

## **APPENDIX 5.17**

# **DETAILED TABLES OF BARRIERS AND STRATEGIES IDENTIFIED BY PARTICIPANTS**

# PARTICIPANTS WITH PARKINSON'S DISEASE

## BARRIERS

### Theme 1: The impact of the primary disease process upon the person's ability to physically 'do'

#### Movement

##### Upper and lower limb movement control problems

- Balance problems LG[1], WE[1], FL[2], MC[2], EI[3]
- Tremor PV[1], WE[1], FL[2], EI[3]
- Falls WE[1], AD[2], JM[3]
- Abnormal gait pattern PV[1], BJ[2]
- Parkinson's disease affecting dominant upper limb PV1, MC2, AD2, FL2
- Slowness of movement LG[1], FL[2], MC[2], EI[3]
- Rigidity PV[1], BJ[2], FL2, EI[3]
- Unspecified problems GW[2], FP[3], HA[3]
- Clumsiness MC[2], EI[3]

##### Oro-facial and breathing control problems

- Soft, receding voice PV[1], LG[1], FL[2], EI[3], JM[3]
- Dribbling EI[3]
- Rigidity PV[1], BJ[2], FL[2]
- Swallowing difficulty FL[2]

##### Difficulty with specific routines

- Difficulty with fine motor tasks LG[1], PV[1], BJ[2], MC[2], EI[3]
- Dressing WE<sup>1</sup>, FL<sup>2</sup>, EI<sup>3</sup>
- Maintaining a conversation EI<sup>3</sup>, JM<sup>3</sup>
- Hand sewing WE<sup>1</sup>
- Writing PV[1], AD[2], FL[2], MC[2], EI[3]
- Piano playing AD<sup>2</sup>
- Talking on the phone EI<sup>3</sup>, JM<sup>3</sup>
- Dressmaking WE<sup>1</sup>

#### Medication Management

Participants reported a number of issues related to their medication that presented barriers to occupational performance.

- Side effects: depression or increased tremor CH<sup>1</sup>, nausea LG<sup>1</sup>; dizziness LG<sup>1</sup>, MC<sup>2</sup>; hallucinations EI<sup>3</sup>
- Effectiveness of medication is reducing LG<sup>1</sup>, MC<sup>2</sup>, EI<sup>3</sup>
- Accidental overdose HA<sup>3</sup>
- Spending a lot of precious community time at pharmacy NP<sup>3</sup>
- Allergy to medication HA<sup>3</sup>
- Medication requires finer adjustment than is offered by doctors LG<sup>1</sup>, PV<sup>1</sup>, BJ<sup>2</sup>, FL<sup>2</sup>
- Perceived need to reduce medication PV<sup>1</sup>, BJ<sup>2</sup>
- Allergy to medication HA<sup>3</sup>
- Fear, ignorance of what might happen if miss a dose MC<sup>2</sup>
- Accidental overdose HA<sup>3</sup>

## Reduced Energy

Participants reported low energy levels described as:

- 'Feeling buggered' or 'old, feeble and shaky' LG<sup>1</sup>, WE<sup>1</sup>, FL<sup>2</sup>, MC<sup>2</sup>, EI<sup>3</sup>, HA<sup>3</sup>,
- Slowness WE<sup>1</sup>
- Not able to do as much as you would like DB<sup>1</sup>, LG<sup>1</sup>, WE<sup>1</sup>, MC<sup>2</sup>, EI<sup>3</sup>
- Feeling of heaviness DB<sup>1</sup>

They reported these feelings were exacerbated by:

- Insomnia LG<sup>1</sup>, PV<sup>1</sup>, EI<sup>3</sup>
- Shortness of breath LG<sup>1</sup>
- Pain LG<sup>1</sup>, EI<sup>3</sup>
- Depression HA<sup>3</sup>

And resulted in:

- Reduced community access MC<sup>2</sup>, NP<sup>3</sup>, EI<sup>3</sup>,
- Difficulties with household tasks WE<sup>1</sup>
- Anxiety WE<sup>1</sup>
- Difficulty travelling MC<sup>2</sup>, EI<sup>3</sup>
- Difficulty playing bowls FL<sup>2</sup>

## Cognition

Participants reported difficulties with cognitive function:

- Conscious of deficiency DB<sup>1</sup>, WE<sup>1</sup>, BJ<sup>2</sup>, MC<sup>2</sup>, EI<sup>3</sup>
- Difficulty moving between thoughts WE<sup>1</sup>, BJ<sup>2</sup>, EI<sup>3</sup>
- Loss of focus PV<sup>1</sup>, WE<sup>1</sup>, BJ<sup>2</sup>
- Interruption of thought EI<sup>3</sup>
- Hallucinations EI<sup>3</sup>
- Memory WE<sup>1</sup>, BJ<sup>2</sup>, EI<sup>3</sup>, JM<sup>3</sup>,
- Slowed reaction time PV<sup>1</sup>, MC<sup>2</sup>
- Loss of concentration DB<sup>1</sup>, FL<sup>2</sup>
- Confusion EI<sup>3</sup>

Resulting in difficulty with tasks such as:

- Problem solving DB<sup>1</sup>, FL<sup>2</sup>
- Cooking WE<sup>1</sup>
- Dressmaking DB<sup>1</sup>
- Holding a conversation EI<sup>3</sup>, JM<sup>3</sup>,

## Other Factors

### Problems with doing associated with Parkinson's disease

#### Pain

- Pain arising from reduced movement on affected side LG<sup>1</sup>, PV<sup>1</sup>, EI<sup>3</sup>
- Cramps in legs and feet MC<sup>2</sup>
- Low back pain BJ<sup>2</sup>

#### Sleep disturbance

- Pain wakes up (cramps, shoulder pain) LG<sup>1</sup>, PV<sup>1</sup>, MC<sup>2</sup>, EI<sup>3</sup>
- Insomnia PV<sup>1</sup>, BJ<sup>2</sup>, HA<sup>3</sup>,
- Tremor wakes up LG<sup>1</sup>, EI<sup>3</sup>

#### Nausea

- limits travel MC<sup>2</sup>, EI<sup>3</sup>

#### Other

- Feeling 'bad' LG<sup>1</sup>, BJ<sup>2</sup>, MC<sup>2</sup>, EI<sup>3</sup>
- Depression DB<sup>1</sup>, HA<sup>3</sup>,
- Labile BJ<sup>2</sup>, MC<sup>2</sup>, EI<sup>3</sup>
- Reduced vision resulting from past fall AD<sup>2</sup>
- Sensitive to noise EI<sup>3</sup>
- Dry mouth FL<sup>2</sup>
- Painful neck resulting from past falls JM<sup>3</sup>,
- Tactile hypersensitivity HA<sup>3</sup>
- Incontinence GW<sup>2</sup>

### Interaction with Other Health Issues

Participants reported a range of other health problems that interacted with their Parkinson's disease:

- Cardiovascular disease LG<sup>1</sup>, FL<sup>2</sup>, HA<sup>3</sup>,
- Low back pain BJ<sup>2</sup>
- Depression pre-dating PD diagnosis CH<sup>1</sup>
- Asthma WE<sup>1</sup>
- Arthritis MC<sup>2</sup>
- Reduced night vision FL<sup>2</sup>
- Confusion between what is normal ageing and what is PD WE<sup>1</sup>

## THEME 2: Secondary personal limitations

### Dealing with the Disease - How do I do this?

#### The daily impact

Participants found the following difficult to deal with:

- Unpredictability of primary symptoms LG<sup>1</sup>, BJ<sup>2</sup>, EI<sup>3</sup>, JM<sup>3</sup>
- Cumulative effect of multiple health problems LG<sup>1</sup>, BJ<sup>2</sup>, FL<sup>2</sup>, MC<sup>2</sup>
- Difficulty with time management LG<sup>1</sup>, BJ<sup>2</sup>
- Strategies that were successful no longer work HA<sup>3</sup>
- Poor understanding of disease processes LG<sup>1</sup>
- No longer able to hide symptoms MC<sup>2</sup>
- Being forced to accept disease CH<sup>1</sup>
- Loss of control of dying EI<sup>3</sup>

## Dealing with own responses

Loss of a sense of personal control led to the following responses, hampering occupational performance:

- Depression DB<sup>1</sup>, CH<sup>1</sup>, LG<sup>1</sup>, BJ<sup>2</sup>, EI<sup>3</sup>, HA<sup>3</sup>
- A reduced sense of self-efficacy LG<sup>1</sup>, PV<sup>1</sup>, WE<sup>1</sup>, MC<sup>2</sup>, EI<sup>3</sup>, HA<sup>3</sup>
- Anxiety, Stress and Panic DB<sup>1</sup>, WE<sup>1</sup>, BJ<sup>2</sup>, MC<sup>2</sup>, EI<sup>3</sup>
- Self criticism: FL<sup>2</sup>; MC<sup>2</sup>, EI<sup>3</sup>; HA<sup>3</sup>
- Sense of inferiority CH<sup>1</sup>, MC<sup>2</sup>, EI<sup>3</sup>
- Loss of motivation DB<sup>1</sup>, WE<sup>1</sup>, HA<sup>3</sup>
- Frustration DB<sup>1</sup>, EI<sup>3</sup>, JM<sup>3</sup>
- Anger DB<sup>1</sup>, EI<sup>3</sup>,
- Lability BJ<sup>2</sup>, EI<sup>3</sup>
- Grief DB<sup>1</sup>

## Damage to sense of self

### Who am I?

Sense of self was damaged by changes to what the participant could *do*. They reported:

- Loss of occupational role performance LG<sup>1</sup>, PV<sup>1</sup>, BJ<sup>2</sup>, FL<sup>2</sup>, MC<sup>2</sup>, EI<sup>3</sup>
- Loss of sense of purpose DB<sup>1</sup>, FL<sup>2</sup>
- Loss of independence MC<sup>2</sup>, EI<sup>3</sup>
- Loss of ability to 'do' LG<sup>1</sup>, MC<sup>2</sup>
- Time drags FL<sup>2</sup>, MC<sup>2</sup>
- Sense of self lost or altered LG<sup>1</sup>, MC<sup>2</sup>
- Loss of choice MC<sup>2</sup>, EI<sup>3</sup>
- Risk-taking problematic BJ<sup>2</sup>
- Loss of being an active person EI<sup>3</sup>

### Fears for the future

Participants feared what lay ahead:

- Not knowing how their PD will develop LG<sup>1</sup>, PV<sup>1</sup>, BJ<sup>2</sup>, MC<sup>2</sup>
- Awareness of continuing deterioration LG<sup>1</sup>, BJ<sup>2</sup>, MC<sup>2</sup>, HA<sup>3</sup>
- Fear medication will lose effectiveness PV<sup>1</sup>, BJ<sup>2</sup>, FL<sup>2</sup>
- Unpredictable nature of PD in the short term LG<sup>1</sup>, BJ<sup>2</sup>, EI<sup>3</sup>
- Fear of falling WE<sup>1</sup>, MC<sup>2</sup>
- Fear of loss of community participation CH<sup>1</sup>
- Fear of loss of partner MC<sup>2</sup>
- Fear of impact of other health problems FL<sup>2</sup>
- No future HA<sup>3</sup>
- PD taking over MC<sup>2</sup>
- Death FL<sup>2</sup>

## THEME 3: Secondary social limitations

### Attitudes towards disability – balance and reciprocity

- Perceive or fear that others do not understand LG<sup>1</sup>, PV<sup>1</sup>, MC<sup>2</sup>, BJ<sup>2</sup>, EI<sup>3</sup>, HA<sup>3</sup>
- Insensitivity of others LG<sup>1</sup>, PV<sup>1</sup>, BJ<sup>2</sup>

- A sense of inferiority CH<sup>1</sup>, DB<sup>1</sup> EI<sup>3</sup>. HA<sup>3</sup>,
- Others' expectations do not fit expectations of participant LG<sup>1</sup>, PV<sup>1</sup>, BJ<sup>2</sup>, EI<sup>3</sup>
- Loss of balance in relationship CH<sup>1</sup>, PV<sup>1</sup>, EI<sup>3</sup>,
- Embarrassed by symptoms PV<sup>1</sup>, MC<sup>2</sup>, EI<sup>3</sup>
- Feeling exposed (symptoms visible) PV<sup>1</sup>, EI<sup>3</sup>
- Hard to get others to understand LG<sup>1</sup>, DB<sup>1</sup>
- No longer meeting own social expectations AD<sup>2</sup>, JM<sup>3</sup>

## **Decline in the quality of relationships – imbalance and dependency**

### **Partnership**

- Dependency DB<sup>1</sup>, MC<sup>2</sup>, EI<sup>3</sup>, JM<sup>3</sup>, HA<sup>3</sup>
- Limitations Pd puts on partner causes concern MC<sup>2</sup>, CH<sup>1</sup>, EI<sup>3</sup>, HA<sup>3</sup>
- Loss of sense of balance DB<sup>1</sup>, MC<sup>2</sup>, EI<sup>3</sup>
- Partner taking over MC<sup>2</sup>, EI<sup>3</sup>
- Reversal of role tasks EI<sup>3</sup>, HA<sup>3</sup>
- Worry partner will get fed up MC<sup>2</sup>, EI<sup>3</sup>
- Dealing with partner's expressions of frustration EI<sup>3</sup>
- Fear of going against partner EI<sup>3</sup>
- Partner is controlling EI<sup>3</sup>
- Loss of partner (separation) PV<sup>1</sup>

### **Other Relationships**

#### Family

- Need to be able to control interactions not well received WE<sup>1</sup>, MC<sup>2</sup>, HA<sup>3</sup>
- Relationship with children has declined FL<sup>2</sup>, EI<sup>3</sup>
- Geographical isolation MC<sup>2</sup>, EI<sup>3</sup>
- Feeling unable to help and support as would like WE<sup>1</sup>
- Reluctant to impose on children HA<sup>3</sup>
- Relationship with parents declined PV<sup>1</sup>

#### Friendships

- Communication problems EI<sup>3</sup>, JM<sup>3</sup>
- Poor understanding about Pd LG<sup>1</sup>, MC<sup>2</sup>
- Reduced community access MC<sup>2</sup>
- Loss of equality and reciprocation EI<sup>3</sup>

#### Work

- Not able to physically do the work PV<sup>1</sup>, CH<sup>1</sup>
- Not able to deal with the stress of work BJ<sup>2</sup>
- Bullying from boss BJ<sup>2</sup>
- Not able to run her household as she would like CH<sup>1</sup>
- Fear that will be perceived as unable to do the job PV<sup>1</sup>

#### Health professionals

Participants perceived a lack of resources to help them. They found health professionals provided some barriers through their lack of understanding:

- Health professionals not trustworthy or reliable LG<sup>1</sup>, PV<sup>1</sup>, BJ<sup>2</sup>, FL<sup>2</sup>, EI<sup>3</sup>
- No attempt to consider other health problems together with PD FL<sup>2</sup>, BJ<sup>2</sup>

- Information available about disease is poor CH<sup>1</sup>, LG<sup>1</sup>, PV<sup>1</sup>, BJ<sup>2</sup>, MC<sup>2</sup>
- Use up energy going to see health professionals about lack of energy LG<sup>1</sup>
- Too much theory LG<sup>1</sup>, PV<sup>1</sup>
- Advice not possible to follow HA<sup>3</sup>
- Hard to talk to LG<sup>1</sup>, PV<sup>1</sup>

#### **Theme 4: Outcomes - Consequential barriers to community occupational role performance**

##### **Community Related Losses**

###### **Access**

- Lost ability to drive MC<sup>2</sup>, AD<sup>2</sup>, BJ<sup>2</sup>, GW<sup>2</sup>, EI<sup>3</sup>, HA<sup>3</sup>, JM<sup>3</sup>, NP<sup>3</sup>  
Ability reduced LG<sup>1</sup>, FL<sup>2</sup>,
- Walking difficult MC<sup>2</sup>, EI<sup>3</sup>
- Reduced energy MC<sup>2</sup>, EI<sup>3</sup>, NP<sup>3</sup>

###### **Loss of spontaneity**

- Loss of confidence limiting CH<sup>1</sup>, LG<sup>1</sup>, WE<sup>1</sup>, MC<sup>2</sup>, HA<sup>3</sup>, EI<sup>3</sup>, MC<sup>2</sup>,
- Person supporting community access may not like to do same things as you HA<sup>3</sup>
- Prefer to have someone with you MC<sup>2</sup>, AD<sup>2</sup>
- Loss of independent access (car) limits social opportunities NP<sup>3</sup>
- Doctor's appointments use up 'good' time LG<sup>1</sup>, HA<sup>3</sup>
- Having to be infinitely flexible about plans HA<sup>3</sup>
- Loss of ability to 'just do' things MC<sup>2</sup>

###### **Fear of Loss**

- Fear of falling WE<sup>1</sup>, AD<sup>2</sup>, MC<sup>2</sup>, EI<sup>3</sup>, HA<sup>3</sup>
- Fear will not be able to keep up with others on a group holiday DB<sup>1</sup>
- Fear of people bumping into you WE<sup>1</sup>, EI<sup>3</sup>
- Fear of slippery floors MC<sup>2</sup>
- Community access is worrying DB<sup>1</sup> (will she cope, can she escape if needed)
- Fear of loss of community membership CH<sup>1</sup>

##### **Losses in Valued Roles and Routines**

###### **Social isolation**

- Geographical separation MC<sup>2</sup>, AD<sup>2</sup>, EI<sup>3</sup>, HA<sup>3</sup>
- Partner taking over MC<sup>2</sup>, EI<sup>3</sup>
- Poor communication:
- Loss of ability to travel MC<sup>2</sup>, EI<sup>3</sup>
- Difficulty using telephone MC<sup>2</sup>, EI<sup>3</sup>, JM<sup>3</sup>, NP<sup>3</sup>
- Handwriting problems AD<sup>2</sup>

- Reluctant to commit to social engagements LG<sup>1</sup>, MC<sup>2</sup>, BJ<sup>2</sup>, EI<sup>3</sup>
- Losses in significant roles WE1, PV1, MC2, HA3
- Inability to participate in a range of community activities HA<sup>3</sup>
- Loss of spontaneity limits contact with friends DB<sup>1</sup>

### **Loss of specific roles and routines**

#### **ROLES**

- Club member WE<sup>1</sup>, MC<sup>2</sup>, FL<sup>2</sup>, JM<sup>3</sup>, NP<sup>3</sup>, QR<sup>3</sup>
- Work PV<sup>1</sup>, CH<sup>1</sup>, BJ<sup>2</sup>
- Traveller EI<sup>3</sup>, MC<sup>2</sup>
- Mother MC<sup>2</sup>, EI<sup>3</sup>
- Friend MC<sup>2</sup>, EI<sup>3</sup>
- Holiday maker DB<sup>1</sup>, EI<sup>3</sup>
- Ballroom dancer HA<sup>3</sup>
- Church member JM<sup>3</sup>
- Yoga NP<sup>3</sup>
- Competitive bowler DB<sup>1</sup>
- Pilot PV<sup>1</sup>

- Golfer EI<sup>3</sup>
- Pianist AD<sup>2</sup>

- Bush walker BJ<sup>2</sup>

#### **ROUTINES**

- Loss of ability to hide symptoms MC2
- Lost of independence MC<sup>2</sup>, EI<sup>3</sup>
- Shopping MC2
- Carpet bowls HA3
- Cards HA3
- Loss of communication skills JM<sup>3</sup>
- Loss of ability to plan HA<sup>3</sup>

### **Loss of a future**

- Loss of plans for their future LG<sup>1</sup>, EI<sup>3</sup>, HA<sup>3</sup>

## **PARTICIPANTS WITH PARKINSON'S DISEASE**

### **STRATEGIES**

#### **THEME 1: Factors that minimise the impact of the primary disease process upon the person's ability to physically 'do'**

##### **Movement**

Participants described movement problems that interfered with mobility and upper limb control.

##### **Strategies related to upper and lower limb movement problems**

- Medication PV1, CH1, LG1, WE1, AD2, FL2, GW2, MC2, BJ2, EI3, HA3, JM3, NP3
- Exercise LG1, PV1, FL2, BJ2, EI3, WE1, DB1
- Limit mobility MC2, JM3, NP3
- Anchor body part LG1, PV1
- Therapy PV1, JM3
- Conscious control BJ2

##### **Strategies related to performance of specific routines**

- Dressing: - equipment FL<sup>2</sup>, GW<sup>2</sup>; - Assistance of partner WE<sup>1</sup>, AD<sup>2</sup>, FL<sup>2</sup>, GW<sup>2</sup>, EI<sup>3</sup>
- Time difficult tasks to fit with medication or with 'feeling good' PV<sup>1</sup>, MC<sup>2</sup>, BJ<sup>2</sup>, GW<sup>2</sup>, FL<sup>2</sup>
- Driving: - Give up EI<sup>3</sup>, MC<sup>2</sup>; - Limit LG<sup>1</sup>, FL<sup>2</sup>
- Avoidance LG<sup>1</sup>, FL<sup>2</sup>, MC<sup>2</sup>, EI<sup>3</sup>
- Modification: PV<sup>1</sup>, HA<sup>3</sup> Bed mobility: - satin sheets and pyjamas MC<sup>2</sup>, HA<sup>3</sup>,
- Writing: - Printing FL<sup>2</sup>
- Swallowing: - Cut food small FL<sup>2</sup>

##### **Strategies related to communication problems**

- Avoidance/withdrawal:  
In person EI<sup>3</sup>  
On the phone MC<sup>2</sup>, EI<sup>3</sup>, JM<sup>3</sup>,
- Speech pathology PV<sup>1</sup>, FL<sup>2</sup>, JM<sup>3</sup>

##### **Medication**

- Develop own medication regime, adjusting for frequency, timing and amount LG<sup>1</sup>, PV<sup>1</sup>, MC<sup>2</sup>, FL<sup>2</sup>, BJ<sup>2</sup>,
- Request change in type of medication LG<sup>1</sup>, PV<sup>1</sup>, FL<sup>2</sup>, BJ<sup>2</sup>
- Stop medication without reference to doctor LG<sup>1</sup>, PV<sup>1</sup>, BJ<sup>2</sup>,
- Learn to live with symptoms LG<sup>1</sup>,
- Seek alternate means of controlling symptoms PV<sup>1</sup>, BJ<sup>2</sup>,
- Work with doctor to get optimum effects CH<sup>1</sup>
- Retain control of your medication at all times BJ<sup>2</sup>
- Organise meals and meal timing to

PV<sup>1</sup>

optimise effects of medication BJ<sup>2</sup>

### Reduced Energy

- Medication CH<sup>1</sup>, LG<sup>1</sup>, WE<sup>1</sup>, BJ<sup>2</sup>, FL<sup>2</sup>, GW<sup>2</sup>, MC<sup>2</sup>, EI<sup>3</sup>, HA<sup>3</sup>
- Partner takes heavy tasks DB<sup>1</sup>, WE<sup>1</sup>, MC<sup>2</sup>, AD<sup>2</sup>, EI<sup>3</sup>, HA<sup>3</sup>, JM<sup>3</sup>
- Share tasks with partner WE<sup>1</sup>, AD<sup>2</sup>, MC<sup>2</sup>, EI<sup>3</sup>
- Planning, prioritisation and elimination of routines DB<sup>1</sup>, LG<sup>1</sup>, FL<sup>2</sup>, MC<sup>2</sup>, BJ<sup>2</sup>, EI<sup>3</sup>, NP<sup>3</sup>
- Environmental management LG<sup>1</sup>, MC<sup>2</sup>, BJ<sup>2</sup>, FL<sup>2</sup>, EI<sup>3</sup>, HA<sup>3</sup>
- Timing DB<sup>1</sup>, LG<sup>1</sup>, PV<sup>1</sup>, BJ<sup>2</sup>, GW<sup>2</sup>, JM<sup>3</sup>
- Naps BJ<sup>2</sup>, MC<sup>2</sup>, GW<sup>2</sup>, EI<sup>3</sup>, NP<sup>3</sup>
- Go to bed early FL<sup>2</sup>, HA<sup>3</sup>, EI<sup>3</sup>
- Role withdrawal PV<sup>1</sup>, MC<sup>2</sup>, HA<sup>3</sup>, NP<sup>3</sup>
- Slow down LG<sup>1</sup>, BJ<sup>2</sup>
- Break up the task LG<sup>1</sup>, DB<sup>1</sup>
- Pay someone to do task FL<sup>2</sup>

### Cognition

- Avoidance/withdrawal PV<sup>1</sup>, FL<sup>2</sup>, MC<sup>2</sup>, BJ<sup>2</sup>, EI<sup>3</sup>
- Aides memoire PV<sup>1</sup>, BJ<sup>2</sup>, EI<sup>3</sup>
- Accept performance level LG<sup>1</sup>, FL<sup>2</sup>
- Keep calm LG<sup>1</sup>
- Allocate extra time to problem tasks BJ<sup>2</sup>
- Concentrate LG<sup>1</sup>
- Partner substitutes EI<sup>3</sup>
- Persistence FL<sup>2</sup>
- Wait for an optimal moment to do FL<sup>2</sup>
- Slow down LG<sup>1</sup>
- Choose cognitively challenging pastimes MC<sup>2</sup>
- Humour EI<sup>3</sup>
- Use past experience FL<sup>2</sup>

## Other Factors

### Problems with doing arising from Parkinson's disease

#### Pain

- Living with pain LG<sup>1</sup>, PV<sup>1</sup>, MC<sup>2</sup>, BJ<sup>2</sup>, EI<sup>3</sup>
- Working through pain LG<sup>1</sup>, PV<sup>1</sup>, BJ<sup>2</sup>
- Medication PV<sup>1</sup>, EI<sup>3</sup>,
- Consciously achieving joint movement LG<sup>1</sup>, PV<sup>1</sup>
- Exercise PV<sup>1</sup>

#### Sleep Disturbance

- Routine early bed-time MC<sup>2</sup>, DB<sup>1</sup>, HA<sup>3</sup>, JM<sup>3</sup>.
- Afternoon nap MC<sup>2</sup>, EI<sup>3</sup>
- Avoiding late nights DB<sup>1</sup>

#### 'Feeling bad' and labile

- Avoid social commitments and/or ensure escape route in social situations LG<sup>1</sup>, MC<sup>2</sup>, EI<sup>3</sup>

#### Nausea

- Avoid long journeys MC<sup>2</sup>, EI<sup>3</sup>.

#### Sensitivity to noise

- Avoid noisy places EI<sup>3</sup>

#### Dry mouth

- Drink plenty of water FL<sup>2</sup>

### Interaction with other Health Problems

- Modify behaviour to accommodate LG<sup>1</sup>, FL<sup>2</sup>, MC<sup>2</sup>
- Work with doctor to develop medication that has optimum impact on both depression and P.d. CH<sup>1</sup>
- Vision:  
Avoids driving<sup>1</sup> at night FL<sup>2</sup>  
Glasses help BJ<sup>2</sup>,
- Develop own medication regime BJ<sup>2</sup>

## Theme 2: Factors that minimise secondary personal limitations

### Dealing with the Disease – how do I do this?

#### Coping with the daily impact

- Try hard DB<sup>1</sup>, LG<sup>1</sup>, MC<sup>2</sup>, HA<sup>3</sup>,
- Keep active CH<sup>1</sup>, PV<sup>1</sup>, BJ<sup>2</sup>, FL<sup>2</sup>,
- Partner's expectations keep them going WE<sup>1</sup>, AD<sup>2</sup>, EI<sup>3</sup>,
- Persist LG<sup>1</sup>, PV<sup>1</sup> MC<sup>2</sup>,
- Understanding nature of problems LG<sup>1</sup>, PV<sup>1</sup>, BJ<sup>2</sup>,
- Be creative problem solver PV<sup>1</sup>, AD<sup>2</sup>, BJ<sup>2</sup>,
- Accept limitations FL<sup>2</sup>, MC<sup>2</sup>, EI<sup>3</sup>,
- Live in the moment LG<sup>1</sup>, PV<sup>1</sup>, BJ<sup>2</sup>,
- Set own agenda LG<sup>1</sup>, PV<sup>1</sup>, BJ<sup>2</sup>,
- Use health professionals LG<sup>1</sup>, PV<sup>1</sup>, BJ<sup>2</sup>,
- Slow down LG<sup>1</sup>, BJ<sup>2</sup>,
- Tell others if need to stop 'doing' LG<sup>1</sup>

#### Coping with own responses to the disease

- Persistence LG<sup>1</sup>, PV<sup>1</sup>, WE<sup>1</sup>, FL<sup>2</sup>, MC<sup>2</sup>, BJ<sup>2</sup>, EI<sup>3</sup>,
- Compare self with those who are
- Denial of P.d.(initially) BJ<sup>2</sup>, JM<sup>3</sup>,
- Partner MC<sup>2</sup>, EI<sup>3</sup>,

- worse LG<sup>1</sup>, PV<sup>1</sup>, WE<sup>1</sup>, BJ<sup>2</sup>, MC<sup>2</sup>, JM<sup>3</sup>
- A positive attitude DB<sup>1</sup>, LG<sup>1</sup>, WE<sup>1</sup>, BJ<sup>2</sup>, EI<sup>3</sup>, NP<sup>3</sup>,
- Push self DB<sup>1</sup>, LG<sup>1</sup>, PV<sup>1</sup>, MC<sup>2</sup>,
- Be grateful LG<sup>1</sup>, WE<sup>1</sup>, MC<sup>2</sup>, EI<sup>3</sup>,
- Friends CH1, LG<sup>1</sup>, PV<sup>1</sup>, MC2
- Be strong LG<sup>1</sup>, PV<sup>1</sup>, EI<sup>3</sup>,
- Hope LG<sup>1</sup>, PV<sup>1</sup>, BJ<sup>2</sup>,
- Family LG<sup>1</sup>, MC<sup>2</sup>,
- P.d. support group FL<sup>2</sup>, MC<sup>2</sup>,
- Doctor's reassurance EI<sup>3</sup>
- Prayer LG<sup>1</sup>
- Compare self with those without P.d. DB<sup>1</sup>,

### **Preventing or repairing damage to sense of self**

#### **Awareness of self and disease**

- Membership of a group LG<sup>1</sup>, PV<sup>1</sup>, BJ<sup>2</sup>, FL<sup>2</sup>, MC<sup>2</sup>, EI<sup>3</sup>,
- Acceptance of limitations LG<sup>1</sup>, BJ<sup>2</sup>, FL<sup>2</sup>, MC<sup>2</sup>, EI<sup>3</sup>, HA<sup>3</sup>,
- Performance of valued roles CH<sup>1</sup>, DB<sup>1</sup>, LG<sup>1</sup>, PV<sup>1</sup>, BJ<sup>2</sup>, MC<sup>2</sup>,
- Doing something absorbing: LG<sup>1</sup>, PV<sup>1</sup>, BJ<sup>2</sup>, MC<sup>2</sup>, FL<sup>2</sup>, EI<sup>3</sup>,
- Giving up (e.g. driving) LG<sup>1</sup>, PV<sup>1</sup>, FL<sup>2</sup>, MC<sup>2</sup>, EI<sup>3</sup>,
- A sense of humour LG<sup>1</sup>, PV<sup>1</sup>, BJ<sup>2</sup>, EI<sup>3</sup>,
- Recognising there is more to you than your P.d. LG<sup>1</sup>, PV<sup>1</sup>, BJ<sup>2</sup>,
- Choose activities that reduce stress LG<sup>1</sup>, FL<sup>2</sup>, BJ<sup>2</sup>
- Develop new roles: PV<sup>1</sup>, BJ<sup>2</sup>, FL<sup>2</sup>
- Be in touch with self LG<sup>1</sup>, PV<sup>1</sup>, BJ<sup>2</sup>,
- Patience LG<sup>1</sup>, MC<sup>2</sup>, EI<sup>3</sup>,
- Develop personal theories about problems PV<sup>1</sup>, BJ<sup>2</sup>
- Develop activities that 'pass the time': LG<sup>1</sup>, MC<sup>2</sup>
- Understanding disease PV1, BJ<sup>2</sup>
- Enjoy being cared for by partner EI<sup>3</sup>
- Acceptance of social isolation MC<sup>2</sup>
- Doing something for others LG<sup>1</sup>,
- Retirement BJ<sup>2</sup>
- Staying calm LG<sup>1</sup>

#### **Fears for future**

- Live in the moment LG<sup>1</sup>, PV<sup>1</sup>, BJ<sup>2</sup>,
- Hope LG<sup>1</sup>, PV<sup>1</sup>, BJ<sup>2</sup>,
- Choosing not to think too much about it FL<sup>2</sup>, MC<sup>2</sup>
- Knowing that P.d. not terminal FL<sup>2</sup>
- Prayer LG<sup>1</sup>

## THEME 3: Factors that minimise secondary social limitations

### Attitudes towards disability – contribution, reciprocity and balance

#### Strategies that assist with social dissonance

##### Fitting in with others

Hide symptoms and problems:

- Avoidance of social activities that might be problematic LG<sup>1</sup>, MC<sup>2</sup>, BJ<sup>2</sup>, EI<sup>3</sup>
- Put on a show for others LG<sup>1</sup>, PV<sup>1</sup>, MC<sup>2</sup>, BJ<sup>2</sup>,
- Minimise own needs to others PV<sup>1</sup>, MC<sup>2</sup>, EI<sup>3</sup>,
- Escape from the label of having P.d. CH<sup>1</sup>, PV<sup>1</sup>

Deflect others' attention:

- Humour LG<sup>1</sup>, PV<sup>1</sup>, BJ<sup>2</sup>, EI<sup>3</sup>
- Passivity MC<sup>2</sup>, EI<sup>3</sup>
- Self deprecating to others MC<sup>2</sup>, EI<sup>3</sup>
- Convince people by your behaviour that it is not relevant PV<sup>1</sup>,

##### Defying the attitudes of others

- Choose friends who make effort to understand LG<sup>1</sup>, MC<sup>2</sup>, EI<sup>3</sup>
- Ignore others when important PV<sup>1</sup>, LG<sup>1</sup>, MC<sup>2</sup>
- Lobbying for P.d. support LG<sup>1</sup>, PV<sup>1</sup> Persistence PV<sup>1</sup>, BJ<sup>2</sup>
- See other's concern as 'their problem' PV<sup>1</sup> (e.g. flying)

#### Partnership

- Protect partner from P.d.:CH<sup>1</sup>, WE<sup>1</sup>, HA<sup>3</sup>
- Stoicism PV<sup>1</sup>, WE<sup>1</sup>, MC<sup>2</sup>, EI<sup>3</sup>
- Enlist health professionals or support group to educate partner about P.d. HA<sup>3</sup>, MC<sup>2</sup>, EI<sup>3</sup>
- Teamwork AD<sup>2</sup>, EI<sup>3</sup>
- A partner who cares MC<sup>2</sup>, EI<sup>3</sup>
- Push self to do thing for partner's sake MC<sup>2</sup>, EI<sup>3</sup>
- Sharing an enthusiasm MC<sup>2</sup>, EI<sup>3</sup>,
- Show appreciation MC<sup>2</sup>, EI<sup>3</sup>
- Try to be 'mates' with partner EI<sup>3</sup>
- Submitting to partner EI<sup>3</sup>

#### Family relationships

- Family outings and get togethers PV<sup>1</sup>, LG<sup>1</sup>, MC<sup>2</sup>
- Educate family about P.d. MC<sup>2</sup>, WE<sup>1</sup> Family understanding produces support MC<sup>2</sup>
- Family give sense of fit LG<sup>1</sup>, MC<sup>2</sup>
- Sharing a love of sport PV<sup>1</sup>, MC<sup>2</sup>
- Dynamic family relationships LG<sup>1</sup>, MC<sup>2</sup>
- Reminiscence EI<sup>3</sup>

#### Friendships

- Highly supportive friends LG<sup>1</sup>, CH<sup>1</sup>,
- Avoidance of friends EI<sup>3</sup>

- MC<sup>2</sup>, EI<sup>3</sup>
- Education of friends about P.d. LG<sup>1</sup>, MC<sup>2</sup>, EI<sup>3</sup>
- Contacting friends LG<sup>1</sup>, PV<sup>1</sup>,
- Stoicism DB<sup>1</sup>
- Finding ways to maintain reciprocation MC<sup>2</sup> (e.g. partner does mowing for KF<sup>P2</sup>; they take sister-in-law shopping)
- Reminiscence EI<sup>3</sup>,
- Attending P.d. group MC<sup>2</sup>

### Work relationships

- Retirement BJ<sup>2</sup>
- Be up-front about P.d. with others PV<sup>1</sup>
- Convince others you are useful to them PV<sup>1</sup>
- Volunteering BJ<sup>2</sup>
- Work out ways to work smart in order to get work PV<sup>1</sup>,
- Developing ongoing successful work partnerships PV<sup>1</sup>

### Health professionals

- Be assertive LG<sup>1</sup>, PV<sup>1</sup>, BJ<sup>2</sup>
- Search for right person LG<sup>1</sup>, PV<sup>1</sup>, BJ<sup>2</sup>
- Avoid health professionals PV<sup>1</sup>, BJ<sup>2</sup>,
- Educate self about P.d. PV<sup>1</sup>, BJ<sup>2</sup>
- Use alternate health workers PV<sup>1</sup>

## Theme 4: Outcomes - Factors that minimise barriers to community occupational role performance

### Community participation

- Specific skill that can offer to others LG<sup>1</sup> PV<sup>1</sup> MC<sup>2</sup>
- Voluntary work LG<sup>1</sup>, PV<sup>1</sup>
- Group membership LG<sup>1</sup>, PV<sup>1</sup>
- Maintaining a sense of contribution PV<sup>1</sup>
- Sport PV<sup>1</sup>

### Community access

#### Physical Access

- Drives self DB1, LG1, CH1, PV1, WE1, FL2.
- Partner who drives AD2, MC2, EI3, HA3, JM3, QR3.
- Do community things with partner MC<sup>2</sup>, AD<sup>2</sup>, JM<sup>3</sup>, HA<sup>3</sup>
- Familiar neighbourhood LG<sup>1</sup>, FL<sup>2</sup>, MC<sup>2</sup>
- Walk LG<sup>1</sup>, BJ<sup>2</sup>, EI3.
- Problem solving PV1, BJ2, DB1
- Set priorities LG<sup>1</sup>, BJ<sup>2</sup>
- Build in your escape LG<sup>1</sup>, MC<sup>2</sup>
- Partner has taken over community task altogether MC<sup>2</sup>, EI<sup>3</sup>
- Partner's arm or shopping trolley give support MC<sup>2</sup>, HA<sup>3</sup>
- Keep flexible LG<sup>1</sup>, BJ<sup>2</sup>
- Avoid commitment LG<sup>1</sup>, EI<sup>3</sup>
- Take breaks MC<sup>2</sup>
- Partner drops off and waits MC<sup>2</sup>,
- Community transport BJ2, NP3.
- Limit driving LG<sup>1</sup>, FL2.
- Give up driving MC2, EI3.
- Avoid long car journeys MC<sup>2</sup>, EI<sup>3</sup>

- Taxis GW2

### **Social Access**

- Maintain a sense of contribution PV<sup>1</sup>, MC<sup>2</sup>, LG<sup>1</sup>, BJ<sup>2</sup>, GW<sup>2</sup>, AD<sup>2</sup>
- Groups and clubs helpful DB1, MC<sup>2</sup>, BJ<sup>2</sup>, EI<sup>3</sup>
- Establish or maintain routines such as family Sunday lunch AD<sup>1</sup>, WE<sup>1</sup>
- Stop worrying about what others think PV<sup>1</sup>, BJ<sup>2</sup>
- Telephone AD<sup>2</sup>,
- Reminiscence EI<sup>3</sup>
- Friends who contact them LG<sup>1</sup>

### **Strategies to Facilitate Community Occupational Role Performance**

#### **Increasing a sense of predictability**

- Planning WE1, DB1, LG1, PV1, BJ2, MC2, HA3
- Routine WE1, GW2, AD2, JM3
- Simplification LG1, WE1, AD2, BJ2
- Choose low energy activities AD2, GW2, MC2
- Avoid having a routine BJ2

#### **The Future**

- Live in the moment LG<sup>1</sup>, MC<sup>2</sup>, BJ<sup>2</sup>, EI<sup>3</sup>
- Acceptance MC<sup>2</sup>, EI<sup>3</sup>

## **BARRIERS IDENTIFIED BY PARTNERS OF PARTICIPANTS WITH PARKINSON'S DISEASE**

### **Theme 1: The impact of the primary disease process upon the person's ability to physically 'do'**

#### **Movement**

##### **Barriers for partner with Pd**

- Dressing SD<sup>p2</sup>, VW<sup>p2</sup>, PA<sup>p3</sup>, RI<sup>p3</sup>, AM<sup>p3</sup>.
- General safety PAp3, AMp3, RIp3
- Bed mobility PA<sup>p3</sup>.RIp3
- Falls a problem AM<sup>p3</sup>, OR<sup>p3</sup>
- Writing ORp3
- Difficulty articulating words AMp3
- Festination or 'rushing' OR<sup>p3</sup>.
- Lost ability to exercise OR<sup>p3</sup>.
- Getting 'stuck' ORp3
- Soft, receding voice ORp3

##### **Barriers for self**

- Not able to stand or walk far because of back pain UL<sup>p2</sup>, VW<sup>p2</sup>.

#### **Medication Management**

##### **Barriers for partner with Pd**

- Occasionally forgets medication KC<sup>p2</sup>, SD<sup>p2</sup>.
- Effectiveness of medication is reducing PA<sup>p3</sup>, RI<sup>p3</sup>.
- Often needs help with medication PA<sup>p3</sup>.
- Unable to take a higher dose because of adverse reaction PA<sup>p3</sup>.
- Anti depressants interact with Pd medication PA<sup>p3</sup>.
- Medication causing hallucinations? RI<sup>p3</sup>.

#### **Reduced energy**

##### **Barriers for partner with Pd**

- Sometimes partner is 'not up to it' KC<sup>p2</sup>, RI<sup>p3</sup>, AM<sup>p3</sup>, PA<sup>p3</sup>.

##### **Barriers for self**

- Get tired RI<sup>p3</sup>, AM<sup>p3</sup>, PA<sup>p3</sup>.

## Cognitive difficulties

### Barriers for Partner with Pd

- Partner has some cognitive problems AM<sup>p3</sup>, RI<sup>p3</sup>, PAp<sup>3</sup>
- Partner not safe with task performance PA<sup>p3</sup>, RI<sup>p3</sup>.
- cognitive difficulties affect communication AM<sup>p3</sup>, RI<sup>p3</sup>.
- Partner has bouts of confusion PA<sup>p3</sup>.
- Partner needs constant supervision because of cognitive problems ORp<sup>3</sup>, RIp<sup>3</sup>
- 

### Other factors

#### Pain

##### Barriers for self

- Low back pain UL<sup>p2</sup>.
- Hip pain RI<sup>p3</sup>.

#### Sleep Disturbance

##### Barriers for self

- Sleep disturbed by partner AM<sup>p3</sup>, PA<sup>p3</sup>.
- Insomnia UL<sup>p2</sup>.
- Medication routine disturbs sleep RI<sup>p3</sup>.

#### Interaction with other Health Problems

##### Barriers for self

- Back pain VW<sup>p2</sup>, UL<sup>p3</sup>.
- Osteo-arthritis PA<sup>p3</sup>, RI<sup>p3</sup>.
- Cardiovascular UL<sup>p3</sup>, PA<sup>p3</sup>.
- Digestive PA<sup>p3</sup>.

## Theme 2: Secondary personal limitations

### Dealing with the disease – how do I do this?

#### The daily impact

##### Barriers for self

- Worthwhile breaks away from partner difficult to arrange KC<sup>p2</sup>, PA<sup>p3</sup>, RI<sup>p3</sup>, AM<sup>p3</sup>.
- Unpredictability of primary symptoms KC<sup>p2</sup>, PA<sup>p3</sup>, RI<sup>p3</sup>.
- Need to pick up whatever needs doing SD<sup>p2</sup>, KC<sup>p2</sup>, VW<sup>p2</sup>.
- Get no time or opportunity for own activities and projects AM<sup>p3</sup>, PA<sup>p3</sup>, RI<sup>p3</sup>.

- Partner needs 24 hour care – physical and emotional exhaustion PA<sup>p3</sup>, RI<sup>p3</sup>, AM<sup>p3</sup>
- Difficulty dealing with partner's behaviour PA<sup>3</sup>, RI<sup>p3</sup>, OR<sup>p3</sup>
- Not enough sleep PA<sup>p3</sup>, AM<sup>p3</sup>, RI<sup>p3</sup>
- PD support group pleasant, but can't get useful strategies there KC<sup>p2</sup>, PA<sup>3</sup>, RI<sup>p3</sup>.
- Hard not to take over PA<sup>p3</sup>, RI<sup>p3</sup>.
- Depression is something they both have to beat PA3
- Stress exacerbates partner's problems RI<sup>p3</sup>

## Dealing with own responses to the disease

### Barriers for self

- Anxiety UL<sup>p2</sup>, AM<sup>p3</sup>, RI<sup>p3</sup>, PA<sup>p3</sup>.
- Behaviour disturbing RI<sup>p3</sup>, PA<sup>p3</sup> OR<sup>p3</sup>.
- All decisions and activities in own life are controlled by partner's Pd symptoms KC<sup>p2</sup>, PA<sup>p3</sup>, RI<sup>p3</sup>..
- Resentment about the impact of the disease KC<sup>p2</sup>, AM<sup>p3</sup>
- Fluctuating levels of function confusing PA<sup>p3</sup>.
- Caring is stressful PA<sup>p3</sup>, RI<sup>p3</sup>.
- Partner is demanding OR<sup>p3</sup>, PA<sup>p3</sup>.
- Partner's dementia emotionally difficult to deal with RI<sup>3</sup>.
- He is unhappy that family and friends do not understand KC<sup>p2</sup>.
- Every other role subordinated to that of Carer PA<sup>p3</sup>.
- Depression UL<sup>p2</sup>.
- A reduced sense of self-efficacy UL<sup>p2</sup>.

## Damage to sense of self

### Who am I?

#### Barriers for Partner with Pd

- Puts self at risk AM<sup>p3</sup>, PA<sup>p3</sup>, RI<sup>p3</sup>.
- Difficulty accepting loss of significant occupational task performance OR<sup>p3</sup>, AM<sup>p3</sup>.
- Depression PA<sup>p3</sup>.
- Worries about his health UL<sup>p2</sup>.

## Fears for the future

### Fears for partner

- Worry about the future PA<sup>p3</sup>, RI<sup>p3</sup>, AM<sup>p3</sup>,

### Fears for self

- Fears of not receiving good care if get sick (partner not able to care) UL<sup>p2</sup>, PAp3
- Attending Pd support group not supportive, but rather, frightening UL<sup>p2</sup>,
- Fears partner will lose cognitive abilities UL<sup>p2</sup>

## Theme 3: Secondary social limitations

### Attitudes towards disability – contribution, reciprocity and balance

#### Barriers for Partner with Pd and self

- Fluctuations in function not obvious to others UL<sup>p2</sup>, PA<sup>p3</sup>, RI<sup>p3</sup>.
- People do not understand AMp3, RIp3

### Decline in the quality of relationships – imbalance and dependency

#### Partnership - dependency and a sense of burden

##### Barriers for Partner with Pd

- Distress at the sacrifices partner is making KC<sup>p2</sup>, PA<sup>p3</sup>, AM<sup>p3</sup>
- Pressure from partner to go out KC<sup>p2</sup>, AM<sup>p3</sup>
- Wives felt the Pd eroded partner's sense of manhood UL<sup>p2</sup>, OR<sup>p3</sup>.

##### Barriers for self

- Unhappiness of partner difficult to deal with KC<sup>p2</sup>, KF<sup>p2</sup>, PA<sup>p3</sup>, AM<sup>p3</sup>, RI<sup>p3</sup>, OR<sup>p3</sup>,
- Social isolation KC<sup>p2</sup>, UL<sup>p2</sup>, PA<sup>p3</sup>, AM<sup>p3</sup>, RI<sup>p3</sup>,
- Having to be the carer is stressful KC<sup>p2</sup>, PA<sup>p3</sup>, RI<sup>p3</sup>, AM<sup>p3</sup>, OR<sup>p3</sup>
- Poor communication difficult and upsetting UL<sup>p2</sup>, AM<sup>p3</sup>, RI<sup>p3</sup>, OR<sup>p3</sup>,
- Role reversal is difficult UL<sup>p2</sup>, OR<sup>p3</sup>, RI<sup>p3</sup>.
- Having to be 'ogre' OR<sup>p3</sup>, RI<sup>p3</sup>, AM<sup>p3</sup>
- Becoming distanced from partner UL<sup>p2</sup>, AM<sup>p3</sup>, PAp3
- Partner without Pd takes frustrations out on spouse RI<sup>p3</sup>, AMp3
- Partner with Pd takes frustrations out on spouse OR<sup>p3</sup>,
- Loss of role as spouse PA<sup>p3</sup>,

### Other relationships

#### Family

##### Barriers for Partner with Pd

- Family do not understand Pd KC<sup>p2</sup>, OR<sup>p3</sup>, RI<sup>p3</sup>,
- Family expect too much KC<sup>p2</sup>, OR<sup>p3</sup>.
- Can't nurse her grandchild and grandchildren shun her AM<sup>p3</sup>,

##### Barriers for self

- Geographical isolation – see family less than would like KC<sup>p2</sup>, UL<sup>p2</sup>, RI<sup>p3</sup>.
- Lack of family understanding hurtful. UL<sup>p2</sup>, KC<sup>p2</sup>, AM<sup>p3</sup>.
- Family not able to share the load of caring RI<sup>p3</sup>, OR<sup>p3</sup>.
- Family expect partner to 'fix' family problems related to partner's Pd. OR<sup>p3</sup>, KC<sup>p2</sup>.
- Not getting support from family UL<sup>p2</sup>,

RI<sup>p3</sup>, OR<sup>p3</sup>.

### Friendships

The quality of friendship appeared to change and in many cases decline.

#### Barriers for Partner with Pd

- Social isolation. RI<sup>p3</sup>, OR<sup>p3</sup>, AM<sup>p3</sup>
- 
- No longer see friends often RI<sup>p3</sup>,
- Non-Pd friend puts limits on the relationship IY<sup>p1</sup>
- Non-Pd friend keen to avoid fostering dependency IY<sup>p1</sup>,
- Partner does not make friends easily UL<sup>p2</sup>.

#### Barriers for self

- Too busy caring for partner to maintain friendships. RI<sup>p3</sup>, AM<sup>p3</sup>.
- Many friends have died or become ill themselves UL<sup>p2</sup>.
- Have to limit what can offer due to other demands on time IY<sup>p1</sup>.
- Husband is a major barrier to friendship now MC is ill YF<sup>f2</sup>
- Afraid of overstaying welcome YF<sup>f2</sup>.

### Health professionals

#### Barriers for Partner with Pd

- Health professionals can't do anything KC<sup>p2</sup>, PA<sup>p3</sup>,
- 
- Health professionals provide conflicting treatment and advice PA<sup>p3</sup>, p.8 KC
- Health professionals seem to have a cavalier attitude to medication PA<sup>p3</sup>,
- OT is obstructive rather than helpful PA<sup>p3</sup>,
- Going to hospital a major problem for someone with Pd PA<sup>p3</sup>,
- Alternative health supporters and practitioners are potentially harmful PA<sup>p3</sup>,

#### Barriers for self

- Gets no support from doctor PA<sup>p3</sup>, RI<sup>p3</sup>.
- Alternative health 'gurus' are worrying PA<sup>p3</sup>,

## **Theme 4: Consequential barriers to community occupational role performance**

### **Community Related Losses**

#### **Losses in community access**

##### **Barriers for partner with Pd**

- Gendered toilets problematic PA<sup>p3</sup>, RI<sup>p3</sup>,  
Partner tires quickly RI<sup>p3</sup>, PA<sup>p3</sup>,  
People cut in front causing a 'stall' OR<sup>p3</sup>,
- Transferring in/out of car a problem OR<sup>3</sup>,
- Partner has panic attacks PA<sup>p3</sup>,

##### **Barriers for self**

- Day trips and holidays have disappeared. KC<sup>p2</sup>, PA<sup>p3</sup>, AM<sup>p3</sup>, RI<sup>p3</sup>,
- Partner does not want to go out KC<sup>p2</sup>, UL<sup>p2</sup>, RI<sup>p3</sup>,
- Do not like to leave partner alone PA<sup>p3</sup>, RI<sup>p3</sup>, AM<sup>p3</sup>
- Cannot go out at night UL<sup>p2</sup>, RI<sup>p3</sup>, PA<sup>p3</sup>,
- Friends and relatives not reliable as sitters PA<sup>p3</sup>, AM<sup>p3</sup>,
- Time limit on time away PA<sup>p3</sup>, RI<sup>p3</sup>,
- Do not want to pay for professional sitter now as will need the money more later PA<sup>p3</sup>, RI<sup>p3</sup>
- Partner has difficulty driving at night and she does not drive UL<sup>p2</sup>,
- Partner does not want to be baby-sat AM<sup>p3</sup>
- Shopping difficult because of back pain UL<sup>p2</sup>,
- Fears partner will fall AM<sup>p3</sup>

#### **Loss of spontaneity**

##### **Barriers for Partner with Pd**

- Partner may get sick before or during outing KC<sup>2</sup>, PA<sup>3</sup>,

#### **Losses in Valued Roles and Routines**

##### **Social isolation**

##### Barriers for Partner with Pd

- Social isolation a major problem for Partner with Pd OR<sup>p3</sup>, RI<sup>p3</sup>, UL<sup>p2</sup>, AM<sup>p3</sup>.
- Partner reluctant to commit to social events KC<sup>p2</sup>, UL<sup>p2</sup>, RI<sup>p3</sup>.
- Had to give up committee work due to his speech problems QRp3

### Barriers for self

- Reduction or loss of independent community access  $KC^{p2}$ ,  $PA^{p3}$ ,  $RI^{p3}$ ,  $AM^{p3}$
- Social isolation  $KC^{p2}$ ,  $PA^{p3}$ ,  $AM^{p3}$ .
- Given up almost all community activity related to own interests  $PA^{p3}$ ,  $RI^{p3}$ ,  $AM^{p3}$ ,
- Consuming nature of carer role eliminates other roles  $PA^{p3}$ ,  $RI^{p3}$ ,  $AM^{p3}$
- Partner reluctant to commit to social events  $KC^{p2}$ ,  $UL^{p2}$ ,  $RI^{p3}$ .
- Given up community roles they had shared with partner  $KC^{p2}$ ,  $PA^{p3}$ ,  $RI^{p3}$ ,
- Trying to help partner maintain roles time consuming and tiring.  $AM^{p3}$

### **Loss of a Future**

#### **Barriers for both**

- Loss of plans for the future  $PA^{p3}$ ,  $RI^{p3}$ ,
- Loss of the future  $PA^3$ ,  $AM^3$ ,
- Fears collapse of independence necessitating nursing home care for them both  $UL^{p2}$ ,

# **PARTNERS OF PARTICIPANTS WITH PARKINSON'S DISEASE**

## **STRATEGIES**

### **Theme One: Factors that minimise the impact of the primary disease process upon the person's ability to physically 'do'**

#### **Movement**

##### **Strategies to assist partner with P.d.**

Hands-on assistance:

Dressing

- occasional SD2, VW2
- daily RI3, PA3, AM3
- Assistance with toilet PA3, RI3, AM3
- Bed mobility RI3, AM3, PA3
- Eating UL2, AM3, OR3
- Assistance with showering PA3, RI3,
- Transfers PA3, RI3
- Partner assists with heavy or dangerous objects SD2, KC2
- Cooking assistance SD2,
- Fetching and carrying PA3
- 'Everything' PA3

Assisting partner to continue occupational role performance

- Do shopping together KCp2 takes her
- Cooking AMp3 they do it together

Providing guidance/direction to partner:

- Ensures partner exercises UL2, RI3
- Time difficult tasks/social events to fit with medication levels PA3

##### **Strategies to help them survive together**

- Environmental modification RI3, AM3, OR3, VW2, SD2
- Taking over tasks: VW2, SD2, PA3
- Does most or all of cooking VW2, RI3
- Care for self in order to care for partner SD2
- Share whatever needs doing KC2

##### **Strategies to make things easier for self**

- Delegation of work to third parties VW2, SD2, UL2
- Make sure partner is independent in a particular task so it is easier for self OR3, PA3
- Bowls UL2
- Walking UL2

## Medication

- Watch time and partner SD2, KC2, PA3, RI3
- Establish and maintain a routine RI3
- Take the trouble to be knowledgeable about medication PA3
- Make sure take own medication UL2
- Juggle medication for partner RI3

## Cognition

- Partner needs to be watched at all times for safety reasons PA3, RI3
- Microwave cooking only because it is safe for partner to use PA3
- Tries to keep partner stimulated & keep her brain going RI3

## Other Factors

### Sleep Disturbance

- Try to catch up on sleep during the day PA3

## Interaction with other Health Problems

### Strategies to assist partner

- Ensure good nutrition UL2

### Strategies to make things easier for self

- Take care of self (e.g. protect back when helping partner) in order to be able to support partner SD2, RI3, PA3
- Try not to worry about both their health UL2

## Theme Two: Factors that minimise secondary personal limitations

### Dealing with own responses to the disease. How do I do this?

### Coping with the daily impact

#### Assisting partner to maintain/restore control

- Being proactive KC2, UL2, OR3, PA3, AM3, RI3
- Putting partner first KC2, PA3, AM3, RI3
- Helping partner to maintain independence as much as possible TE1, VW2, UL2, OR3
- Taking over AM3, RI3
- Watching KC2, RI3, PA3
- Supports attendance at P.d support group – she feels comfortable there RI3, KC2
- Pushes self to perform well UL2

#### Strategies to make things easier for self

- P.d. support group helpful KC2, SD2, OR3, PA3, RI3
- Respite care (but problematic) RI3, PA3

- Positive self talk. UL2, RI3, AM3

### **Coping with own responses to the disease**

#### Assisting partner to cope with his or her responses

- Try to be understanding KC2, VW2, RI3, PA3, AM3
- Helping partner to keep thinking positively TE1, YF2, UL2, OR3

#### Coping with own responses to partner's disabilities and consequent needs and

#### behaviour

- Stoicism KC2, SD2, YF2, UL2, PA3, AM3, RI3, OR3
- Acceptance KC2, AM3, PA3, RI3
- Learning new ways to relate to partner UL2, OR3, PA3, RI3, AM3
- Belief in doing what is right AM3, PA3, RI3 OR3

### **Preventing or repairing damage to sense of self**

#### **Maintaining/restoring partner's sense of self**

- Try to respect and maintain their past selves UL2, RI3

#### Maintaining/restoring of own sense of self

- Having a break KC2, UL2, OR3, PA3, RI3, AM3
- Doing things for others SD2, OR3
- Being a carer VW2, AM3, RI3, OR3
- Putting partner first KC2
- Believes being a carer is doing the right thing AM3, RI3, PA3, OR3
- Starting a new role (painter) VW2

#### **Fears for the future**

- Live in the present AM3, PA3
- Plan for the future UL2, RI3
- Hope it won't happen TE1, VW2,

## **Theme Three: Factors that minimise secondary social limitations**

### **Attitudes towards disability**

#### **Social dissonance**

- Advocacy KCp2, PAp3, RIp3

### **Decline in the quality of relationships**

#### Partnership - dependency and a sense of burden

- Tries to understand UL2, KC2, RI3, PA3, AM3, OR3
- Dealing with change of balance in relationship. KC2, RI3
- Try to encourage communication UL2, RI3
- Try to be friends with partner RI3, PA3
- Sharing an interest SD2, OR3
- Accepting partner's efforts to lighten their load OR3
- Try to lessen/rectify inequality in relationship RI3
- P.d. support group helpful in dealing with changes to balance of relationship OR3
- Negotiate OR3

### **Decline in quality of family relationships**

- Dynamic family relationships VW2, SD2
- Family support emotional rather than practical in nature RI3
- Educate family about P.d. OR3
- Advocate for partner when unable to attend family events KC2

### **Decline in quality of friendships**

- Partner now maintains social contacts SD2, RI3
- Highly supportive friends RI3, OR3
- Work hard to maintain friendship YF2
- Live from day to day UL2

### **Relationships with health professionals can be problematic**

- Be a 'good patient' and accept doctor as part of both their lives UL2
- Anticipate and be assertive on partners behalf. PA3
- Become knowledgeable about medication PA3
- Learn that health professionals are often talking generally and don't try to apply it to self or partner PA3

## **Theme 4: Outcomes - Factors that minimise barriers to community occupational role performance**

### **Community access**

#### **Physical access for partner**

- Driver KC2, SD2, RI3, PA3, AM3, OR3
- Planning and implementing specific strategies UL2, KC2, PA3, OR3
- Having a routine VW2, SD2, RI3
- Expects community participation from partner SDp2, VWp2
- Makes partner go out RIp3, ORp3
- Be understanding and accommodate partner's needs UL2, KC2
- Provide an escape route PA3, KC2
- Limit time out together KC2
- Public transport VW2
- Do things together PA3
- Lets partner set the agenda KCp2
- Simplify KCp2

### **Social access for both partners**

- Groups and clubs can allow participation for both ptrs. KCp2, SDp2, VWp2, RIp3, PAp3
- Encourage to keep going out UL2
- Be flexible and seize the moment KC2, RI3, PA3
- Ensures they maintain full range of community roles and occupations VW2 'we don't muck about'

### **Community access for self**

- Leave ptr. at home alone ULp2, KCp2, PAp3, ORp3
- Allows or encourages partner to push self to go out for partner's sake KCp2, VWp2, RIp3
- Find community roles and activities that will facilitate contact UL2, AM3, OR3
- Limits time out alone PA2, KC2, RI3
- Maintaining a sense of contribution SD2
- Stoic PA3

### **Strategies to Facilitate Community Occupational Role Performance**

#### **Increasing a sense of predictability**

For partner

- Pushes partner to go out into community AM3

For self

- Maintains community roles VW2, SD2, KC2
- Maintaining routine community commitments SD2, VW2
- Maintaining a sense of contribution SD2

#### **The Future**

- Planning for specific problems can see ahead UL2, RI3, AM3,
- Acceptance of circumstances RI3, AM3, PA3
- Live in the present AM3
- Hope UL2
- Doesn't think things will change much KC2

## **APPENDIX 5.18**

# **EXAMPLES OF THE FINAL STAGE OF ANALYSIS – MODEL DEVELOPMENT**

## Cycle of Perceived Control Analysis - Wendy Egan – PD Level 1

NB Wendy Egan has no problems moving around the cycle – she is cognitively OK and hence able to come up with ways of regaining control.

### Barrier

Parkinson's disease on left plus possibly a small stroke on right affect her mobility and she has had falls.

### Problem definition

She is able to define an important problem clearly

*I think what **worries** me more is my legs. I have ... lot of trouble with my legs. They get to be very shaky ... I feel as if I want to sit down all the time, you know, which is **annoying**. Sometimes ... if I get a bit **upset** about something, I notice that happens. ... you **feel** as if you're **walking on eggshells** all the time.*

*... when I'm **walking** around **standing** up that I get really **tired**, you know.*

*I've had a couple of nasty falls. I had one down the back steps the other day, a few weeks ago now. ... Oh I had a nasty leg for a while. And **I felt so silly** too, you know.*

She is concerned about possible consequences of a fall

*That's what I mean to say, **most people of my age** might break their hip or something, you know... these people that have these backpacks, oh gosh, they can knock you for six. I hate those backpacks.*

She analyses and defines carefully why she fell

*I've got to be careful when I'm turning. ... I know what I did wrong [when she fell at back steps]. When I was walking up the steps I didn't put my foot properly flat on the step, you know, you put your foot like that, and when I went to lift this foot up this one left, my left foot give away and down I went.*

Again:

*I was up at a, we were on holidays a few months ago up at Tweed Heads and we went to the movies and we were coming out of the movies, it's all carpeted,*

*and as I walked out of the movies I didn't know that the, as I walked around the corner it sort of slanted away, and I fell, took great big skin off my leg and sheared all this skin off my leg. And it was carpet I fell on.*

### **Strategy**

Applying what she learned from her analysis or problem definition

*I've got to be careful when I'm turning. ... I know what I did wrong [when she fell at back steps]. When I was walking up the steps I didn't put my foot properly flat on the step, you know, you put your foot like that, and when I went to lift this foot up this one left, my left foot give away and down I went. ... When you're walking you've got to be careful where you're walking and how you, even if you walk round a door you can knock yourself, you know, fall over.*

*You find, you've got to be careful you don't start to shuffle because when you're walking, like over there at the exercises [Parkinson's exercise group]*

*she says take bigger steps, you know. You lift your feet up, take bigger steps.*

### **Feedback**

Expectations of husband: He reinforces that she should be self-sufficient. She finds it helpful. Perhaps in encourages her to struggle to maintain her self-identity and fit.

*I mean my husband's good. If I start to ... say I'm hopeless, ... he'll say, 'Now there's nothing wrong with you,... you're doing alright and don't forget it'. ... He's very positive about it. **That pushes you along a bit.** He's never been sick himself. And he doesn't think anybody else should be sick I don't think. **He just thinks you've got to do the best.***

### **Outcomes**

*Oh yes, I'm very careful when I'm walking up steps. Oh definitely. You've got to be really careful you don't fall.*

She was asked if she had lost confidence

*No I don't think so. I'm careful walking. I always watch that I don't trip on something. ... No I'll go out and walk ... Well **I've got to keep moving**, that's it, you know.*

## Problem

PD and stroke together have affected bilateral hand function.

*I just wish I could get back into a bit of sewing and that that we used to love, you know. Things like that that I can't do now. Because it's just hard trying to, I used to do a lot of hand sewing too, you know, which I can't do any more. If you've just got to sew a button onto something it's a real **big effort**. You wouldn't think so, would you? When that first started, when that first started here in my life I thought why can't I do this. It seems so stupid, you know.*

## Strategy

Persistence

So when you're faced with a situation, say you have to sew a button on or something like that, do you, would you battle through and just do it yourself or do you get help?

*Yeah. No. I'll have a go at it myself. As long as I can get that needle threaded.*

## Feedback

Would you ask your husband to thread the needle?

*Oh he's hopeless. He says Oh no, you can thread a needle.*

## Strategy

*I just, sometimes it will take a little while and I put it down and I think **I'll come back** and do that in a minute. And then later on it will work out for me. And then sometimes I go to the machine and I thread the needle and I think gee that went in straight away, you know, the needle went through straight away. Cause if you can't get that needle threaded you can't use the sewing machine.*

## **Acceptance**

The need to sew is no longer a strong – no financial incentive any more – not a **useful** thing to do any more. No longer a way of reinforcing her self identity and social fit.

*When my kids were young I used to make a lot of their stuff, you know. I'm not a real good sewer but I mean enough. But I haven't done much for the grandchildren, cause I find you can buy the stuff cheaper than you can try to make it.*

## **Problem**

Reduced energy. She used to enjoy helping out, but is no longer able to. She has ten grandchildren.

*I try and help out a bit if I can, if they want them minded or something. But the trouble with this complaint is you really can't help other people much, you know what I mean? You haven't got the strength to do it. You haven't got the confidence. You think, Oh I couldn't do that, you know. And I mean all this voluntary work you read about and you think, Gee I'd love to be able to do that. But you haven't sort of got the mobility to do it, you know. You're sort of slow at everything you do.*

## **Strategy**

*... they've got to behave themselves when they come here.*

## **Problem**

*I love getting out in the garden too, but that's another thing I haven't been able to do much because I get down on my knees and they start shaking and I can't do any more, you know. The garden's gone to wreck out the front. It was so nice here once.*

## **Strategy**

*So what I did this week, I thought if I can't have a few flowers, so I went and bought some pansies and violas and I spent all this week potting and put them out on the back verandah. ... It gives me a little garden. I don't have to get down and dig it.*

## **Problem**

Maintaining the tradition of family lunch – major means of family contact for her and forms important function for family too. But there are 12 children and 10 grandchildren in the family. She can no longer manage to cook for all of them

## **Strategy**

She noted at her PD support group that there was an information booklet available. She brought up her strategy in the context of the lunch problem.

## **Decision**

She went straight to implementing the plan.

## **Implementation**

- She gave all her children information booklets about PD.

*I've handed them all these little books that explains it better ... It just explains what's happening with that person. Cause you don't know about the thing, you don't know what's happening, you know. So I've given each one of the family one of them. I said, If you think your mother's going off her brain she's not really, she just can't do anything about it.*

## **Outcome**

- So informed, her daughters-in-law all bring food so she doesn't have to cook for everyone.

NB Did she experiment or not? She decided on her strategy and went straight to implementation? It worked, but if had not worked, she would have had to go around the cycle again. She thought about it and possibly rehearsed it in her head e.g. what would x think about being given a booklet? When will I give it to them? Should I explain why or just give it to them? Etc.

## **Problem**

Cognitive problems with cooking – difficult holding a task sequence in her head.

*And now if I'm going to cook or make a cake or something it takes me longer to do that **because I've got to keep going back and think what have I put in***

*there and what I haven't you know. You find you forget what you've done.*

*Simple little things like that, you know.*

She denies it is a memory problem, although concedes her memory is better for long ago than yesterday. and seems not to think it relates to concentration either.

*I So things like, has it also affected your memory and concentration?*

*R Oh no. I've got a good memory.*

*I Yep. Concentration?*

*R I think I've got a good - I'm like a lot of people, you've got a better memory of what happened years ago than what happened yesterday.*

*I Yep. That's true. Your concentration – what about that?*

She believes it is lack of practice

*R Well I think it's because you don't do as much cooking and you get out of the habit of it. And so you think oh, like sort of, when you do, when you're cooking when you're young you just throw everything in and do it like that silly woman does on television, you know.*

*R It does sound easy. But as you get older you sort of take a little bit longer to do those things cause you've got to remember what you're doing and then you'll put a cake in the oven and forget it's there and, you know, something like that. I've often done that.*

## **Acceptance**

The issue of denial – she is not in favour

*No, some people don't want to talk about it[PD]. I find if you bring it up you can tell, as soon as you say what sort of tablets are you taking, what do you do. Sometimes they'll say, Oh well you know, they don't affect me at all and I don't like them, or something. They won't continue on and you know they don't want to talk about it any more. But then some people do want to talk about it, you know. And **I really think it's better to talk about it, than to ... pretend you haven't got it.** ... I know a lady and she's was diagnosed with Parkinson's. Anyway I rang her up and I said, Well I'll pick you up and take*

*you down to the meeting, you know. Anyway she was real upset about like being diagnosed with it and she said, she went and bought some books and she wished she hadn't bought them then. And I said to her later on, oh she rang me up after that and said I'm not coming again, I really don't want to know anything about it. So, you know, she just wanted to put it behind her. **But you can't do that.** I mean you're living with it from day to day. **You have to sort of say, Well I've got to accept this thing and do the best I can, you know.***

## **Blueprint**

Diagnosed 7 years ago – time to accommodate to impact of PD

### **Self Identity**

Someone who helps out where needed.

*I used to be really, when I was a bit younger, I was always helping out in the schools or doing things, but I just don't do that any more.*

*I've got a friend and she does a lot of volunteer things and I think, Jeez I'd love to get out and do that too, but I couldn't do it. Because I'd be too slow for a start and I don't know whether I'd be able to handle it all, you know.*

It is easy to forget things about yourself as you are now and assume you are the same as before

*... it takes me ages sometimes just to get dressed, you know. Mostly putting your shoes and socks on too and things like that because **you just don't realise you can't do it any more.***

A competent cook

*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 8 or, 7 or 8 people in the house in and out, you know, for meals.*

Interviewer: Is it too much for you to think about or is it the actual physical work ... ?

*No, I think I just get a bit worried ... that's it all going to sort of ... when you're putting all the food on the plates and cooking it all. I try and cook*

*something that I find is not going to be too hard. Like a piece of corned beef with veggies or something ... I like baked dinners too but I find, I find they're a bit fiddly sometimes because you've got to make sure your meat's cooked properly and that sort of thing.*

Her sense of self efficacy is being eroded.

### **Social Fit**

*I used to be really, when I was a bit younger, I was always helping out in the schools or doing things, but I just don't do that any more. I miss it too, in a way, you know. Cause it gets you meeting other people.*

*I've got a friend and she does a lot of volunteer things and I think, Jeez I'd love to get out and do that too, but I couldn't do it. Because I'd be too slow for a start and I don't know whether I'd be able to handle it all, you know.*

*... for years I've always had ... seven or eight people in the house in and out, you know, for meals. ... I haven't done that for a while*

### **Rule**

*I've got to keep moving.*

*Because I'd be too slow for a start*

*I don't know whether I'd be able to handle it all, you know.*

***But you can't do that.** I mean you're living with it [PD] from day to day. **You have to sort of say, Well I've got to accept this thing and do the best I can, you know.***

## Cycle of Control Analysis – Arthur Morgan

This interview was difficult to analyse because he is whirling round the cycle of control, jumping about – oh well this - but then that. For every solution he sees a problem.

### Blueprint

He sees himself as his wife's Carer.

You're also a carer? Do you agree with the use of that term?

***Too bloody right. Full time. For which I receive a carer payment.***

*He sees Husband and Carer as one and the same role.*

You're a husband. Do you see that as separate from being a carer?

*No. It's a life time role I took on.*

So husband, would you see that as a role for you?

***Too bloody right.***

Caring for his wife makes him frustrated, tired and irritable, but he wouldn't have any other way.

*The only thing is, and I regret this very much, it does make me tired and it makes me irritable.*

So when you consider that a lot of your time now is sort of dedicated to that role of caring and home duties, do you ever feel frustrated about that?

*Oh yes, frequently. On the other hand **I wouldn't have it any other way.** ... she mightn't realise but even when I'm irritable **I do enjoy doing these things for her.***

Do you think your wife feels that? That sometimes you feel frustrated.

*Oh she knows that. Oh yeah. Oh yes. I'm pretty bad tempered. Well I just sort of don't talk for a while. For a time **I withdraw** .... So I'm not very proud of myself when I go through those periods. I think **I'm a cycler.** I have highs and lows.*

*I'm very interested in gardening and I find that a great emotional outlet.*

He finds the role of carer stressful

Do you feel it's a stressful role?

R *Oh yeah.*

## Partnership dynamics

So when you consider that a lot of your time now is sort of dedicated to that role of caring and home duties, do you ever feel frustrated about that?

*Oh yes, frequently. On the other hand **I wouldn't have it any other way.**  
... she mightn't realise but even when I'm irritable **I do enjoy doing these things for her.***

Do you think your wife feels that? That sometimes you feel frustrated.

*Oh she knows that. Oh yeah. Oh yes. I'm pretty bad tempered. Well I just sort of don't talk for a while. For a time **I withdraw** .... So I'm not very proud of myself when I go through those periods. I think **I'm a cycler.** I have highs and lows.*

*... because she's so much better in the neck, **I wanted her to** be involved in as much social activity as she can. And so yes. Several days a week she's involved in some meeting somewhere. So I take her to and from those to fill in the time. So **I find that a bit wearing.***

*Because [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.*

... do you feel that she feels frustrated that you are constantly ?

*Yes, oh yes. **She's very aware of how she's hindered life.** Very self conscious of it. ... she says it. **She even says she wishes she could die so that I'd be free.** That's natural. **Not much in life for people with Parkinson's.** And somebody said to me once, Well at least Parkinson's you don't die from it. And I thought well how, you speak to a few Parkinson's and all they ask for is release, release. So there's the public misconceptions of Parkinson's. The quality of life. It's pretty important.*

*And I went through a very resentful period. But there are no worries now.*

*With good grace.*

Well I was just about to say, do you feel you're in acceptance?

*Oh yes. You don't - see some people don't. They go through hell.*

Her symptoms have social effects that distress him.

*I think in Parkinson's **it hurts me** that because they **can't ideate as we can** and they're **slow in speech**, they can't put thoughts into words. **The act of speaking produces slurring** and they are **socially isolated** in a group of people. **It hurts me** that they talk to me rather than her. And this is a painful reality of the disease. **It's very isolating**. People think that you're mentally deficient and sure, **she's lost cognitive skills, but she's very on the ball**.*

He feels her faith puts her in touch with a lot of very supportive people. He does not share it.

*it gives [Jenny] wonderful support from it.*

Yeah. So if she didn't have to go, you wouldn't go?

*I wouldn't go. No, no. She says when she dies will I go and I say no. And she gets hurt about that. But no, oh no. I see when she was ill in the hospital all last year, she had the most marvellous support from all the church folk. And for that I'm eternally grateful.*

Okay. So it's part of her, as sort of, to support her that you go?

*Oh yes, I certainly will do anything to support.*

*Actually [Jenny] still does a bit of ironing. I don't like seeing her standing up and have the iron falling on her. But she, 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.*

*Well as I say, apart from my irritability, I think I care very well. Something, sometimes I think, and I think other carers feel this, that they'd like the caree to say You're doing a good job. Encouragement I think, sometimes you'd like a bit of encouragement. You know they're appreciative.*

You'd like to hear it a bit more often?

*Yeah, that's right. Just occasionally. But somebody with a chronic illness, I think they become very introspective and that's understandable. You*

*focus on, you know, daily miseries and it stops you I think becoming egocentric. It's understandable.*

Thinking of yourself as a carer, do things ever go wrong and you think Oh I just, didn't do well today?

*Oh yes. Too definitely right. It's all part of the frustration. Yes, I don't think I've ever been an even, good tempered person. I can hide it from the public. You're a street angel, home devil, you know the business. It's a reality.*

### **Blueprint for Carer Role**

If you think of someone who would be considered a good carer, what do you think qualities they would have?

*Emotional stability, unqualified love, empathy, and skills. What else? Is that enough?*

*I don't enjoy ironing. I love washing up, I don't mind that at all. I'd rather if [Jenny] left the washing up, but she feels that she needs to do it occasionally. But ironing I find a real bug bear so we don't do much of it. I'm glad of the winter because I can put pullovers over un-ironed shirts.*

### **Family dynamics**

*Because of her lack of power **she can't nurse her grandchild**, and I think that **her appearance and inability to express** places a **barrier** between her and the young children who don't understand what's going on. And I think the two grandchildren from Wales, who are five and three, look to me and not her for these reasons. **And I get hurt because of that. And I know our son gets hurt because of that.** But that's the reality of life. I can understand. **But it hurts me that she can't get pleasure out of it.** And then of course when their first child, they came out here when they were about 6 months old, the first time we'd seen the child, and prior to their arrival [Jenny] with her Parkinson's, fell and fractured her wrist. And that was in Katoomba. And [inaudible] we were attending a funeral up there. And so she sat through the funeral and the cremation service with this fractured wrist and I brought her back to Sydney jogging through the car ... and no complaint out of her. But of course if you have dyskinesia inside a plaster cast and just between the two ... she was in*

*constant pain. And so yes, then she couldn't nurse the grandchild when she came out.*

### **Strategy**

He has become her carer as well as her husband. This means he has taken over some of her tasks as a wife.

*And I think she is very resentful of not being able to cook meals, although together we cook casseroles and things like that. But she's got the expertise and I've got the manual labour. But mostly I prepare the meals and make the soups for lunch. And with Parkinson's **you can't spread things**. She can pat things but not spread. And so I, and **she can't cut her meat up** now so I cut all her meat up if we have chops or steak or something like that, or a roast.*

... are you physically having to help her a lot during the day?

*Only to dress and undress. She can't do her bra. She can't pull pullovers over her head, and so I have to help her off with that. And she baths and dries herself. And we have satin sheets on the bed so she can turn, and bed rails, and we're within 2 steps of the toilet. We've turned the bed right around so she has one step to the hand rail on the door and she's there. So no, at this stage she's very independent. **Too independent I think which is partly why she falls.***

He drives her everywhere and identified Chauffeur as an important role that he had.

### **Problem Definition**

He cannot leave her.

Before the interview had really got underway he blurted out the following.

He has had to give a lot of things that were for him in order to care for her because he feels she needs 24 hour care because she has a torrid history of falls, which means that he does not feel able to leave her on her own.

This belief is supported by:

## The History

*Last year as a result of the fall - she had 2 very severe falls when she strikes the back of her head and she caused damage to her cervical spine, and the result of that was **very severe compression of the eighth cervical nerve on the right hand side**. And she was on morphine twice a day without any relief and she had a surgical procedure to relieve the pressure on the nerve, but didn't relieve the pain, and as a result of that the neurosurgeon referred us to an orthopaedic man who specializes in mobility disorders of the neck, and she had a **5 hour operation** this time last year virtually in which she had the seventh cervical and the first [thoracic] vertebrae plated together and wired at the back and disc, and the vertebrae distracted to allow bone grafting front and back. And she had rather a stormy convalescence in that. But since then she's had **12 months relatively pain free**. But because of the state of her cervical spine, **if she goes on having falls she can have similar damage above and below**. And **in the last week or two she's been having more falls again for no accountable reason**.*

*And so I really don't have any activity outside the house. The Probis Club runs walking, walks once a month and outings, but **I don't really feel that I can ever participate** in those. ... And it's for retired business and professional people and for anyone really of goodwill. It's been a marvellous organisation of which I was President 5 years ago and **loved the involvement**, and **I took up bowls** at that stage, but **I didn't feel justified in being away out of the house for 4 hours regularly** so I've given that up.*

*And **I used to do a lot of bush walking** when I was with the Probis Club and I've given all that up now. And so yes, **it's had a severe impact on me**.*

*Well I used to belong to the Liberal Party but I don't go to that now because it takes me away at night. I would never go to an evening function really. Except that there's this course the church wanted me to go and the local Minister wanted me to go to and that's every Wednesday night for 12 weeks, and I rather enjoy that because I have a meal brought to me. Get waited on.*

*(Laughing).*

*I find that [eating at home] difficult, by the time I get the meal. I don't have, 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 of that.*

*The other thing I used to was U3A. Have you ever heard of U3A? University of the Third Age. Oh that was a, oh that's a wonderful organisation, groups everywhere. And I did 12 months geology with them, but again you see, it takes me away for 3 hours. I used to sing with choir ... U3A, for instance, have a choir and I've been so often asked to join that, but I can't make that commitment. I get a lot of pleasure out of singing.*

His role as Carer is full-time.

So what I hear from you, is it correct to say that your role as a carer has taken over from a lot of the things?

*Oh full time.*

Twenty four hours?

*Oh yes.*

This change in their relationship seems to have come following surgical intervention for her PD. He is a little unclear about this, as he says she had the pallidotomy to relieve her dyskinesia and it did, but then she developed dyskinesia.

*And it really all goes back to her pallidotomy, you see. She probably told you she had 2 pallidotomies done 5 years ago.*

*Well because of her Parkinson's she has Sinemet of a day to relieve it. A side effect in a small percentage of people apparently they get severe dyskinesia – uncontrolled movement of limbs – and as a result of that she had a pallidotomy done 5 years ago with such a good result, but that only cured one side and then she started off [inaudible] the other side and so six months later she had a pallidotomy the other side, and that's relieved the limb but what pallidotomy doesn't cure is the dyskinesia which developed after that. And that's part of the neck problem. And then unfortunately on Christmas Eve I think 12 months later, she was admitted to North Shore Hospital with bronchopneumonia, which very nearly was the end of her. And she was in North Shore for, oh, for 3 weeks and that knocked her about as well.*

He is also experiencing difficulty in working on a book of his family's history he is writing.

*And so in terms of writing this book for instance, the 12 months last year **I didn't go out**, I wasn't able to do a thing. Because unless you can sit down and devote an hour or two to it, **it's not worth starting**. And so I found that irritating to me. Because, the imperative to get it done was because my sister is 84 and my brother is 82, and he's in very ill health, and I wanted them to see the result of my labours before anything happens to them. ... And so **I felt a lot of frustration** wanting to get on but not being able to.*

### **Community Access is Poor**

*But it means **we haven't been for a holiday for 18 months**, except for these 2 quick dashes up to Forster to see my brother. We're actually doing that Monday. And I don't like **making Beth come** because she doesn't enjoy the car trip with her neck and there are not the conveniences in the motel that there are at home and so it's, **it's something that she does for me**. But I don't like going. And we've given up going away. **It's just not worth the effort**. My daughter's husband has a cottage up the coast and we did that once, but it's up 2 flights of stairs and it's not really on.*

*And I think she's reached the stage where she's more [convinced?] so when we come to the time to go – I'd like to get out for picnics but she's not really anxious to do it. We occasionally get to a film but usually there are stairs. At the Marion Street Theatre it's fairly level going. Except that I've got to drop her outside and take her in and get her seated. We go with an elderly person and once I had the horror, they were standing outside while I got the car and [Jenny] **fell** and pulled this elderly person on top of her. And so I kind of risk that happening. The other person had a fractured hip as a result of it.*

*... there's this honeymoon period before you become too immobile to do it, and we missed that period. We could have done it, in that respect. But I feel cheated, **we feel cheated about that**.*

## Strategy

Someone could sit with her.

## Barrier

*See the awkward part is there are so many people who would come and sit with her but she doesn't, at this stage, want to be baby sat. And in fact I had an elderly woman who came and I found it was [Jenny] who was carrying the hot soup to the table for her. And you know, **that's the one I'm worried about is scalding with carrying hot things**. And so I, there are plenty of people of goodwill I could call on.*

## Strategy

He does leave her.

*Oh I go up the street and do a bit of shopping for half an hour.*

He is on the Parkinson's Support Group Committee

*I leave [Jenny] for the two and a half or three hours. That's of a morning.*

## Problem definition

All the caring, housework, taking granddaughter to day care, gardening etc. make him tired and then he gets irritable.

*The only thing is, and I regret this very much, it does make me tired and it makes me irritable.*

## Strategy

Gardening

*... fortunately I'm very interested in gardening and I find that a great emotional outlet, although physically it becomes a bit tedious at times and I don't like to see it deteriorate. We've been here 30 years and it is my joy and a conversational piece with all the passing neighbours. And so it's a sort of source of social contact.*

Are there ever times of the day when you have just time to yourself? Just you in a task, something that you do?

*Not really. Only in the garden.*

## **Strategy**

Attending a carer's support group

*I attended a carer's support group for about 12/18 months. ... Yeah, well when I was President of the Parkinson's Support Group I told so many people to go I thought I really should go myself and find out what went on there. And I enjoyed it very much. I enjoyed the participation because I felt I was able to contribute to the support group.*

## **Barrier**

He has given up the group because he worries too much if he leaves her now.

*But I found that took me out for 2 hours and **I didn't feel that was justified any longer**. So I gave that up about 18 months ago. I had 2 years as President of the local support group and I enjoyed that greatly and I think we ran a very good group. I also sat on the State Council for those 2 years but I couldn't take myself away for that period of time. **And I worry too much when I'm away.***

## **Strategy**

*What we do at the Parkinson's Support Group, periodically, about 3 times a year, we break up into groups – the carer's group and the sufferers. And we've had support of psychologists from the Lady Davidson and sometimes from North Shore Hospital. Other times we're just a group on our own. And yes, I think they're very useful. Oh yes, it's a common story. We all feel that. And I think the great thing about these, these support groups is that you realise that other people's problems is a damn sight worse than your own.*

## **Problem Definition**

Social isolation. He has given up Probis club, bush walking, bowling and time away from the house on his own, and replaced them with time spent with his wife caring for her.

*I worry too much when I'm away. So there's no pleasure in me being away. I don't ever go to town.*

### **Strategy**

#### Gardening

*We've been here 30 years and it is my joy and a conversational piece with all the passing neighbours. And so it's a sort of source of social contact.*

### **Strategy**

*What we do do, we have the social outings and we subscribe to the Theatre sessions at Marion Street and Glen Street. But those are afternoon matinees cause [inaudible] can't go out at night. Because after about 8 o'clock she's wiped out. And she's in bed by half past 8.*

### **Problem definition**

He gets anxious about her a lot.

*I'm anxious about so many things. I'm anxious. Every time I hear a thump outside I think [Jenny] ... fallen somewhere and I dash out. It's as simple as that. And so you live with a constant anxiety. ... But in the days before, ... while she was independent, she walked up the street on her own without walkers or anything, and two of my friends walked home with her, and she'd collapsed on her face and broke a tooth on a plate and I thought she'd fractured her maxilla, and she'd cut her face and, oh, it was a terrible mess. And so that's when she was **forbidden** to travel alone.*

*And yes, I very rarely have a rest, a restful night, because she's up to the bathroom 2 or 3 times a night. ... Oh well you wake. And so I think I'm lucky if I get 6 hours at night but ... If I occasionally get seven and a half or eight, that's fabulous.*

When you think of yourself as a carer and the future, what do you see happening there? Is that a, is it a concern for you or are you not worried about it?

*Yes it is a concern for me because I think we're in a honeymoon period again now and I can't see this lasting for very much longer. You know the average duration of life for Parkinson's after the diagnosis is 10 years and [Jenny] is in her 15<sup>th</sup> year. And so she's done terribly well so, yeah, the future isn't all that bright. And she's very much less mobile I think the last few weeks than she used to be. And I think she's fearful of slipping. We've had a ramp put down the yard so there's no steps for her to come up. And so it means that when we ever go out I let her out there. I come in, lock the door there and go out the front door. So there's all that added. And likewise, when we come home I've got to come in the front door, come right through the back and open the back door. So, you know, I don't look too far ahead.*

When you say a honeymoon period, what do you mean by that?

*Well where the disease isn't catching up on her. She's, I look at other people and, in our support group, and [Jenny] has done extraordinarily well. Other people have gone down very much more quickly than she has. ... Luck of the business. I think like a lot of disease, the earlier you get it sometimes the quicker it progresses. It's true of a lot of cancers I think. They're more aggressive the younger you get them. On the other hand I can think of one person who had it for 38 years and she was really only in [Jenny's] state now. So I think honeymoon period inasmuch as you haven't progressed from a stage 4 which [Jenny] is in now into stage 5 where you're totally dependent. So for me that's a honeymoon period.*

### **An Overall Strategy for the Future**

He or they must have been looking forward to a time when he would no longer be able to manage. He or they had considered a retirement village, but found it would not offer the facilities she will need.

*And of course you know they're building big additions to this retirement village over the road and **we had our name down to get into one of the units**, because the original concept was that there would be a nursing home there and so, should she need full time nursing care, she'd go direct from the unit into the nursing. But that concept changed with the passage of time and now they have assisted care units but no nursing home, and so she ... would have to*

*go from there to Gordon and so there's no advantage moving whatever. So we finally opted out of that and we'll stay here, because they do provide nursing care services in the home if she needed bathing and so on. We had the District Nurse in when she came home after her leg surgery for 2 or 3 weeks. But she copes with that at the moment on her own.*