’s support group to find out as much as he could. He kept files of information of particular interest him. He tried to apply what he was learning in his own life. He said *“I think it’s quite a fascinating intellectual challenge ...”* He and Peter (early phase) both discussed various theories they had developed from their knowledge of the disease and their observations of their physical and psychological responses. They used these theories to try to better understand and control what was happening to them. In addition they both said that a good understanding helped them to achieve a sense of detachment. This allowed them to accept the disease more readily. They used contrast to clarify their ideas. Both spoke of people they had met through their respective support groups who personified for them how not to go about dealing with Pd. Taking back control was most important to them both.

Lynne (early phase) was emphatic that she was more than her disease. Her focus was on her life and who she was. She dealt with the Pd as she had to, but kept it firmly in the background (as much as she could). She said *“I’m so much more than a person with Parkinson’s”*.

Participants spoke of taking steps to *reduce stress*. Bruce was a physics schoolteacher. As he developed Pd it became more difficult for him to feel in control at work. He found it very stressful – His head of school was not understanding and did not make allowances for him. The stress only exacerbated his symptoms and, as a physics teacher, he made one or two potentially dangerous mistakes with his class demonstrations. After struggling for a while he decided to retire early. He found this to have been an excellent decision. He resolved to have fun in his life. He said *“So as far as I’m concerned everything I do is for relaxation or enjoyment these days”*.

Having a *sense of purpose* was identified by the majority of participants as being most important. This is what enabled them to keep motivated and therefore to keep going. A number of people spoke about their membership of specific groups of people. They gave great value to their ability to continue with the roles associated with these groups. These roles produced relationships and interactions that boosted a positive sense of self. Michelle felt comfortable and secure within her own family circle and valued the role of mother highly. Lynne was a nun. Her whole life was built around her vocation. Active membership of her congregation was an integral part of that.

Some participants had highly valued roles that were not so much about relating to others as about the central activity of the role. Peter was a pilot. He lived to fly. Because of his health beliefs, he stopped taking his Pd medication. His frank symptoms led him to give up his pilot’s licence. He subsequently resumed Pd medication. Between his first and second interview, he regained his pilot’s licence and flew from rural NSW to the famous Birdsville races in Queensland. His demeanour at the second interview was strikingly different – he was much more confident, outgoing and positive. He explained, *“I’ve had a fix. That’s a flying fix!”* Bruce’s role as a poet helped him. He found it was a great outlet. He published a

book of poetry through Parkinson's NSW shortly after completing his interviews for this study.

Some participants had developed challenging new roles since, and as a consequence of, being diagnosed with Pd. Peter had to give up his horticultural business as his symptoms became more prominent. He managed to set up a new career using his existing skills as a plumber. He tendered for a wide range of work in his area. He and his partner enjoyed taking on the jobs others found too hard. He no longer did the hands-on work, but rather used his experience and problem solving skills to find solutions and apply them. He now called himself an entrepreneur.

Some found having absorbing routines helped to carry them along. Frank walked to the shops most days and spent quite some time there window shopping and comparing prices. He rarely bought anything, but he said he found it an interesting pastime, and it gave a purpose to his walks.

Personal barriers to occupational role performance arising from an altered sense of self as perceived by perceived by participants who were partners, both for their partners and for themselves.

Some reported their partner with Pd was depressed or had *difficulty accepting loss*. Three partners of people in the late phase felt their partners put themselves at risk through not accepting their limitations. For example, Phillip saw the home environment as a threat to both their safety because of his wife's habit of getting up and doing things such as making a cup of tea while he was asleep. He worried there would be a fire.

Partners appeared to experience damage to their own sense of self through loss of opportunities for validation. Particular issues they discussed related to their losses of ORP in other valued roles where the role of carer had become overwhelming.

Strategies developed by participants who were partners to support their partners' occupational role performance.

Partners recognised their partner's need to maintain a sense of themselves as occupational beings. Una tried to respect Frank's need to still "feel a man". She respected the traditional style of their marriage and did not impinge on matters that had always been his province as a husband. For example, she did not discuss money matters with him. Steve tried to ensure that Adele could continue in as many of the roles they shared together as possible. He contributed much of the 'doing' in various roles, but left most of the decision making up to her.

Partners whose partners with Pd were in early phase were still able to continue with their own occupational role performance much as before. However, the majority of partners discussed the damage Pd had wreaked upon their own sense of self. They spoke of the need for time away from their partner, and out of the role of partner or carer. Partners of those in middle phase felt able to leave them for a few hours, while partners of people in late phase had great difficulty in getting time away. Rex and Arthur used their workshops as an escape. Rex said it was a good tension breaker. They were still in the house, but able to be on their own for a while. Even so, they could not leave their partners for very long. Arthur found gardening a "*great emotional outlet*" because it gave him a chance to chat to his neighbours. Partners found listening to music and reading helped.

Steve (middle phase partner of Adele) and Olive (late phase widow) both said things which indicated they got satisfaction out of doing things for others (in addition to their partners). Olive's husband had passed away about twelve month's prior to her interviews for this study, but she still attended a Parkinson's support group and expressed her great pleasure at being able to give others the benefit of her experience. Steve drove a community bus and had been president of a Parkinson's support group for the past eight years.

For those partners who felt they had the role of carer, it brought its own rewards and satisfactions. They believed they were doing the right thing as a husband or wife. Some partners spoke of trying hard in their caring role, and were comfortable saying they felt they did a good job. Arthur said, "*She mightn't realise, but even when I'm irritable I do enjoy doing these things for her*". However, he thought it would be nice to get some appreciation

from his wife. He said, “*Sometimes, ... and I think other carers feel this, they’d like the caree to say ‘You’re doing a good job’*”.

### ***What Will I Become? Fears for the Occupational Self***

#### Personal emotional barriers linked to possible future functional losses as perceived by participants with Parkinson’s disease.

Participants’ sense of themselves as occupational beings was compromised by concerns about future ORP. Fear of what the future held was evident among participants with Pd and their partners. A sense of purpose about their present ORP was affected by these worries, and it seemed to sap motivation to keep going with valued ORP. A major concern reported by four participants was uncertainty. What would happen next? They were aware of continuing deterioration. Would they have a fall? Would they develop major cognitive problems? Would they have difficulty talking and swallowing? Three participants feared making arrangements and then having to break them, or becoming ill whilst out, due to the unpredictable nature of Pd. Participants feared their medication would cease to work effectively. For participants in the late phase, the future was already here, and their fears had been realised. Helen said “*I just feel so lifeless really. And, you know, there’s no future. If you had something that you could hang onto ...*”

#### Personal strategies reported by participants with Parkinson’s disease to regain control of emotional fears about the future.

Participants with Pd spoke of living in the present and not thinking too much about the future. A number of participants spoke of the need to hope – for a cure to be developed, for the course of their disease to avoid some of the more frightening aspects such as dementia, and for being able to continue meaningfully with the important aspects of their lives, such as their personal relationships, for as long as possible.

Personal emotional barriers to occupational role performance linked to possible future functional losses as perceived by participants who were partners, both for their partner and for them both as a couple.

Three partners worried about the future of their partner. Two partners of participants in the late phase of Pd felt they had lost their own future, in that they and their partner could not think or plan for their future together.

Personal strategies reported by participants who were partners to regain control of emotional fears about the future.

Participants with partners in the early phase of Pd seemed to hope that they would be lucky, and their partners would somehow miss the worst ravages of the disease. Partners of those whose Pd was in late phase did not hope in the same way. Phillip tried not to think too much of the future and to live in the moment instead. Rex was just beginning to think about planning the next stage, when he could no longer care for Enid at home.

Una had a major fear that she and Frank could wind up in a nursing home. She sensed Frank was not able to be proactive and make decisions as before. She felt the need to pick up the 'slack' in terms of managing things. She said "*I've got to push myself*". She kept the house and garden perpetually spotless and well maintained so that they could sell it at a moment's notice. If there was crisis they would at least be able to release their capital.

### **Summary of Theme Two**

Both participants with Pd and their partners demonstrated a strong sense of self as an occupational being, and a strong awareness of the impact of Pd upon their sense of self. This awareness was not static, but developed in response to their experiences. Opportunities to express themselves by actively engaging with their environment were important to how they felt about themselves. Participants spoke of barriers to dealing with the impact of Pd on a daily basis and described how that affected their opportunities for self expression. This in turn limited their opportunities to experience themselves in positive ways. The unpredictability of symptoms made it difficult to experience mastery in anything.

Participants with Pd tended to express a reduced sense of self efficacy and depression,

anxiety and stress. They criticised themselves and experienced loss of motivation. Partners expressed concern for how their partner with Pd must be feeling. A sense of lost control was pervasive, particularly among those who had progressed along the disease's trajectory to the late phase.

To counteract this negative sense of self, participants seemed to be using their knowledge of themselves and the beliefs they had developed from their own experiences over a lifetime to help them maintain their occupational sense of self. They used their knowledge and beliefs as the basis for the strategies they developed to deal with impact of the disease upon their occupational sense of self. As the disease progressed, both those with Pd and their partners drew upon these resources to develop skills and attitudes to help them in practical ways and to help them deal with their feelings of loss.

Participants with Pd in the early phase appeared to discuss strategies for dealing with the disease from an emotional perspective on a daily basis more frequently than participants in the middle or late phases. Discussion of strategies to prevent or minimise damage to their perceptions of themselves as occupational beings appeared more evenly spread across the three phases. For partners there was a much clearer trend across both sub-themes from early to late phases of the disease, with partners of those in the late phase discussing coping strategies related to this theme most often, and those in the early phase, least. See Table 6.2 for a summary of the sub-themes and strands of Theme Two.

<b>Theme One: The Impact of the Primary Disease Process Upon ‘Doing’ in Everyday Roles, and Strategies to Minimise the Impact</b>
<p><u>The impact of specific symptoms</u></p> <ul style="list-style-type: none"> <li>• Movement: Personal barriers and strategies to regain control</li> <li>• Medication management: Personal barriers and strategies to regain control</li> <li>• Reduced energy: Personal barriers and strategies to regain control</li> <li>• Cognitive difficulties: Personal barriers and strategies to regain control</li> <li>• Other factors: Personal barriers and strategies to regain control</li> </ul>
<p><u>General strategies that supported ‘doing’</u></p> <ul style="list-style-type: none"> <li>• Personal beliefs that maintain perceptions of control of everyday role performance</li> <li>• Personal occupational performance knowledge</li> </ul>
<b>Theme Two: Secondary Personal Limitations to Occupational Role Performance and Strategies to Regain Control</b>
<p><u>Sense of self as an occupational being</u></p> <ul style="list-style-type: none"> <li>• Definition of self as it relates to role</li> <li>• Formation and changes to sense of self as occupational being</li> <li>• Maintaining a role related sense of self</li> <li>• Expression of self through active engagement</li> <li>• Occupational role performance as a source of self expression</li> </ul>
<p><u>The impact of Parkinson’s disease upon sense of self as an occupational being</u></p> <ul style="list-style-type: none"> <li>• The emotional impact of dealing with the disease: personal barriers and strategies to regain control</li> <li>• The emotional impact of Parkinson’s disease upon a sense of being: personal barriers and strategies to regain control</li> <li>• The cumulative impact of an altered sense of self as an occupational being upon occupational role performance: personal barriers and strategies to regain control.</li> </ul>
<p><u>The cumulative impact of an altered sense of self as an occupational being upon occupational role performance</u></p> <ul style="list-style-type: none"> <li>• Who am I? An altered sense of occupational self</li> <li>• What will I become? Fears for the occupational self</li> </ul>

**Table 6.2 Theme Two. Personal barriers and strategies, sub-themes and strands affecting both types of participants.**

## **6.4 Theme Three: Secondary Social Limitations to Occupational Role Performance and Strategies to Regain Control**

This theme related to the individual's sense of fit within their social environment or *context*. Social limitations arose in one of two ways. The changes to participants with Pd's ability to *do*, together with negative changes to their sense of self as an occupational being, led to social limitations, and limitations arose as a result of negative attitudes and beliefs that participants perceived were held by some of those around them. These limitations led to losses in participants' personal sense of social fit. Participants employed strategies to overcome barriers to social participation, in order to maintain or restore a sense of social fit. To do this, they used their knowledge of themselves and their various role partners, and a set of beliefs about what was efficacious in dealing with others that they had developed over the years. Both those with Pd and their partners worked to overcome negative social attitudes towards disability and a perceived decline in their relationships with others.

Two sub-themes emerged from within theme three:

- A personal sense of social fit
- Impact of Pd upon sense of social fit

### **6.4.1 A Personal Sense of Social Fit**

Participants all said things which appeared to indicate they had a strong sense of where and how they fitted into their particular socio-cultural context. They related how they did or did not fit. They identified factors that appeared to contribute to a sense of good fit or to a sense of poor fit. Those who had marital partners identified them as a major part of their social context. Participants perceived their interactions with those around them as dynamic and ongoing. Such interactions greatly informed their sense of fit, and they identified barriers to social participation. Participants sought strategies to ensure these relationships were maintained and that they evolved to meet their need to feel they belonged and were valued by the world around them.

Two strands emerged from this sub-theme:

- Definition of a personal sense of social fit
- Maintenance of a personal sense of social fit

### ***Definition of a Personal Sense of Social Fit***

Participants described the various ways in which they perceived they fitted in their social context. They identified *roles* and *occupations*, and discussed the nature of their relationships. The qualities that appeared particularly important from the data for a positive sense of social fit were a sense of *contribution*, and *reciprocation*.

Valued *roles* were important to a sense of fit. Participants gave a succinct account of how they fitted their context, identifying specific roles that were central to fit. Table 5.3 in Chapter Five showed the three most important roles identified by each participant. As a group, participants in this study identified the role of spouse as their most important role, closely followed by that of family member. *Occupations* provided a sense of fit. Jenny Morgan (late phase) found shopping helpful “... *it’s something to do, and you feel you’re part of the world*”. Phillip (late phase husband of Helen) spoke of a poor sense of ‘fit’. He said, “*It’s very hard to spend ... all your waking hours with a person in the same room*”.

### ***Maintenance of a Personal Sense of Social Fit***

Active engagement, through expression of self, allowed participants to experience satisfaction that could be seen as relating to their sense of social fit. Participants identified roles and occupations which gave them a sense of *contribution* and *reciprocation*. Steve and Adele (middle phase) were both very active in their local Parkinson’s support group. Steve said “*Yes, nearly finished eight years of that now. ... I can’t get anybody yet to take over. It’s easy to get into these jobs, it’s hard to get out of.*” Olive (late phase widow) felt their Pd support group had been of central importance to both herself and her husband. Now that he was dead, she devoted a great deal of time and energy to supporting others through the support group. Some participants identified having a *skill* that others valued and wanted as a good way to achieve social fit. Peter (early phase) said “... *flying is ... something that others can’t do and I can do, and that sort of gives you a good thing*”. Conversely, Gwen said,

*“You feel very selfish ... when things are done for you and you don’t do much for society”*. Being able to *contribute* and *reciprocate* seemed to give a sense of *balance* to participants’ relationships which made them feel comfortable.

Participants demonstrated *knowledge* of their social fit as it related to occupational performance. They showed that this knowledge was evolving rather than static, and that they used it to inform their sense of self. Participants used this type of information to develop and apply *beliefs* that they used to help them improve their sense of social fit. Participants, both those with Pd and their partners, had beliefs about fitting in with others – particularly with the people who were most important to them. Beliefs were about the expectations of others, meeting the needs of others, and fitting in.

#### ‘What others expect of me’

In order to maintain social fit, participants had beliefs which helped them understand and therefore fit with the expectations of others. Where there was dissonance between this and their own expectations, they used language that made it clear that these beliefs were at odds with their own expectations. Helen said, *“I know I have to be a good patient, won’t I? If I’m going to exist”*. Lynne said, *“People ... say ‘how have you been? Have you been busy?’ You’re only worth what you do as a person. Apart from that you’re not worth anything”*.

#### ‘What I do to accommodate the expectations and needs of others’

Participants voiced a number of role specific strategies that could be directly related to their beliefs about being a good partner. Early phase participants with Pd described the ways in which they tried to protect their partner from knowing how much the disease was affecting them. Middle phase participants with Pd tried to give something in return for the support they received from their partner. Michelle knew that her husband enjoyed going on bus trips. She found such trips uncomfortable, but said, *“I feel I should go because of my husband, you know”*. Late partners considered that the full-time care they were giving to their partner with Pd was part of being a good spouse. Phillip said, *“I just made up my mind that I have a responsibility”*.

### What enables me to 'fit' with role partners

Participants spoke of specific interactions with others that felt good. Being able to talk was an important part of self expression. Lynne said, *"But you can say anything to ... real ... friends ... You just feel you can be yourself"*. They had beliefs that related to their style of interacting with others – the strategies they used to fit in. Some were about how to present themselves. Lynne said, *"You're putting up a front and they're accepting it"*. Other strategies were more about not being a nuisance. Yvonne would have liked to spend more time with her friend Michelle, but she said, *"I don't smother her. ... I know when to step back. .... I don't stay long"*.

Some participants identified resources in their environment that assisted them to 'fit'. For some it was their partner. Enid said, *"I'm lucky to have him [Rex]. Without him it would be a bit difficult"*. Social recognition seemed important. Michelle said playing the piano for others, *"... does give you pleasure. Especially if they sing"*. Rex (late phase partner of Enid) appreciated official recognition of what he was doing. He said:

*"So the carer's pension ... was quite a bonus. I think, sounding very immodest, I deserve it too ... I think if I wasn't caring for her and she had to go somewhere else it would cost the government a lot more than me looking after her."*

#### **6.4.2 The Impact of Parkinson's Disease upon Participants' Sense of Social Fit**

The limitations and frustrations that participants were experiencing meant that, more than ever, they needed opportunities to interact with others, express themselves, and reassert their sense of who they were. Barriers to this process led to losses in participants' sense of self and in their sense of social fit. Participants spoke of reduced opportunities to interact with those around them because of the negative impact of Pd upon their ability to *do* and their sense of self. This in turn led to reduced opportunities to express themselves in a self-perpetuating cycle.

Most participants with Pd indicated ways in which they felt they did not fit in. They referred to *roles*; *social norms*; the perceived *expectations* of others; a *dissonance* between such expectations and the expectations they had of themselves; of failing their own

expectations for social interaction; and of negative changes in their socio-cultural environment. Participants developed strategies to overcome or lessen these losses, thus facilitating their sense of social fit.

Two strands emerged from this sub-theme:

- Barriers to social fit and strategies to regain control
- Barriers relating to valued role relationships and strategies to regain control

### ***Barriers to Social Fit and Strategies to Regain Control***

Participants described many instances of losses in occupational performance which affected their active engagement in occupational roles. This in turn affected their sense of fit. For example, Peter went rally driving with friends. He said, “*They found out that ... I was only worth having as a driver in the mornings. ... I was just too tired to drive [at other times]*”. The lack of understanding of others was limiting. Lynne said, “*I do wish that people would know when I’m feeling rotten. Just to give you the space to feel rotten*”. Peter found having a visible difference inhibiting. He said, “*[I want to] just be myself. ... Other people can see the problems that you’ve got, and they look at the long term, you know?*” The interviewer said, “So they don’t see you, they see the tremor ...?” He replied, “*... that’s what I think they see*”. Participants in the late phase of Pd had great difficulty in actively engaging with their environment. They spoke of an empty present and a non-existent future. Helen Adams (late phase) said, “*There’s no future*”, while Phillip, her husband, said, “*... so I don’t really have any life*”. The Irwins felt the same. Enid said, “*We can’t do anything. Die, or anything*”. Rex was not so down, but he said “*Haven’t been out at night for quite a long while*”. None of those who lived alone had partner support. They had to work out other ways of managing the routines of daily life.

The poor understanding of Pd experienced by most participants led them to behave in two different ways. They tried to engage people in ways that hid their Pd, *fitting in* with the expectations of others to be well. At the same time, there was *defiance*. Participants sometimes ignored the attitudes they sensed or experienced in others and brazened it out. A strong sense of self was necessary to do this.

Personal barriers related to social dissonance or role conflict as perceived by participants with Parkinson's disease.

When participants participated in social intercourse they did not always feel comfortable. Six believed or feared that others did not understand. Participants reported ways in which they felt they failed to fit the *norms* of the society they lived in. Peter said *"People have trouble putting me in the right box because I'm young and I'm ... semi-retired."*

Some participants identified instances where their *expectations* of themselves were at odds with the expectations they perceived others had of them. Some participants received confronting information about how others perceived them. Peter reported an exchange with his ex-partner. He asked her *"... do you think I'm an invalid?"* She replied *"Yes, of course you are!"* He said *"... that was hard to take"*. Six participants felt that family and friends did not understand the disease because of the seemingly minor outward signs and the fluctuations in its impact. Dorothy (early phase) said. *"You can look alright and appear alright and the damn thing is getting you inside"*. This led to a fear that people might think they were not really ill. Participants feared their symptoms could be misconstrued. Michelle said: *"But sometimes when I'm out ... they might think 'Oh, she's on drugs'. You don't know what people think"*. Participants did not always experience a sense of fit with the health professionals they encountered. Bruce (middle phase) said:

*"... and the dentist said 'Oh, ... you are affected with Pd ... in view of your limited life expectancy, do you think it is worthwhile investing [in] full top and bottom dentures?' I said 'Yes I certainly do'. I thought it was an interesting tale."*

Some participants reported a loss of a sense of *balance*. They perceived they were not meeting expectations in terms of making a *contribution*. Jenny said *"I don't feel able to be involved as much as I should be"*. They felt different and perhaps feared others saw them as inferior. Caroline (early phase) said: *"I'm managing pretty well at participating as if I was still ... normal"*. Clearly, she did not feel normal. She said, *"I feel that I've self isolated myself to quite a degree ... You shouldn't feel ashamed, but I do ... If you become like this in the community you become a burden and worry people ..."*. Participants in the late phase of

Pd seemed to feel the most at odds with their social context. Helen (late phase), in discussing how she felt others saw her, said, "... *and so I'm a problem in the end*". Some expressed resentment that their symptoms were easily observable to others and therefore labelled them as 'not fitting in'. Enid hated eating in public. She said "*Dribble and drool. That does embarrass me*". Peter said:

*"The thing I don't like about Parkinson's is that you may have a tumour or something and if you choose not to tell us ... we don't know. But I've got Parkinson's disease. I shake like crazy and you've got no question that I've got Parkinson's disease because you've seen it, haven't you?"*

Personal strategies to regain control of occupational role performance in the presence of perceived social dissonance or role conflict, as reported by participants with Parkinson's disease.

A sense of inferiority or loss of social status meant that participants in the early and middle phases worked hard to present themselves to others as *not needy* or disabled. Four participants spoke of *avoiding* social situations where they might not be able to leave easily if they went 'off'. Four participants in early and middle phases talked of *putting on a show* of being OK for others, and of minimising their own needs. Some tried to *protect* those around them from the impacts of the disease. Participants who were in the early phase still had the opportunity to hide their Pd. At this stage participants appeared determined to handle the disease as much as possible alone. Dorothy said, "... *but you don't always like to worry other people*". Participants found ways to dodge the label of having Pd. Peter said "*Oh you stick your hand in your pocket and do all that ...*" Late phase participants could not hide anything. Their symptoms were obvious to everyone.

Those in the early and middle phases of the disease tried to *deflect* attention away from what they could not hide. They worked to make themselves amusing company. Bruce wrote funny poems about Pd and performed them publicly. Peter said "*I use humour a lot ... I say 'just hang onto my hand and I'll shake it' – that sort of stuff*". He appreciated it when others showed by humour that they understood. He said, "*And the people that know me if they'd see me in the coffee shop ... they'd say to someone, 'have you got a jumper? This fellow's cold' ... So I like that*".

Some participants spoke of *distancing* themselves from friends who did not understand. Despite her dementia, Enid had a sweet manner, and used humour, “*Oh, there I go again*”, to deflect possible censure when her conversation collapsed, as it frequently did. At the Parkinson’s support group she was observed to be obedient to others, inviting them by her manner to give her direction. Apart from the support group, she avoided social interactions, even with her closest friends, because she felt her dribbling and difficulties with social intercourse destroyed her ability to fit in.

Some participants recounted stories which showed their willingness to defy others. Peter Vaughan recounted a flying incident:

*“... the Air Operations Manager and the Flight Inspector [were] there ... we were having drinks ... in this little pilot's room in Birdsville ... and I was shaking ... I didn't take the other pill to settle me down ... and I thought 'well that's their issue'. I did my flight test three weeks ago. I can prove I've passed.”*

Participants worked hard to maintain *meaning* in their lives. Some developed new and valued roles to replace the social losses they had experienced. The maintenance of meaning counterbalanced feelings of inferiority by permitting continued expression of themselves as individuals.

Personal barriers related to social dissonance or role conflict as perceived by participants who were partners.

Participants who were partners experienced these issues mostly through observation of their partners’ interactions. Three whose partners were in the late phase of Pd saw that they were treated differently. Phillip said “... *you go with ... normal people and they don't really understand*”. Arthur found that when they were out socially together Jenny got ignored. He said “*It hurts me that they talk to me rather than her. ... It's very isolating. People think that you're mentally deficient ...*”.

Strategies reported by participants who were partners to assist their partner with Pd to cope with social dissonance or role conflict.

Partners generally stood ready to jump in and *protect* their partner with Pd from the erroneous attitudes and assumptions of others. Steve worked hard to present his partnership with Adele as equal. Three partners spoke of having to act as an *advocate* for their partner with Pd, with family, friends and with health professionals. Ken, Rex and Phillip all *informed* themselves about Pd so that they could discuss their wives' treatment with their doctors. In particular, they wanted to discuss medication.

***Barriers Relating to Valued Role Relationships and Strategies to Regain Control***

There was a general perception of decline reported in the relationships participants with Pd had with their partners in valued roles. As the degree of dependency increased from participants in the early phase to those in the late phase, they identified a shift in the balance of the relationship. This provoked feelings of anxiety and a sense of failure in some participants, and a number of them spoke of attempts to minimise the impact of disease progression upon their partners.

The marital partnership: personal barriers to maintaining a satisfactory balance perceived by participants with Parkinson's disease.

Five participants with Pd discussed their perceptions of a slowly increasing level of *dependence* which shifted the balance in their relationship with their marital partner. Dorothy (early phase) said "*I'm not fulfilling everything like I was, because ... [my husband] does quite a bit for me now*". Four participants with Pd were anxious about the *burden* they perceived they now represented to their husbands. Caroline (early phase) said "*... I try to minimise the drag that I must put on him because I can't hide the difficulties from him*". Jenny (late phase) was asked how satisfied she felt in her role as a wife. She said "*I'd feel more satisfied if I didn't have Parkinson's. I feel that gets in the way a bit ... Well, it restricts my husband ... So I feel I'm a bit of a failure to him*".

This sense of dependence and burden meant that participants no longer experienced *balance* in their relationships with their partners. It seemed Enid felt that there had been a considerable reversal of role tasks in their marriage. Although she acknowledged there were

safety issues because of her erratic behaviour, she believed Rex had taken over more than was necessary. She appeared to feel he was controlling her. She said “... *if ever I defy [Rex], well, I've got nobody to look after me then*”.

The marital partnership: personal strategies to maintain or regain an acceptable balance reported by participants with Parkinson's disease.

Participants worked to maintain the functional nature of their relationship. They described how they tried to keep their partner going. Some described strategies based around trying to protect their partners from the impacts of Pd by avoiding dependent behaviour, and of how they worked together as a team.

Five participants described strategies that were designed to *protect* their partner. Stoicism was an important part of this. Caroline (early phase) spoke of trying to prevent her husband from perceiving some of her difficulties. She said “*I'm struggling to put on the armour of presenting myself as able ... in very many situations at the moment*”. Helen tried to find ways of giving her husband a break from her. She said “*I'm trying to get to do things that I don't need [him for] ... because ... I feel he wants a break too*”.

Wendy said she and her husband Tom shared the attitude that you just have to get on with it. This entailed a determination to *appear able* on her part. She was asked whether she ever asked her husband for help. She said “*No. Just battle through*”. She described how he supports her stoic attitude: “*If I start feeling sorry for myself, he says: 'Now, there's nothing wrong with you and don't you forget it. You're doing alright'*”. Helen believed her husband Phillip felt she made too much of her problems. She asked her doctor to talk to him and found the talk was helpful in giving him a better understanding of her difficulties.

Adele described a partnership that had *maintained its balance* despite change. She and her husband Steve did everything as a team, with each contributing what they could to the task in hand. She tended to do the thinking, planning and organising. He tended to do the going, getting and doing. As her symptoms progressed, they both adjusted what they did to accommodate the changes.

The marital partnership: personal barriers to maintaining/regaining it perceived by participants who were partners.

Partners knew their partner with Pd would give anything to be able to protect them from the disruption caused by the disease. Some felt their partners put themselves at risk by striving to be too independent, in an attempt to take the weight off them. They sometimes found this stoicism difficult. Arthur said, "... [Jenny] is a most uncomplaining woman. And I think this is part of the problem, I never really know how she feels. She hides it magnificently". Some were concerned that their partner was depressed, and five said they found the unhappiness of their partner hard to deal with. Olive (late phase widow) said, "He'd say to me ... 'I'm useless aren't I?'". Other partners said they assumed their partner must be unhappy.

Five partners, mostly of participants in the late phase, found having to be the carer was stressful and three felt they were becoming distanced from their partner. Nearly all partners of those in the late phase of Pd found their partner's *behaviour* hard to deal with. Some spoke of resentment and depression. Olive found her husband could be very difficult and demanding, wanting her company all the time and getting her to run around for him when she felt he could do things for himself. Rex found Enid's hallucinations and disordered behaviour disturbing. Her cognitive problems were most distressing to him because it meant they could not have a proper conversation.

The *fluctuations in function* were hard to understand and deal with. Phillip described how he might be woken up by Helen to take her to the toilet because she was completely unable to go alone. Then, within a short time, she would be up and down the passage on her own making herself a cup of tea. He used to wonder if she was "*having a bit of me*". Participants with partners in the late phase all spoke of being anxious and worried about their partner's health, safety, and medication.

Some participants with partners in the middle phase and all participants with partners in the late phase spoke of their own unmet needs. Some participants felt it was hard to get the sort of information they needed in order to understand how Pd was affecting their partners. For late phase partners, the need to spend twenty-four hours a day caring for their partner was very draining. They did not blame their partners for this, but rather perceived that there

was a lack of resources to allow them any time outside the caring role. Some partners of participants in the late phase discussed respite care as one solution to meeting their own need for breaks, but perceived it as an unpleasant, and therefore undesirable experience for their partners.

The marital partnership: personal strategies to restore a sense of balance reported by participants who were partners.

Partners tried to be as *understanding* as possible of what was happening to their spouse. Several described how their marriage used to be one of equal partners. Now, their partners had to rely on them and the balance had changed. They tried to see things from their partner's perspective. Rex (late phase partner of Enid) said, "*I've taken over all the housework and she's bored, and I know she's bored*". Arthur (late phase partner of Jenny) said, "*Somebody with a chronic illness - I think they become very introspective and that's understandable. You focus on ... daily miseries ...*". Some spoke of the things that had helped both of them to deal with the changes in the balance of their relationships. Olive said, "*... the support group and the exercise class was the makings of us. We would have just sat home and put up with it*". She described how her husband had insisted, right up to the end, that she continue to go to the weekly raffle night at her club. She understood and accepted that he was doing something for her by giving her a break.

Some partners in the middle to late phases identified that the sexual part of their relationship had ended, but that their *companionship* was still strong. Some, like their partners, spoke of trying to stay friends. Rex said "*I still love her very much. She's my girl. Always has been*". *Sharing* interests was mentioned by some partners as important in maintaining their relationships. Steve and Adele Dewar shared their strong interest in music, for example. Arthur (late phase husband of Jenny) summed up what he felt was needed to be a good carer: "*Emotional stability, unqualified love, empathy, and skills*".

Family relationships: personal barriers to a sense of fit perceived by participants with Parkinson's disease.

Family roles were important to a sense of fit. Lynne (early phase) was asked what was important to her about her family. She said "*Well the love. It's security. Memories, lots*

*of wonderful memories. It gives me an identity that I know who I am and ... where I came from.*” Some participants felt they had to cut back on their involvement with the family because of their disabilities, and some participants identified a deterioration in their relationships with their children since developing Pd. It appeared that family members did not always understand about Pd and could even take offence at participants’ behaviour. Three participants said their reluctance to commit to large family events where ‘escape’ could be difficult had caused problems. Michelle Coffey would not agree to attend a grandson’s wedding because it involved travelling and staying overnight away from home. Her daughter could not understand why she felt unable or unwilling to attend.

Family relationships: personal strategies to regain control of a sense of fit reported by participants with Parkinson’s disease.

Participants identified family gatherings and shared family interests as an important means of supporting a sense of social fit. As with their partners, participants with Pd were keen not to be a burden on their families. A number of them described the strategy of *educating* their families about Pd to facilitate positive family relationships. Michelle’s daughters had gone with her to a meeting of her support group and she felt that had helped their understanding. Wendy Egan obtained some booklets provided by Parkinson's Australia. She said, *“So I’ve given each one of the families one of them and I said ‘if you think your mother’s going off her brain, she’s not really’.”*

Family relationships: personal barriers to a sense of fit perceived by participants who were partners.

Partners talked about their families’ lack of understanding. Arthur described how Jenny was unable to pick up or nurse her grandchildren. He was distressed to observe that their grandchildren tended to ignore her. Both Ken (middle phase husband of Michelle) and Olive (late phase widow) felt that their children expected too much.

Family relationships: personal strategies reported to restore a sense of fit by participants who were partners.

Vince (middle phase husband of Gwen) and Steve (middle phase husband of Adele) both said that they had strong and dynamic family relationships. They felt *being mobile* and *keeping in touch* on an almost daily basis helped a great deal to maintain relationships. Their families enjoyed lots of get-togethers and outings, and Gwen and Adele were able to participate.

Ken found he had to stand up for Michelle with the rest of the family. He recounted how, on the occasion of their grandson's country wedding, his daughter had told him, "You've got to make Mum come". He said to her: "Hey, I'm the father, you're the daughter. I don't have to do anything! If your mother's O.K. we'll come. If she isn't we're stopping home". Rex found his family were very supportive emotionally, but did not really understand what he and Enid's life was like now, so their support was not viewed as practical.

Friendships: personal barriers to a sense of fit perceived by participants with Parkinson's disease.

Friendships were sometimes very strong. Yvonne was a very close friend and neighbour of Michelle and Ken. She said, "... *the thing is, my life centres around Meals on Wheels, and my family, and [Michelle] and [Ken]. Because they are my extended family*". Most participants who discussed friendship identified balance and reciprocation as an important part of the relationship. Social isolation, communication problems, loss of spontaneity, reduced community access, and a lack of understanding of the disease were all reported as factors acting to erode participants' sense of balance in their friendships. Participants found some friends dropped away and that the relationship with others changed from friendship and reciprocity, to support and caring.

Friendship: personal strategies reported by participants with Parkinson's disease to restore a sense of fit.

Friends were identified as a great source of emotional support. They were seen by most participants as non-judgemental. Caroline said, "... *and those friends give me a great*

*opportunity to just be, which is just [so] good.*” She described her friends as a lifeline to the community. She was delighted that they were still eager to be with her.

In terms of maintaining both family relationships and friendships, participants often sought to maintain a sense of *reciprocity*. Michelle’s sister-in-law was very supportive of her. In return, Michelle and Ken would take her shopping, because she lacked transport. Participants who were in late phase Pd had fewer opportunities for reciprocation and it seemed relationships had deteriorated. Enid avoided social occasions with her friends. She reminisced about how these relationships used to be, during her interviews. She appeared to prefer her memories of these friendships to the present reality, despite her friends’ ongoing support.

Friendship: personal barriers to a sense of fit perceived by participants who were partners.

Late phase partners talked the most about difficulties with friendships. Rex was no longer able to have a conversation with Enid, and he missed his social outlets. He said, “... *now I’m not getting together with my mates as often as I used to, so I’m not expressing my thoughts ... like I used to*”. He rated his role as a friend as third in importance to him.

Friendship: personal strategies to maintain/restore a sense of fit reported by participants who were partners.

Rex and Steve said whereas before their wives had maintained all their social contacts, now they were the ones who did this. Good, supportive friends were a great help. Enid no longer wanted to see their friends for meals, but Rex still occasionally arranged lunches with them, when Enid was more likely to feel up to it. In addition, they kept in touch by telephone, talking to Rex rather than Enid. Olive said her husband had two good friends who would visit him every week, and give her a little break.

Yvonne Freeman spoke passionately about her friendship with Michelle. It was clear she felt there were now many obstacles in the way of their friendship, but she worked hard to overcome them. Ken tended to be protective of Michelle, and Yvonne had resorted to popping in when she knew he was out. She felt unable to stay as long as she would like,

because Ken did not leave her for long. Other than that, she would satisfy herself with giving Michelle a wave as she passed by her window.

Relationship with health professionals: personal barriers perceived by participants with Parkinson's disease.

All participants looked to health professionals for help in managing the disease. Some participants found health professionals caused barriers through their lack of understanding. Helen Adams was being treated for depression. Her doctor advised that she should get out for at least two hours a day and forget about Pd. She said that she asked him *"How do you forget something that you've got to really plan your day upon?"*

Despite the fact that they attended Pd support groups, and that these groups ran regular educational talks from health professionals about Pd, five participants with Pd said they felt unable to access information that was pertinent to their problems. Possibly they were not able to make the links between the general nature of the information presented and their own specific problems, but they spoke of poor availability of useful information about medication and other therapy, and about strategies for dealing with common problems. Some complained that too much theory was presented.

Five participants felt that health professionals were not reliable. A number believed doctors were not sufficiently skilled to ensure they got the most out of their medication. There were a number of stories about doctors, pharmacists and nurses and errors with medication, with two participants complaining that their medication regimes were wrecked by hospital staff withholding drugs or administering them incorrectly. In one case this had led to a second hospital admission. Two participants recounted differences they had had with occupational therapists, and two participants felt that health professionals made no attempt to consider their other health problems, focusing only on the one they were being consulted about.

Relationship with health professionals: personal strategies to regain control reported by participants with Parkinson's disease.

Three participants identified the need to be assertive with health professionals. Being assertive is easier when you are well informed, so some participants tried to find out as much as they could about what was happening to them and what therapies were available to them. Some participants described the need to find the right health professional. The person needed to be someone they could talk to and who was prepared to listen. Some tried to avoid health professionals. Peter consulted a couple of counsellors (who, from what he said, did not appear to be qualified) and a naturopath. It seemed that participants distrusted the advice of health professionals and made their own decisions. Some sought out a health professional who would advise them in ways that fitted with their own attitudes and ideas.

Relationship with health professionals: personal barriers perceived by participants who were partners.

Barriers were similar to those identified by their partners with Pd.

Relationships with health professionals: personal strategies reported by participants who were partners.

Partners had learned to anticipate and be assertive with health professionals. For example, Helen had been admitted to hospital twice, and Phillip had learned to be firm with ward staff about coordinating food and medication. He brought Helen sandwiches himself, and monitored her medication, rather than relying upon the hospital to do this.

### **Summary of Theme Three**

Participants demonstrated a strong sense of social fit. This sense of fit was a major factor driving how they felt about their situation in life. They compared how they fit now with how they used to fit. For participants with Pd and for their partners, there had been changes that were mostly defined as losses. Participants with Pd identified ways in which their perceptions of themselves were now at odds with those around them. They identified significant losses in their relationships with their family, friends, and most importantly, their partner. The losses in occupational performance described in theme one, together with the

losses in sense of self outlined in theme two led to a sense of dependency by those with Pd upon their role partners, leading to a perception of imbalance that had not previously been present in their relationships.

Both participants with Pd and their partners identified coping with barriers to their sense of social fit as being important to them. They sought to restore a sense of personal control using their knowledge of how to interact socially with others. Participants with Pd in the early phase discussed the attitudes of others often. Participants in the late phase hardly mentioned this. Partners, on the other hand, spoke most about other people's attitudes when their partner was in the late phase of the disease.

In discussing strategies to cope with personal barriers to their relationships with others, partnership was a very important issue. Participants' relationships with their partners were often discussed, as were the ways in which partners without Pd could support their partner to maintain their sense of social fit. Participants with Pd in the early phase spoke most about strategies to deal with their relationships with others, while those in the late phase spoke least. Partners, again, reflected the opposite trend, with those in the late phases discussing this the most. See Table 6.3 for a summary of the sub-themes and strands of Theme Three.

<b>Theme One: The Impact of the Primary Disease Process Upon ‘Doing’ in Everyday Roles, and Strategies to Minimise the Impact</b>
<u>The impact of specific symptoms</u> <ul style="list-style-type: none"> <li>• Movement: Personal barriers and strategies to regain control</li> <li>• Medication management: Personal barriers and strategies to regain control</li> <li>• Reduced energy: Personal barriers and strategies to regain control</li> <li>• Cognitive difficulties: Personal barriers and strategies to regain control</li> <li>• Other factors: Personal barriers and strategies to regain control</li> </ul>
<u>General strategies that supported ‘doing’</u> <ul style="list-style-type: none"> <li>• Personal beliefs that maintain perceptions of control of everyday role performance</li> <li>• Personal occupational performance knowledge</li> </ul>
<b>Theme Two: Secondary Personal Limitations to Occupational Role Performance and Strategies to Regain Control</b>
<u>Sense of self as an occupational being</u> <ul style="list-style-type: none"> <li>• Definition of self as it relates to role</li> <li>• Formation and changes to sense of self as occupational being</li> <li>• Maintaining a role related sense of self</li> <li>• Expression of self through active engagement</li> <li>• Occupational role performance as a source of self expression</li> </ul>
<u>The impact of Parkinson’s disease upon sense of self as an occupational being</u> <ul style="list-style-type: none"> <li>• The emotional impact of dealing with the disease: personal barriers and strategies to regain control</li> <li>• The emotional impact of Parkinson’s disease upon a sense of being: personal barriers and strategies to regain control</li> <li>• The cumulative impact of an altered sense of self as an occupational being upon occupational role performance: personal barriers and strategies to regain control.</li> </ul>
<u>The cumulative impact of an altered sense of self as an occupational being upon occupational role performance</u> <ul style="list-style-type: none"> <li>• Who am I? An altered sense of occupational self</li> <li>• What will I become? Fears for occupational self</li> </ul>
<b>Theme Three: Secondary Social Limitations to Occupational Role Performance and Strategies to Regain Control</b>
<u>A personal sense of social fit</u> <ul style="list-style-type: none"> <li>• Definition of a personal sense of social fit</li> <li>• Maintenance of a personal sense of social fit <ul style="list-style-type: none"> <li>- What others expect of me</li> <li>- What I do to accommodate the expectations and needs of others</li> <li>- What enables me to ‘fit’ with role partners</li> </ul> </li> </ul>
<u>The impact of Pd on participants’ sense of social fit.</u> <ul style="list-style-type: none"> <li>• Barriers to social fit and strategies to regain control</li> <li>• Barriers relating to valued role relationships and strategies to regain Control <ul style="list-style-type: none"> <li>- Marital Partnership</li> <li>- Family relationships</li> <li>- Friendships</li> <li>- Relationships with health professionals</li> </ul> </li> </ul>

**Table 6.3. Theme Three. Personal barriers and strategies sub-themes and strands affecting both types of participants.**

## **6.5 Theme Four: Occupational Role Performance Limitations in Valued Roles and Strategies to Regain Control**

The final theme deals with the impact the factors described in the other three themes had upon participants' ORP. This impact can be described in terms of significant losses and fears. Most participants intimated that they were not leading the kind of life that they would prefer; in particular, they identified community access and community participation were major problems. A variety of barriers to fuller community participation were described by the participants. Nevertheless, participants actively engaged in their community environments, using a range of strategies to maintain, regain or minimise loss of control in their community related roles and routines. They spoke in ways that indicated that, when successful, they experienced a level of satisfaction that gave rise to a positive sense of personal control.

The data suggested three sub-themes:

- Perceived control and community occupational role performance
- The impact of Parkinson's disease upon community access
- The impact of Parkinson's disease upon community occupational role performance

### **6.5.1 Perceived Control and Community Occupational Role Performance**

It appeared that the level of satisfaction experienced by participants in relation to sense of self and sense of social fit informed their sense of personal control. This sense of control could be seen in relation to a sense of role mastery in ORP and pride in achievements.

The strands identified for this sub-theme are:

- ORP satisfaction and perceived control
- Control and time

### ***ORP Satisfaction and Perceived Control***

Through *active engagement* participants were able to express themselves and experience fit. This afforded a greater or lesser degree of satisfaction, which in turn contributed to the participant's general perception of control. Where satisfaction with active engagement was high, then perceptions of personal control were positive. Where satisfaction with active engagement was low, then perceptions of control were negative. In this way, active engagement in valued roles provided participants with a sense of mastery, leading to high levels of satisfaction. This strongly reinforced participants' sense of themselves. Peter Vaughan experienced an enormous boost to his sense of self in his major role as a pilot when he got back his pilot's licence. Conversely, problems with ORP in highly valued roles reduced that sense of self. Dorothy referred to her role as wife. She said, "*And personal things ... like sex and that – it's not the same, you know. You've lost your interest ... I'm a bit nervous about it. It's changed*". The imposed role of being someone with a chronic illness or their partner produced strong statements about perceptions of positive and negative personal control.

### ***Perceived Control and Time***

Time was an important element. Participants spoke of the past in order to compare it to the present. This appeared to be done to provide themselves with some gauge of how their sense of control was changing over time. The past could be a source of comfort, with participants taking pride in past mastery of roles while describing present losses. They referred to the future in relation to attempts at prediction – trying to achieve a sense of control through having some knowledge of what was ahead of them.

Partners of those with Pd in the early and middle phases of the disease process saw change as happening slowly. For those whose partners were in the late phase changes to their sense of perceived control happened rapidly. The following statements were made, one at each of three interviews, over a fourteen week period. Rex (late phase partner of Enid) said:

- 1) "*I think I'm doing a bloody good job. ... I try hard because I want [Enid] to be OK. Sometimes I might say something to her and I shouldn't have said it ... but I think I'm doing alright with her. ...*"

- 2) *“But I’m getting very testy with her lately. Very short with her when I shouldn’t be”.*
- 3) *“The bad days are getting more often ... and I just can’t see what’s going to happen in the future”.*

### **6.5.2 The Impact of Parkinson’s Disease upon Community Access**

Most participants identified community roles that had been significantly reduced or lost as a result of Pd. A major issue they identified was difficulty with community access. This led to a consequent loss of spontaneity in their daily lives. These factors led to losses in ORP in relation to valued roles and routines.

Two strands arose from within this sub-theme:

- Barriers to community access and strategies to regain control
- Barriers to being spontaneous

#### ***Barriers to community access and strategies to regain control***

Participants identified difficulty moving around their neighbourhood and out into the wider community as a serious barrier to community participation. They found their inability to drive, difficulty in walking, and fear of falling or getting ‘stuck’ while out, all acted to sap their confidence and restrict their community participation. Participants utilised a range of *resources* to help them improve their community access.

#### **Personal barriers to community access perceived by participants with Parkinson’s disease.**

Reduced mobility meant that a number of participants could not *walk* far, and needed the support of their partner to negotiate crowded uneven pavements and shopping centres. Inability to *drive* was identified by eight participants in the middle and late phases as an important barrier. They were dependent upon their partner every time they undertook any sort of community activity. Participants without a spouse were forced to use public or community services transport. Nancy (late phase, no partner) was an outgoing person, but her social interactions were largely limited to interactions with community services staff. She had recently made a new friend, and they had met for coffee a few times and discussed doing

other things together, “*But*”, she said, “*neither of us had a car, so we didn't get far did we?*”. Several participants said that because it took longer to get going and do things within the home, the time available to spend in the community was reduced.

Participants reported being fearful when in the community and therefore fearful of accessing the community. Many had a constant fear of falling. Wendy (early phase) had already had two serious falls and was nervous that she might have another. She hated people with backpacks who might bump her when they turned around. Michelle had a fear of slippery floors that was inhibiting. She had given up indoor bowls because she feared a fall. She was an active member of her local Senior Citizens Club but feared the floors there, and she dreaded slippery floors when out shopping. Some participants in the late phase of Pd reported such difficulties with walking that they felt at risk not only in the community but inside their own homes. Participants were keen to maintain their community participation, but worried that it might disappear. Caroline said, “... *I think it's called fear. Fear that if I don't handle it and ... get myself a life, then I'm not going to feel part of the community. And that must be horrible*”.

#### Personal strategies to regain control of community access reported by participants with Parkinson's disease.

Actually getting out into the community was an important issue. Participants in the early phase of Pd identified independence in driving as an important factor. Dorothy described how it offered her an escape route if she began to feel ‘off’. For participants in the middle and late phase of Pd, having a supportive partner who could drive made a huge difference.

Participants in the middle and late phases had difficulty walking independently and perhaps transferring safely when out. A partner's arm for support was very helpful. Michelle used a shopping trolley for support in the supermarket. Participants in the late phase felt having someone to provide physical assistance was crucial. Helen identified her husband Phillip as a major factor in her continued community involvement. She described how he drove her, helped her to move around (including toilet transfers) and stayed with her. She remarked that he was outgoing and popular, which helped.

Community contacts offered material support to some participants. Jenny found fellow church members very supportive and helpful. Friends provided an important reason to go out as well as the support to do so. It appeared that community access, for those in the middle phase and even more so for those in late phase, was dependent upon other people.

In order to remain socially congenial, participants with Pd were stoic about their problems, and tried not to be demanding. At the same time, a number of strategies were developed by participants to maintain contact with family and friends, including developing a routine for visits, providing information about Pd, and adjusting goals for family visits.

Living in a small, familiar community made access simpler. Michelle felt that having lived in the same neighbourhood all her married life supported her community access. She really appreciated being able to step outside her front door and just 'bump into' friends for a chat. Some participants had taken the major step of moving from their home into a retirement village. Their reasons were more complex than just managing problems related to Pd, but the new environment did offer less complex mobility demands, required less work to maintain, and offered assistance and a social life that was close to hand and therefore more accessible.

Personal barriers to community access perceived by participants who were partners for their partner, for themselves, and for both of them as couple.

Partners identified barriers to community access for their partner, arising from his or her level of function. Olive (late phase widow) identified mobility as a particular problem for her husband. In a busy shopping centre or on a pavement, people would cut in on him, throwing him off and causing him to 'freeze'. Transferring out of the car was a particular problem, and they always seemed to have a row about it. Helen needed Phillip's help to use the toilet. If it was gender assigned he could not go in. Sometimes Helen had what Phillip called 'panic attacks'. She would be unable to continue with their outing and he would have to take her home.

Partners of those in the middle and late phases of Pd described a number of barriers to their own community access that were related to their partners' Pd. Several participants said their partner was reluctant to leave home, but could not be left alone. Rex (late phase

partner) described having to do a lot of talking to persuade Enid to get in the car. Fear of their partner having a fall was an issue for some partners. Jenny (late phase) was happy to go out, but Arthur was always fearful for her.

A number of partners did leave their partner with Pd at home, but expressed uneasiness about it. Phillip did not feel able to leave Helen for more than two hours, and even then he worried while he was away. Rex said twenty minutes was about the limit for Enid as she became distressed if she could not find him. Participants discussed the option of having a friend or relative come and sit with their partner, but they believed most people did not understand what was needed. Arthur described being horrified on coming home to find Jenny carrying boiling water from the kitchen to serve tea to her ‘sitter’.

Personal strategies to regain control of community access reported by participants who were partners.

Some partners of people in the early or middle phases of Pd said they encouraged their partners to go out on their own. Una expected Frank to go out to his clubs and to go shopping on his own. Partners of those who had middle to late phase Pd recognised the need to be ready to provide a great deal of support when their partner was out in the community. Vince and Steve (middle phase partners of Gwen and Adele) said they did everything together with their partners. Arthur said: *“I want her to be involved in as much social activity as she can. Several days a week she’s involved in some meeting somewhere. I take her to and from those.”* In addition to providing physical support, partners spoke of the need to be available, ready to mount a rescue if their partner started to ‘feel bad’ while out. Some described filling in time nearby in case they were needed, while their partner was busy at the hairdresser or even having lunch with friends.

Partners spoke of their own need to get out of the house and have some sort of community participation. For those with partners were in the early phase, this was not a problem. It became more difficult for those with partners in middle phase. It was generally possible to leave them at home, but some partners needed to feel things were alright. They usually made sure that phone contact was easy and quick – for instance, by setting up the phone at home to dial the partner’s mobile number directly. They tried not to go too far away or be away too long. This tactic was not so easy for partners of participants in late phase, but

Arthur and Phillip still managed to do it occasionally. The Parkinson's support group was valued as a means of meeting others while still being with their partners. Living in a retirement village seemed to work well because it placed people right in the middle of a ready-made social community. A number of participants who were partners commented that groups and clubs provided them both with the flexibility to be together but have separate social interactions, because of the range of activities that were available.

Partners spoke of give and take. Ken felt that Michelle came to Senior Citizens with him more because he enjoyed it than because she did. At the same time, he made sure he always went with her to her Parkinson's support group because he knew it was important to her. This give and take could become unbalanced as symptoms got worse. Ken and Michelle used to love bus trips. Now Ken was concerned that Michelle tried to go because he wanted to. Rex said he 'made' Enid go out when he knew she did not want to, because it was the only way to get community necessities done, such as the shopping.

### ***Barriers to Being Spontaneous and Strategies to Regain Control***

Loss of spontaneity in community activities was an important issue. A number of participants with Pd and their partners spoke of how they missed being able to 'just do' things. This seemed to be a major source of irritation and negativity, emphasising as it did participants' loss of independence.

Having Pd, with its unpredictable fluctuation of symptoms, meant it was necessary to be infinitely flexible about doing. Paradoxically, this led to a loss of spontaneity. Going into the community represented a commitment of time and energy and necessitated placing oneself outside the security of home. Getting out of the community back home when needed could be problematic and took time. Thus, barriers to community access went beyond those presented by symptoms, to issues related to sense of self.

Seven participants spoke of having lost confidence about going into the community. They referred to their fluctuating symptoms, explaining it was usually difficult to predict what might happen when they were out. This in turn meant that participants felt more secure if they had someone they could rely on with them. Michelle said she would love to be able to

do things on her own, such as getting her hair done. She said, *“I won't say I can't do it, but I won't. I don't feel up to it. You feel you'd like someone with you”*.

The dependency on others introduced the need to fit in with another person. It meant that community activities became more planned and structured, with less opportunity for spontaneity. Partners might not want to do the same thing or might have different priorities or a different timetable for an outing. Having made plans, participants became anxious that they would not be up to it on the day. Visits to family could be very tiring - particularly when small grandchildren were present. Even when careful plans were made, there was no guarantee that they would be carried out.

By late phase all sense of spontaneity for both partners had gone. Not only each day, but each hour had to be taken as it came. If the partner with Pd was feeling up to it, then they could both be active and get things done. If not, then plans had to be dropped. The partner would be forced to stay at home too, regardless of what he or she had planned to do. Helen said, *“... that's probably the most affected part of our life together ... we just can't organise anything. ... We've tried a few times and it just doesn't work”*.

### **6.5.3 The Impact of Parkinson's Disease Upon Community Occupational Role Performance**

Reduced community access meant that participants experienced social isolation that could be quite severe. This, together with their levels of disability and requirements for care, meant that both participants with Pd and their partners experienced losses in valued roles and routines. Participants talked about strategies to maintain meaningful community involvement through the continuance of valued roles and routines.

The data suggested three strands to this sub-theme:

- Social isolation
- Loss of specific roles and routines and strategies to prevent this loss
- Loss of an occupational future

## *Social Isolation and Strategies to Overcome it*

### Personal barriers to social connectedness perceived by participants with Parkinson's disease and their partners.

The majority of participants indicated they did not see as much of their families, friends and others as they would like. A number of reasons were identified for this.

An important barrier for four participants seemed to be the *fear of making a social commitment* and then not being up to it on the day. Three partners identified this reluctance to commit as an important reason for their social isolation as a couple. Five participants identified *communication* as a problem. Jenny (late phase) had major problems with the volume and sustainability of her speech. She found it hard to converse socially. She said, "... *it's very limiting. I find that I speak in a group of people and nobody hears me. And so then you ... drop out of the conversation*". Four participants found using the telephone difficult. Adele used to keep in touch with family and friends by letter, but her handwriting was becoming illegible.

In common with many people in today's highly mobile society, most participants had family and friends who lived at a geographical *distance*. Enid (late phase) and Michelle (middle phase) both identified being *unable to travel* as limiting to family contact. Participants feared being seen as a *burden* by others, making them more circumspect about making contacts. Dorothy (early phase) had been a champion lawn bowler. She expressed frustration at no longer being able to play competitively. She said, "*I'd love to compete more but I can't. ... I just feel I could let them down ... it might be too much, you know?*"

### Personal strategies to promote social connectedness reported by participants with Parkinson's disease and their partners.

The maintenance of social connectedness in ways that remained personally meaningful was identified by all participants as very important to their continued well-being. Dorothy said, "... *if you've had a good day out somewhere ... you come home sort of more motivated*". Caroline described an incident at her bridge club, where no-one knew she had Pd: "... *and when I arrived yesterday, one of the other ladies was waiting in the hallway,*

saying 'I waited to go in because I wondered if you'd be happy to play with me'. It was lovely”.

Participants endeavoured to remain in control of their community participation by seeking to increase the predictability of what might happen. *Simplifying* community involvement without losing the meaning was the aim of most participants, and their cognitive skills were very important in being able to achieve this effectively. Participants used their knowledge and experience to save energy. They manipulated their medication so that they would be under optimal control during community outings. Setting up a regular *routine* was helpful. They *planned* ahead. Importantly, they planned escape routes when they entered the community so they could bale out if necessary. Participants worked hard to maintain personal goals and modify them as needed in ways that retained the meaning attached to them.

Having a sense of contribution to the community was an important factor in maintaining meaningful community involvement. Adele described a daily life in which both she and her husband were totally absorbed in each other's affairs. He was the president of their local Parkinson's Australia support group and she was the treasurer. He was a singer and she helped him to practice and to rehearse performances. He was always available to provide assistance should she need it, but then so was she. She felt good about helping out with her husbands' rehearsals. She said, “... *and because I'm used to doing it ... I think they [the company] like me to be there*”.

### ***Loss of Specific Roles and Routines and Strategies to Prevent Loss***

Personal barriers to specific occupational roles and role related routines perceived by participants with Parkinson's disease.

Loss of important *roles* led to the loss of a *sense of purpose* and could lead to further social isolation. A number of participants had given up or experienced loss in occupational roles that were important to them. Other losses identified were a loss of *independence*, leading to loss of *choice*. For some participants time dragged and it seemed that life lacked *meaning*. Thus loss of ORP led to losses related to sense of self and sense of social fit.

Participants experienced loss of *choice* and hence a *sense of purpose*. They spoke of having to re-adjust their goals and expectations of community involvement. Caroline (early phase) described her idea of a good day:

*“I would prefer to be working a few hours in an office and being of some use to something there and then coming home and doing the shopping, preparing meals and talking to a couple of friends and reading some book. That would be a good day.”*

Just before being diagnosed with Pd, she had started a computer course, in preparation for going back to part-time work. She said, *“I’m not doing the computer course any more. I’m not able to continue with that ...”*.

The need to manage the illness ate up precious time. Helen said, *“Retirement’s when you just get up and go, and we just can’t, because we’ve got doctor’s appointments”*. Nancy said: *“The time’s limited you know, and I spend a lot of time sitting up at the pharmacist waiting for my tablets ...”*. The progression of Pd in the late phase resulted in serious losses of social interaction for both partners.

Some participants felt limited by their partners. They felt they had lost control of community access. Jenny (late phase), said, *“... I’m not allowed to go out on my own - my husband won’t let me”*. The loss of *independence* inhibited community activity.

A major issue for both participants with Pd and their partners was the loss of *holidays*. Even in the early phase, holidays were difficult. Dorothy (early phase) was planning to go with her husband and a group of others to Central Australia, travelling by bus and plane. She was concerned about whether she would be able to keep up with the others. She said:

*“It worries me because I used to be in everything ... Now I find I’m thinking of myself a bit. I think, will I be able to cope ... and if it’s a late night I get concerned ... because I need my sleep.”*

Personal strategies to restore access to specific occupational roles and role related routines reported by participants with Parkinson's disease.

An ongoing process of goal setting and re-setting was employed by most participants in order to maintain role continuity. Wendy Egan has cut down the frequency of the visits of her large family. When they do come around for Sunday dinner she chooses something simple to cook.

Taking holidays required extensive planning. Dorothy had set in place two important strategies for her trip to Central Australia. One was to go in a group that already had another disabled person in it, so that they could support each other and together have a higher profile if needed. The other was to avoid parts of the trip if necessary. She said, "*I think I'll be alright. ... Well, if it's too tiring I can just sit in the bus*".

A number of participants spoke of task *simplification*, using knowledge and experience rather than energy or physical performance. Wendy still baby-sat her grandchildren occasionally. She used her experience with children, rather than her energy, to manage them. She said, "*I enjoy the grandkids. But they've got to behave themselves when they come here*".

Participants chose community activities that used their brains rather than their energy. The local church answered important needs for a number of participants. Bridge was popular. So were discussion groups. Gwen said of her Probis club, "*... I go there for the talks. It keeps your mind open. I go to see the people, but I look forward to the talk*".

The majority of participants described a set weekly *routine* for community participation. This regularity meant participants kept in touch with their community roles and role partners. Several participants described a busy routine that involved a range of fixed community commitments that happened nearly every day of the week. At the time of interview, Steve and Adele had their time packed with regular appointments. They entertained or went out to friends twice a week; they attended church twice a week; they attended regular meetings of their Parkinson's support group, a social club and a charity they supported; and they participated in nearly all the activities that were organised by their retirement village, such as bus trips, concerts and dinners. Gwen had taken the initiative and

established a social structure that brought the community to her. She and her husband ran a discussion group in their own home on Tuesdays, had a video night for fellow retirement village residents on Wednesdays, and had two friends for dinner every Friday. Jenny's community routines by necessity revolved more around her role as a patient. She had to attend her GP, neurologist, speech pathologist and surgeon regularly for ongoing care and she attended monthly Parkinson's support group meetings.

Personal barriers to specific occupational roles and role related routines perceived by participants who were partners.

Some participants with Pd in the middle phase and all those in the late phase left home as little as possible. Partners regretted this and some were puzzled about why this was so. Rex said, *"We bought the caravan to go away in ... And Enid ... won't go in it. ... I think she could but she won't"*. Arthur said, *"There's this honeymoon period before you become too immobile ... we missed that period ... we feel cheated about that"*.

Partners had been accustomed to doing things on their own – even if it was just popping out to see a friend or do some shopping. For example, Ken (middle phase partner) liked to go fishing, play golf and visit the local Senior Citizens Club to play billiards. Now barriers to the community ORP of participants with Pd meant that their partners had to deal with losses in their own lives. Most partners of those in the middle and late phases of Pd had lost valued ORP opportunities because of their reluctance to leave their partner. Partners of those in the late phase felt unable to pursue their own interests at all. Because caring was by now a twenty-four hour a day job, everything else had to take second place.

Arthur had been very active in the community. He listed the roles he had lost: Probis Club member, Bowling club member, Bush walking club member, Liberal Party member, student of University of the Third Age, and Choir member. Instead, he now worked hard trying to help Jenny maintain her community roles by enabling access for her and he found this wearing. He felt unable to leave Jenny because of her serious history of falls. He said *"... and so I don't really have any activity outside the house ... it's had a severe impact on me"*. Similarly Phillip said, *"I don't do anything in the community"*.

Even activities done at home had become harder. Arthur was keen to complete the family history he had started, but could not find the time for it. Olive loved to cook and write letters to friends, but she said her husband was constantly calling her and interrupting what she was doing. Helen Adams went to bed very early and Phillip found he could not play his organ, listen to music or watch television after that time because it disturbed her.

Personal strategies to regain access to specific occupational roles and role related routines reported by participants who were partners.

Partners used detailed planning to try to ensure that a community outing would be a success for their partner, and therefore, for themselves. Such details as medication, time of day, and how much talking would be involved were all mentioned by various partners. The physical characteristics of the environment were considered. Knowing if there was a unisex public toilet where they were going were important to Phillip and Rex, because they needed to be able to help their wives. Some partners needed to know if there were lifts, because their partners found escalators and stairs difficult. They planned short outings rather long ones, so their partner would hopefully last the distance. At the same time, they spoke of the need to be totally flexible and change or abandon carefully laid plans at any moment, depending upon how their partner felt.

Partners tried to maintain their own community roles, although those whose partners were in the late phase of Pd had largely abandoned them. Ken still went fishing occasionally, relying on Yvonne to sit with Michelle while he was gone. He was the only partner who had someone he was able to rely on in this way.

***Loss of an Occupational Future***

Participants feared a bleak future, with increasing losses of the parts of their life that were most important and meaningful to them. Participants with Pd did not discuss strategies to directly control future ORP. Several talked about the importance of living in the moment and enjoying what you had. Some talked of the need for an acceptance of what you could not change.

Some partners of those who were in the middle and late phases expressed fears for the future of their life together. Una Lewis feared that her husband's cognitive function might deteriorate. He had always been the brains of the partnership and she feared she would be unable to manage money matters herself. She believed that if they failed to survive together as a couple she might end up in a nursing home, and this was something she wished to avoid at all costs. Partners of those in the late phase all spoke of their great fears of what lay ahead – they worried particularly about getting sick themselves. Phillip agreed with his wife when he said, *“There's not a lot of future”*.

Some late phase partners had considered the future in detail. Rex had a particular problem because he needed to have a hip replacement. He felt the only solution would be for Enid to go into respite care. Although their children had offered to look after her, he felt they just did not comprehend what was involved, and that it would be too much for them. This discussion extended into one about permanent placement. He felt the ideal would be if they could both be together, and he was thinking of buying a retirement unit somewhere with a nursing home section, so that the transition would be more gentle for Enid when it came. Rex said that sensing that his caring was finite, and likely to end soon, made it easier for him to keep going. He said:

*“I think in the future that maybe Enid will have to be put in a home ... I'd rather be in a home with her than be a free person on my own... But ... I probably won't be able to look after her as I get older.”*

### **Summary of Theme Four**

Participants tended to be anxious about their community participation, but valued it highly and feared they might lose it. Participants with Pd who were at all phases of the disease process found access to the community difficult because of their mobility problems, fluctuating symptoms and low energy levels. Some participants feared going out into the community in case they had a fall, or in case they had a sudden worsening of their symptoms with a consequent need to get home immediately. Most partners of those in the middle and late phases were limited either by their partner's reluctance to go out, their own unwillingness to leave their partner at home, or their fear that their partner might have a fall.

These fears meant that participants felt the need to plan and organise each excursion into the community carefully, leading to a loss of spontaneity, independence and confidence.

The majority of participants felt socially isolated as a result. Both participants with Pd and their partners described a range of specific roles and routines that they had lost. Their discussion of strategies related to this theme centred around community access and coping with barriers to specific ORP.

Strategies relating to access to the community addressed both physical and social access. Fluctuating function was a major barrier to community participation, and a range of strategies addressed this problem. Participants in different phases of Pd discussed strategies for community access in equal proportions, with no particular trend discernable. However, they discussed physical access more frequently than social access. Partners of participants in middle and late phases appeared to discuss community access equally, but no partners of participants in early phase did so. Partners discussed both physical and social access strategies equally. Please see Table 6.4 for a summary of the sub-themes and strands of theme four.

<b>Theme One: The Impact of the Primary Disease Process Upon ‘Doing’ in Everyday Roles, and Strategies to it</b>
<u>The impact of specific symptoms</u> <ul style="list-style-type: none"> <li>• Movement: Personal barriers and strategies to regain control</li> <li>• Medication management: Personal barriers and strategies to regain control</li> <li>• Reduced energy: Personal barriers and strategies to regain control</li> <li>• Cognitive difficulties: Personal barriers and strategies to regain control</li> <li>• Other factors: Personal barriers and strategies to regain control</li> </ul>
<u>General strategies that supported ‘doing’</u> <ul style="list-style-type: none"> <li>• Personal beliefs that maintain perceptions of control of everyday role performance</li> <li>• Personal occupational performance knowledge</li> </ul>
<b>Theme Two: Secondary Personal Limitations to Occupational Role Performance and Strategies to Regain Control</b>
<u>Sense of self as an occupational being</u> <ul style="list-style-type: none"> <li>• Definition of self as it relates to role</li> <li>• Formation and changes to sense of self as occupational being</li> <li>• Maintaining a role related sense of self</li> <li>• Expression of self through active engagement</li> <li>• Occupational role performance as a source of self expression</li> </ul>
<u>The impact of Parkinson’s disease upon sense of self as an occupational being</u> <ul style="list-style-type: none"> <li>• The emotional impact of dealing with the disease: personal barriers and strategies to regain control</li> <li>• The emotional impact of Parkinson’s disease upon a sense of being: barriers and strategies to regain control</li> <li>• The cumulative impact of an altered sense of self as an occupational being upon occupational role performance: personal barriers and strategies to regain control.</li> </ul>
<u>The cumulative impact of an altered sense of self as an occupational being upon occupational role performance</u> <ul style="list-style-type: none"> <li>• Who am I? An altered sense of occupational self</li> <li>• What will I become? Fears for occupational self</li> </ul>
<b>Theme Three: Secondary Social Limitations to Occupational Role Performance and Strategies to Regain Control</b>
<u>A personal sense of social fit</u> <ul style="list-style-type: none"> <li>• Definition of a personal sense of social fit</li> <li>• Maintenance of a personal sense of social fit <ul style="list-style-type: none"> <li>- What others expect of me</li> <li>- What I do to accommodate the expectations and needs of others</li> <li>- What enables me to ‘fit’ with role partners</li> </ul> </li> </ul>
<u>The impact of Pd on participants’ sense of social fit.</u> <ul style="list-style-type: none"> <li>• Barriers to social fit and strategies to regain control</li> <li>• Barriers relating to valued role relationships and strategies to regain Control <ul style="list-style-type: none"> <li>- Marital Partnership</li> <li>- Family relationships</li> <li>- Friendships</li> <li>- Relationships with health professionals</li> </ul> </li> </ul>
<b>Theme Four: ORP Limitations in Valued Roles and Strategies to Regain Control</b>
Perceived control and community occupational role performance <ul style="list-style-type: none"> <li>• Occupational role performance satisfaction and perceived control</li> <li>• Perceived control and time</li> </ul>
Impact of Parkinson’s disease upon community access <ul style="list-style-type: none"> <li>• Barriers to community access and strategies to overcome it</li> <li>• Barriers to being spontaneous and strategies to regain control</li> </ul>
The impact of Parkinson’s disease upon community occupational role performance <ul style="list-style-type: none"> <li>• Social isolation and strategies to overcome it</li> <li>• Loss of specific roles and routines and strategies to prevent loss</li> <li>• Loss of an occupational future</li> </ul>

**Table 6.4 Theme Four. Personal barriers and strategies sub-themes and strands affecting both types of participants**

## **6.6 Primary and Secondary Control**

Across all four major themes it appeared evident from the data that participants were experiencing varying levels of control in their everyday occupational performance that could be related to their perceptions of personal barriers. Participants sought to regain control through the strategies they employed. Some participants appeared to have a stronger desire for control than others. Participants' desire for control appeared to vary from role to role according to how important it was to them, and the or how appropriate they felt it was to want to take control.

### **6.6.1 Primary Control**

A consideration of the strategies identified showed that participants strived to achieve direct, or *primary*, control of their role specific environments. Medication provided a major means of achieving this type of control for participants in early and middle phase. Taking medication management as an example, both Peter Vaughan and Bruce Jones went to great lengths to take primary control. They informed themselves as much as possible and made their own decisions about medication management. By contrast, Michelle Coffey did not appear to know much about her medication. She said she had never once missed taking it on time and had no idea what might happen if she did. Even so, she had recently started taking an extra tablet without seeking medical approval. Participants discussed a wide range of strategies that could be seen as seeking to achieve primary control. Tables 6.5, 6.6 and 6.7 give examples of primary control identified from the data for participants with Pd working alone, partners working alone and for couples working together.

**Table 6.5 Examples of primary control strategies that were employed by participants with Pd**

- Ignoring the attitudes and expectations of role partners in order to do what appeared best for self
- Improving personal knowledge of the disease
- Napping and going to bed early
- Being persistent
- When problem solving, slowing down, keeping calm, concentrating, allocating extra time
- Drawing attention of others towards positive attributes and hence away from overt Pd symptoms
- Deflecting the negative attention of others from symptoms
- Problem solving
- Using aides memoire
- Trying to protect partner and others from impact of disease

**Table 6.6 Examples of primary control strategies that were employed by partners of participants with Pd (particularly late phase partners)**

- Providing partner with physical assistance
- Insisting that your partner does as you say: “She’s not allowed to ...”
- Protecting partner from negative attitudes of others
- Problem solving
- Watching partner to prevent accidents
- Taking over routines and tasks that are problematic
- Maintaining relationships with family and friends

**Table 6.7 Examples of primary control strategies that were employed by both partners working together**

- Managing medication
- Planning
- Priority setting
- Utilising knowledge
- Timing specific routines and tasks to fit with medication regime
- Modifying the environment
- Being assertive
- Utilising resources
- Utilising routine
- Modifying the task
- Educating family and friends about Pd
- Sharing routines with partner

### 6.6.2 Secondary Control

Participants described a number of behaviours and attitudes that related to control, but were not about changing the environment, but rather, about changing themselves. They were trying to achieve *secondary* control. A number of participants commented that they accepted occupational performance standards for themselves now that they would not have found acceptable earlier. Participants also described slowing down the pace of life in order to do less. In the short term, being flexible in everyday goals was considered very important, particularly by partners who sought windows of opportunity in order to carry out important occupational performance.

A large number of strategies were identified in relation to controlling feelings. Some participants described trying to adjust their sense of self downwards in relation to specific roles, but found it hard. For example, Dorothy and Una had both been top lawn bowlers and found it hard to accept they could no longer play at that level. Others seemed to have achieved acceptance, but were aware they were less than they had been.

Una and Enid fostered a positive view of themselves in the past. Enid loved to reminisce. Some participants with Pd tried to maintain a positive view of themselves by talking of how they were better off than other people with Pd. They sprinkled their conversation with phrases such as “*there are others worse off than me*”, “*at least I don’t have that problem*”. Tables 6.8, 6.9 and 6.10 give examples from the data of secondary control for participants with Pd working alone and partners working alone, and couples working together.

**Table 6.8 Examples of secondary control strategies that were employed by participants with Pd**

- Avoided or distanced themselves from people or things they could no longer deal with
- Stopped worrying about other people's responses to their Pd
- Learned to live with pain
- Adjusted personal expectations e.g. they gave themselves permission not to do things "I don't have to ..."
- Did what made them feel good (e.g. Peter Vaughan regaining his pilot's licence)
- Maintained a sense of purpose in life

**Table 6.9 Examples of secondary control strategies that were employed by partners of participants with Pd**

- Practiced denial
- Respected their partner
- Accepted loss
- Adapted their community participation to joint activities
- Were understanding of partner
- Learned new ways to relate to their partner

**Table 6.10 Examples of secondary control strategies that were employed by both partners together**

- Displayed a stoic attitude
- Gave self credit for doing a personally meaningful task well
- Tried to maintain a sense of purpose
- Hoped their disease progression would be better than others
- Valued companionship of partner
- Set up an escape route when out in the community
- Lived in the present
- Practiced positive reappraisal (acceptance of change)
- Tried to make a social contribution
- Used humour to cope with problems
- Shared interests with partner
- Maintained general health (e.g. try to eat well)

## CHAPTER SUMMARY

In this chapter, the personal barriers identified by participants with Pd and their partners have been described. Four basic themes emerged from the data. The order of these themes is significant as they have a cumulative effect.

The first related to the impact of disease processes on *doing*. The participants' Pd produced difficulties in movement control, which led to problems with walking, and a wide range of fine motor tasks such as writing, dressing, and talking. Participants described a range of secondary symptoms such as low energy, cognitive difficulties, pain, and insomnia. These functional difficulties meant that partners became increasingly involved in providing assistance to their partner with Pd as the disease progressed.

The second theme related to the secondary personal limitations produced by these changes. Participants in this study demonstrated a clear, resilient sense of self identity. Interactions with their personal environments served to inform, reinforce or challenge that sense of self. Some participants in the middle and late phases of Pd appeared to have lost confidence in their own ability to do things. Their sense of themselves was threatened by their changing abilities. Participants had experienced or were experiencing a loss of personal control in relation to various aspects of their everyday lives. Partners of participants in the late phase of Pd expressed similar losses of control, due to the hugely demanding nature of their relationship. Pd had taken over their lives.

The third theme related to the social impact participants experienced as a result of the losses of themes one and two, and to the attitudes they perceived others had towards them. They demonstrated a strong sense of social fit, but with the progression of the disease their sense of social fit tended to deteriorate. Participants with Pd made negative comparisons between their perceptions of social fit in the past and at the time of the interview. Some identified significant losses in their most important and valued relationships. The partners of those in the late phase of Pd described how the relationship had changed and all spoke of feeling distanced from their partner in various ways.

These three themes combined to produce the final theme - the consequential barriers to ORP. Primary Pd symptoms made access to the community difficult. Fluctuating

symptoms meant that participants could never tell when they or their partner would become ill or 'off' and need to retreat back home. Fear of falls added to the problems. These difficulties meant that participants experienced challenges to their sense of self and lost confidence in their ability to successfully negotiate their community. This in turn reduced their ability to fully participate in the roles and routines they found personally significant. Participants with Pd in the middle and late phases and their partners described a wide range of role losses.

Whilst these four themes are clear, findings were very diverse, indicating complexity. Personal barriers were often individualistic, because they were the product of the symptom and the individual. Each participant in this study was unique and reacted uniquely to each barrier. It became evident from the data that the secondary psychological and social impacts of the disease were more significant than the symptoms themselves. Sense of self and social fit were highly significant factors in participant's perceptions of the impact of Pd.

There was no direct link between the phase of the disease process and its impact upon the individual. The impact of Pd was mediated significantly from one individual to another. The manifestation of a particular symptom could have a major impact upon one participant and only minor effects upon another. Personal barriers were not always clear cut. One barrier might have a very specific impact, but more often the barrier impacted upon an individual in a variety of ways and at a variety of levels.

Because partners' sense of self and sense of fit had not been eroded in the same way as for participants with Pd, the severity of the barriers they described were generally less. However, for partners of participants with late phase Pd, their level of community participation was severely curtailed and their ORP was largely reduced to the role of carer.

Over time, the barriers gradually caused a wider and wider gap to develop between the individual's progress through life as it might have been without Pd and how it was now with Pd. It appeared that personal barriers had the largest impact when they affected role performance in major roles because it was then that they impacted most strongly upon personal meaning in terms of sense of self and social fit.

The chapter outlined a wide range of strategies relating to the barriers described. Looking across the themes, a number of trends are apparent. The disease appeared mediated by the individual. Participants were not passive recipients of impacts. They all tried to deal with what was happening to them. They were highly individualistic in the way they did this. The *strategies* they employed to soften or deflect the impact of the disease varied widely. Roles that provided an avenue for self expression, providing a sense of self and/or a sense of social fit were generally highly valued.

Participants attempted to maintain control of their lives. It was clear from what participants said that direct control was their aim. The type of control achieved by participants varied according to the stage of the disease process. Participants with Pd appeared able to achieve direct or primary control more frequently in the early to middle stages of the disease than in the middle to late stages. Participants in the late stage appeared to feel they had little control over their ORP. Nevertheless, genuine acceptance of loss seemed to be a form of control.

Generally speaking, partners of those with Pd were not concerned with control issues in the early stage of the disease, supported and worked together with their partner to mitigate problems in the middle stage, and exerted considerable control over their partner in the late stage. At the same time, partners of participants in the late stage of Pd felt they had little control over how they spent their time. Their ORP was limited to the role of carer.

Throughout the data, couples talked of the ways they worked together as a team to achieve their goals. This strategy of teamwork was successful in the early and middle phases of Pd, but was disrupted in the late phase by the severity of symptoms. Teamwork was an important way of maintaining both primary and secondary control. Primary and secondary control strategies were practiced by both partners both as a team and separately. Table 6.11 presents a summary of findings of Chapter Six: Personal Barriers To Occupational Role Performance And Personal Strategies Employed To Enhance Occupational Role Performance. The following chapter extends the findings by further discussing the findings and conceptualising them as a possible dynamic model of control that reflects the barriers and strategies experienced by the participants in the study.

<b>Theme One: The Impact of the Primary Disease Process Upon ‘Doing’ in Everyday Roles, and Strategies to Regain Control</b>
<u>The impact of specific symptoms</u> <ul style="list-style-type: none"> <li>• Movement: Personal barriers and strategies to regain control</li> <li>• Medication management: Personal barriers and strategies to regain control</li> <li>• Reduced energy: Personal barriers and strategies to regain control</li> <li>• Cognitive difficulties: Personal barriers and strategies to regain control</li> <li>• Other factors: Personal barriers and strategies to regain control</li> </ul>
<u>General strategies that supported ‘doing’</u> <ul style="list-style-type: none"> <li>• Personal beliefs that maintain perceptions of control of everyday role performance</li> <li>• Personal occupational performance knowledge</li> </ul>
<b>Theme Two: Secondary Personal Limitations to ORP and Strategies to Regain Control</b>
<u>Sense of self as an occupational being</u> <ul style="list-style-type: none"> <li>• Definition of self as it relates to role</li> <li>• Formation and changes to sense of self as occupational being</li> <li>• Maintaining a role related sense of self</li> <li>• Expression of self through active engagement</li> <li>• Occupational role performance as a source of self expression</li> </ul>
<u>The impact of Parkinson’s disease upon sense of self as an occupational being</u> <ul style="list-style-type: none"> <li>• The emotional impact of dealing with the disease: personal barriers and strategies to regain control</li> <li>• The emotional impact of Parkinson’s disease upon a sense of being:: barriers and strategies to regain control</li> <li>• The cumulative impact of an altered sense of self as an occupational being upon occupational role performance: personal barriers and strategies to regain control.</li> </ul>
<u>The cumulative impact of an altered sense of self as an occupational being upon occupational role performance</u> <ul style="list-style-type: none"> <li>• Who am I? An altered sense of occupational self</li> <li>• What will I become? Fears for occupational self</li> </ul>
<b>Theme Three: Secondary Social Limitations to ORP and Strategies to Regain Control</b>
<u>A personal sense of social fit</u> <ul style="list-style-type: none"> <li>• Definition of a personal sense of social fit</li> <li>• Maintenance of a personal sense of social fit <ul style="list-style-type: none"> <li>- What others expect of me</li> <li>- What I do to accommodate the expectations and needs of others</li> <li>- What enables me to ‘fit’ with role partners</li> </ul> </li> </ul>
<u>The impact of Pd on participants’ sense of social fit.</u> <ul style="list-style-type: none"> <li>• Barriers to social fit and strategies to regain control</li> <li>• Barriers relating to valued role relationships and strategies to regain Control <ul style="list-style-type: none"> <li>- Marital Partnership</li> <li>- Family relationships</li> <li>- Friendships</li> <li>- Relationships with health professionals</li> </ul> </li> </ul>
<b>Theme Four: ORP Limitations in Valued Roles and Strategies to Regain Control</b>
Perceived control and community occupational role performance <ul style="list-style-type: none"> <li>• Occupational role performance satisfaction and perceived control</li> <li>• Perceived control and time</li> </ul>
Impact of Parkinson’s disease upon community access <ul style="list-style-type: none"> <li>• Barriers to community access and strategies to overcome it</li> <li>• Barriers to being spontaneous and strategies to regain control</li> </ul>
The impact of Parkinson’s disease upon community occupational role performance <ul style="list-style-type: none"> <li>• Social isolation and strategies to overcome it</li> <li>• Loss of specific roles and routines and strategies to prevent loss</li> <li>• Loss of an occupational future</li> </ul>

**Table 6.11 Summary of the findings showing each theme, sub-theme and strand**