

Definitions used to Determine Phase of Pd

Functional Performance

Early phase:

Participant does not report any limitations that rate as moderate or severe using the following definitions for mobility, personal care and communication.

Middle Phase:

Participant has no severe ratings, and not more than one moderate rating.

Late phase:

Participant reports at least one limitation that is rated as severe, or two that were rated moderate.

Definitions by occupational performance modality

Mobility:

Mild - generally independent in community mobility. The person is able to move about the local community without assistance. This includes one or all of the following: walking, driving a car, using public transport (including taxis).

Moderate - able to move about the community with assistance. The person is able to move about the local community but requires the assistance of others. This assistance may be in the form of lifts in someone else's car, assistance in negotiating architectural barriers in the community, assistance in managing mobility equipment.

Severe - the person is only able to go into the community on a very limited basis. He or she requires the full assistance of others for any kind of community activity.

Communication:

Mild - generally independent in communication

Moderate - able to communicate with some difficulty e.g. speech is difficult for others to understand at times,

Severe - Finds communication very difficult and/or is hard to understand.

Personal Care:

Mild - generally independent in all aspects of showering, dressing, feeding and toileting.

Moderate - independent in showering, dressing, feeding and toileting with minimal assistance from others. This may take the form of minimal assistance with fine manipulation tasks, or preparation and/or placement of equipment.

Severe - dependent upon others for one or more activities of showering, dressing, feeding and toileting.

APPENDIX 5.9

**INFORMATION HANDOUT GIVEN TO
PARKINSON'S SUPPORT GROUPS AS
PART OF TALK**

The Community Role Performance of Women with Parkinson's Disease and their Partners

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Study Aim

To find out more about how people with Parkinson's disease and their partners continue to actively participate in community life.

Background

Recent major research studies have shown that continued meaningful participation in the areas of life that are important to a given individual has a major impact on well-being and even on survival. Very little is known about how well people with just about any form of disability (including Parkinson's disease) manage to continue on with the things that are important to them. What do they do that enables them to carry on? What stops them? Are their partners affected? In what ways?

Method

We felt that community participation was an important area for most people, and we chose to look at this. We used role as the vehicle for asking people about what they did and how they organised, thought and felt about what they did. We chose to interview women and their partners for this study, again to simplify things for us as this was a small study. We interviewed ten women with Parkinson's disease and eight of the role partners they identified. People were asked about their own personal perceptions at the time of the interview.

Findings for Women with Parkinson's Disease

Stage of Disease

We wanted to have some idea of where people were in the disease process. Being occupational therapists, we were more interested in placing people in terms of what they could do than in terms of their clinical symptoms. We asked participants to tell us a little about what they could and could not do in terms of getting about, doing personal things like getting showered

and dressed and being able to communicate satisfactorily with others. We used this information to place people roughly in terms of where they were in the progression of the disease. We had three stages - early, middle and late. We found we had three people in the early stage, four in the middle stage and three in the late stage.

When we analysed what people had said, we found three major factors that affected community participation. There was the primary disease process of Parkinson's disease and its impact on *doing*. Then there were the secondary personal limitations that developed as a consequence of the disease process. Finally we identified secondary social limitations that also arose out of the impact of the disease process on everyday life. These all added together to form barriers to community participation. We were able to identify a number of these and also things which participants identified as helping them to overcome these barriers. What follows is a very brief summary of the findings.

Primary Disease Process

a) Impact of primary disease process on *doing*

Mobility: balance problems, falls, fear of falling, unable to drive

Other movement: difficulty using upper limbs/hands.

Reduced energy: the need to rest reducing time available for other things, time of day becomes important.

Cognition: memory, planning, complex problem solving.

Medication management: side effects, possibility of overdosing, takes up time and effort.

Communication: difficulty being heard, difficulty using phone, being ignored.

b) Factors that minimise the impact of the primary disease process upon the person's ability to physically *do*

Medication: *very* important.

General exercise: yoga, exercise class.

Therapy: only one person mentioned this.

c) Partner's response to these issues

As the disease progressed, they provided more and more physical support to enable their partner to access the community, function when out, and escape back home as needed.

Secondary Personal Limitations

a) **Personal limitations**

Dealing with the disease: constant - no let-up, dealing with doctors.

Self-efficacy: Early stage women felt inadequate - little knowledge of how to deal with disease, difficulties with motivation. Middle stage women expressed a loss of confidence, but appeared more motivated and in control than early or late stage women. Late stage women expressed a sense of frustration and loss of control.

b) **Factors that minimise secondary personal limitations**

Keeping active: helps to counteract negative feelings.

A positive attitude: acceptance of disease an important part of this.

Persistence: being motivated, pushing oneself to do things, being an active problem solver, making adjustments that are personally acceptable.

Energy saving tactics: having someone else do the heavy work, understanding and using 'good' and 'bad' times of day effectively.

c) **Partner's Response**

In the early stages some strongly expected their partners to maintain full independence. They supported and encouraged their partner's persistence. They took on the heavy jobs to enable their partners to conserve energy for the important things in life. They helped their partners deal with the disease by educating themselves about Parkinson's disease and by acting as an advocate for their partners with others - particularly health professionals.

Secondary social limitations

a) **Social limitations**

Keeping in touch: a wish not to be demanding of others, loss of spontaneity, visits could be tiring, limited time available, communication limitations.

Quality of partnership: decline in sense of equality in early and late stages but not in middle stage.

b) Factors that minimise secondary social limitations

A dynamic partnership: working as a team, protecting partner from your problems where possible, using partner as an ally, helping partner to understand disease as it is affecting you, giving partner breaks away from you.

Stoicism: doing things alone where possible, being determined to 'get on with it', not complaining to others.

Friends: an important, non-judgemental resource, a lifeline to the community, work to maintain reciprocity of relationship.

Keeping in touch: establish routines that work, use telephone, allow others to take initiative in making contact, educate about Parkinson's disease.

a) Partner's response

Partners in the early stage did not make many changes. Those in the middle and late stages maintained a sharing approach to community roles and in other areas of life. They maintained the expectation that their partner would continue to go out into the community. They persisted in suggesting community projects. They maintained a flexible attitude about community outings. They supported their partners when in their community roles and acted at times as an intermediary with others where their expectations were deemed unreasonable. Many partners demonstrated a strong empathy for their wife's situation. They tried to minimise or anticipate problems related to community participation.

Consequential barriers or losses in relation to community role performance

(a) Barriers and losses to community role performance

Loss of access: mobility, reduced energy, slippery floors, need to go with someone else, unable to be spontaneous and flexible, anxiety about planned activities in case not up to it on the day.

Loss of spontaneity: need to plan, need to manage the illness, things at home take longer than before.

Community role losses: need to readjust goals because of limitations, frustration, leads to loss of social contact.

b) Factors that minimise the barriers to community participation

Maintain meaning: very important, keep doing the things that really matter to you, eliminate less important things if necessary, use supportive partner to help you with transport, set up regular routine so can plan ahead effectively, plan escape routes so can bale out if necessary, maintain a sense of contribution.

Resources: supportive husband, community contacts such as church groups, neighbours.

Access: living in familiar community makes easier, driving, taxis, lifts from others, taking breaks e.g. on long drives, using support such as husband's arm or shopping trolley, having assistance with sitting/standing etc., getting people to come to you.

Routine: Allows forward planning and priority setting.

Using problem-solving to save energy: use knowledge and experience, get someone else to do the *doing* bits, but keep doing the thinking bits, choose to do things that involve brain rather than body.

Maintaining control: very important, keep up an ongoing process of goal setting and re-setting to accommodate change, plan carefully to avoid problematic situations without compromising overall goals.

Maintain a sense of contribution: very important to maintaining meaning. Doing things that give pleasure to others, being involved and absorbed in the activities of others.

c) Partner's response

Providing the psychological, social and physical support to enable community access by their partners. Ensuring they do everything together. Being flexible about community activities. Pushing partner to maintain community roles. Protecting partner from adverse community demands.

Impact of Parkinson's Disease on Partner's Community Role Performance

Partners of women in the early stage continued with their own community participation with little change. Some partners in the middle stage and both partners in the late stage experienced significant losses in their own community role performance. This was usually due to the fact that they felt unable to leave their wives alone and were unable to find someone who could provide the right kind of support in their absence.

Community participation continued in the middle stage and to a lesser extent in the late stage. Partners still continued with their own community roles, but some employed strategies

that made it easier to do this. As previously mentioned, a common strategy was that of doing things together. Joint community participation was often made easier by finding ways to ensure continued access to the community in the face of increasing physical problems. Some couples had moved into retirement villages, where community participation was possible on a more local scale and therefore easier to manage. Some had chosen the option of having people come to their homes rather than going out so much as before.

Partners in the middle and late stages also made arrangements so they could leave their wives in such a way that they could be easily be summoned and return home quickly if needed. This happened more rarely in the late stage.

APPENDIX 5.11

EXAMPLES OF INTERVIEW SUMMARIES OF DOING, BEING AND KNOWING INTERVIEWS FOR PARTICIPANTS WITH PD AND THEIR PARTNERS

Frank Lewis - Summary of Doing

Demographics: Mr. Lewis is 79 years old. He was diagnosed with Parkinson's disease 5 years ago. He was born, and has always lived in Australia, and lives at home with his wife. He has two brothers and one sister, and one daughter and two grandchildren. He spends the majority of his time at home and does not do anything he would class as formal work.

Functional performance: Mr. Lewis drives a car, although her prefers not to drive at night, because he finds it harder to see. He walks several times a day to the local shopping centre. He finds his writing is getting shaky and hard to read. He also finds it difficult to do up buttons, shoelaces and other tasks that require 'nimble fingers'. He cuts his food up small because he finds it difficult to swallow otherwise.

Roles: Mr. Lewis identified three roles: Husband, Family member and Friend.

Husband: Mr. Lewis does the majority of the shopping. He shares the washing up with his wife. Sometimes they play indoor bowls together.

Family member: He sees his daughter and her family roughly twice a month, and talks to them on the phone.

Friend: Mr. Lewis sees friends at the RSL Clubs, the bowling club and at functions. He also has other older friends that he sees socially. They arrange to go somewhere together. He no longer sees friends he made through his work. Over the years a number of his friends have died, or he has lost contact with them.

Activity areas: Shopping; Club membership and Relaxation.

Shopping: Mr. Lewis shops regularly - often several times a day. Some of the time is spent checking prices and looking at what is coming into the stores. He is curious about marketing. He pays attention to advertisements to keep informed about new commodities coming on to the market so he can go and see them and form his own opinion of them.

Club member: Mr. Lewis plays lawn bowls every week. He also attends two RSL Club Branch Meetings and Air Force Club meetings regularly. In addition, he attends two or three Parkinson support groups and the exercise group at Concord Hospital.

Relaxation: Mr. Lewis listens to the radio or watches TV to relax.

Regular Activities:

Daily:

- Going shopping (window shopping as well as buying necessities)
- Household tasks
- Watching TV
- Listening to the radio
- Reading

Weekly:

- Going to an RSL Club
- Playing bowls at the Bowling Club

Fortnightly:

- Seeing daughter and her family
- Attending club branch meeting
- Attending Parkinson's support group

Occasionally:

- Seeing brothers and sister
- Air Force Club branch meeting

Summary of Mrs. Enid Irwin's Second Interview - Being

Enid clearly identified her most important role as being a wife. She identified Mother as next most important, then Friend, then Grandmother and last Sports enthusiast. This order was a rough sequence rather than a strict order of value or importance to her. At the first interview, the role of being a Person with Parkinson's disease was identified, but at this interview Mrs. Irwin made it clear that having Parkinson's disease was something that has happened to her rather than being part of who she was, and that therefore it was not a role.

As a wife, Enid appreciates very much what her husband does for her, and feels very good about their relationship. She enjoys the way he looks after her, and thinks he is wonderful. At the same time, she said she does get cranky with him at times, although she feels he doesn't deserve it. She mostly gets cross when she feels he is taking over too much. On the other hand, she feels she has to keep going and keep trying for his sake. She feels sad that they have not been able to realise the plans they had for their later life together.

As a friend, Enid finds it harder to keep in touch with her friends now because she cannot use the telephone, and she is not comfortable in groups of people. She feels things are different now when she sees her friends as a group - not that people leave her out, but just that things have changed and she is no longer on an equal footing with them. She feels she has very good and supportive friends and appreciates them very much.

As a mother she is very proud of her sons. As a grandmother she loves her grandchildren very much. She loves to see all her family.

As a sports enthusiast Enid used to be an enthusiastic golfer and felt it did her good, but now she regrets she is unable to play.

Enid experiences pain in her arm and can become very tired quite suddenly. She is angry about the fact that her fingers will no longer do what she wants. She gets very frustrated about her inability to remember things when she is put on the spot, and her lack of fluency when talking to people. However, she is stoical about her difficulties. She says some things have improved. For example, she feels she no longer worries so much or burst into tears as often as before. She has a good sense of humour which she uses in a self-deprecating way. She loves going down through the park on their almost daily

walks. She also loves sleeping during the day and at night in front of the television. She said she feels very nice when she wakes up. She also enjoys thinking about the past, and she appreciates peace and quiet.

Summary of Mr. Peter Vaughan *Doing*

Peter is 46 years old. He has three children - two adults and one teenager. The younger son is still at school. His daughter is a university student and lives away from home. Peter is divorced from the children's mother, and the younger son lives some of the time with her. Peter built his house himself. His older son lives with him at present and the younger one is also there half the time. Peter and his second wife split up twelve months ago. They are now divorced. This and other family problems mean he experiences high levels of stress.

Mobility

Peter has experienced problems with driving the past (leading him to modify his car) but has none at present. He is not aware of any limit to the distance he can walk and his balance does not seem to be a problem. He works intermittently, plays tennis regularly, and has recently renewed his pilot's licence.

Communication

Peter finds no problem talking to people, but he feels he is slower now in processing information during a conversation than he used to be. He uses a computer for written communication and has learned to use the mouse with his left hand. He can still sign his name, but his signature deteriorates badly if he has to sign repeatedly.

Personal Care

Peter is independent in this area, but has had to teach himself to do most of his personal care tasks (such as shaving and cleaning his teeth) with his left hand, because he is slow and inaccurate with his right hand.

Roles

At interview the following roles were established as being current: Health Manager, Businessman, Brother, Father, Grandfather, Mediator, Home Manager, Friend, Church member, Rotarian, Tennis player, and Water Skier. He identified Father and Businessman as being the roles that were most part of who he was as a person. Shortly after this interview, he regained his licence as a pilot.

Peter is a **Health Manager**. He was diagnosed with Parkinson's disease four years ago. It affects the dominant (right) side of his body. His symptoms include tremor in both his arm and leg. His tremor is worst when he is standing and when he is tired. Peter feels his tremor is a problem in interacting with others - especially people who do not know him. He used to obtain much of his work because he was good at pitching for jobs. He was able to convince people that he was the man they needed. Now he feels the tremor prevents him from doing this effectively. It can also be difficult socially. He has no choice about whether people are aware he has health problems. His tremor advertises the fact. He uses humour to deflect people's reactions.

Peter has difficulty performing tasks requiring dexterity with his right hand. He has also noticed that his memory is not as good as it used to be and that he takes longer to process information than he used to. He uses post-it stickers placed in prominent places to remind himself of tasks he must do. He does not sleep well, is often tired and does not handle stress well. His self-confidence has been affected by all this, but he believes strongly that he must keep going.

At present Peter feels his symptoms are reasonably well controlled. He relies on medication and he experiments to find the right drug and the right dose that suits him. He went off his medication for a while and experienced a major drop in his level of functioning. Now he is careful not to over medicate, and uses naturopathic methods and exercise to help him deal with his symptoms. Strengthening and stretching help him to deal with a shoulder that becomes painful as a result of poor arm swing.

As a **Businessman**, Peter works intermittently. Just prior to his diagnosis with Parkinson's disease, he was looking for a new work challenge and invested in a greenhouse with a view to growing tomatoes. He found he lacked the physical ability to carry this out successfully, because of his symptoms. He found he had to move away from his licensed trade as a plumber for similar reasons.

Peter enjoys taking risks and finding solutions, and uses these traits in the work he does now. He has a partner, and together they tender successfully for difficult jobs and employ others to do the physical work involved. Peter still spends much of his time on site when he is working, but now he is using his experience and knowledge to instruct others. He does some development work as well. He described his work role variously as being a Businessman, a licensed Plumber, Drainer and Gasfitter, a Developer, an Opportunist, and a Co-ordinator.

As a **Brother**, Peter sees his two sisters and brother regularly. One sister lives nearby and he sees her the most. As a **Father**, Peter spends time with all his children and provides a home and support to each of them as it is needed. He is currently engaged in using a software program to organise the family photos. There is a REXLAGE of family pictures on the wall. Peter is **Grandfather** to a boy who is one year old. The child's parents have split up. This makes it difficult for Peter to spend as much time as he would like with his grandson. As a **Mediator** he is trying to help the situation between his son and the son's ex-partner. His son cannot get legal aid, so Peter has been talking to lawyers on his behalf to try and work out how to manage the legal side of the situation. He has been trying to help his son to act in the best interests of the child rather than be punitive towards his ex-partner.

As a **Home Manager**, Peter runs the household, and does the shopping and the cooking. He employs a cleaner on a fortnightly basis.

The role of **Friend** was not identified, but Peter has a number of friends that he sees regularly, both formally and informally. He had recently been on an extensive outback car rally with some friends. As a **Church member**, Peter produces the weekly bulletin for his church as well as attending church regularly. Peter is a **Rotarian** and attends a rotary dinner every week. This role is linked to a possible future role as a fund raiser, as Peter has plans to do some fund raising for Parkinson's disease through Rotary.

Peter has a passion for flying and is very experienced, having been a **Pilot** for 35 years. After a two year break (when he stopped taking medication) he has just returned to flying again. He plans to only take jobs he thinks will suit him from now on, and sees it as his 'last hooray'. Peter is a **Tennis player** and plays as much as four times per week. He plays on his neighbour's court and also at the local tennis club. He is also a **Water skier**, but at present there is not enough water in the dam for water skiing. Once a year he goes with his family to Foster and they water-ski there.

Activities

In addition to Peter's roles, a number of activities were identified at the interview. These were: Playing games, cleaning, driving, bush walking, washing up, playing bowls, cooking, resting, family gatherings, watching TV, gardening, shopping, car maintenance, dancing, swimming, photography, laundry, spending time with grandson, home maintenance, putting out the rubbish, entertaining, cycling, listening to music, exercising,

workshop, mending, eating with friends, talking on the telephone, using the computer, camping, movies, reading, doing accounts.

The Past and the Future

Peter identified the following things he has lost: regular work and therefore income, a relationship, winning at tennis, and flying. He also identified the following possible future roles: Traveller, Pilot, Fund raiser (for Parkinson's disease) and Student (for a builder's licence). Since the interview, Peter has renewed his pilot's licence, but thinks he might only fly for another twelve months.

He finds the uncertainty of his future one of the hardest things he has to deal with. He is trying to make financial decisions that will ensure he will be secure later, but finds it hard to know what would be best. He is determined to face the future, saying 'I'm not an ostrich'.

Summary of what Mrs. Allen *does*

Demographics

Mrs. Allen was born in Australia on 29th July, 1928. Her husband was diagnosed with Parkinson's disease in 1997 and he died in 2002. Mrs. Allen usually lives alone in the same house she has occupied all her married life. She has family staying with her at present.

Mobility, communication and personal care

Mrs. Allen drives a car, talks easily to people and has no difficulties in personal care. She has arthritis in her knees which can affect her ability to walk at times, particularly if she does not exercise.

Routine commitments

Mrs. Allen dusts and sweeps the house daily.

Her weekly routine is as follows:

Day	Morning	Afternoon	Evening
Monday	Parkinson's exercise group		
Tuesday	Shopping		
Wednesday		Raffle	
Thursday	Housework		Family dinner at home
Friday	Housework	Sister visits. Play Yahtzee	
Saturday			
Sunday	Visits family or family visit her		

She also visits the cemetery

Mrs. Allen attends a Parkinson's support group on a monthly basis

Roles

Mrs. Allen identified fourteen roles: Cook; Correspondent; Friend; Grandmother; Home maintainer; Knitter; Mother; Neighbour; Parkinson's supporter; Reader; Sports watcher; Sister; Widow; and Yahtzee player.

She enjoys **cooking** for her family and does so regularly - particularly baked dinners. In addition to the baking she does for fund-raising, she also makes shortbread and large numbers of mince pies to give to people at Christmas time.

Mrs. Allen **corresponds** regularly with a large number of people. Some are friends and relatives of her husband's, some are her own friends and pen-friends.

Mrs. Allen has many **friends**. The Parkinson's group is an important source of friendship, and attending the weekly raffle means she sees another group of friends regularly. Her best friend used to live across the road, but has now moved away. She keeps in touch with friends by letter and by telephone.

As a **grandmother**, she has eight grand-children and two great grand-children. her grandchildren are mostly adult now. She sees them all regularly, although some are overseas travelling at present. One grandchild is living with her temporarily just now. She and her grandchildren have been able to help each other to deal with her husband's death.

As a **Home maintainer** Mrs. Allen is keen to stay in her own home. She has it the way she likes it. She is very organised about her housework and her shopping and sticks to a routine for getting things done. Her sons help out with maintenance jobs as they come up. She keeps the garden tidy, although she is not a gardener. She pays a handyman to mow the lawns regularly.

Mrs. Allen **knits** mainly for fund-raising purposes. Her sister also contributes in the same way. She prefers to knit in the winter as she finds she gets too hot otherwise.

She is **mother** to three sons. She sees all the family regularly. Her sons and their wives come regularly to dinner, and she visits them. For one son this entails going away for the weeRexd. Another son who is separated has come to live with her temporarily and she is enjoying this. She enjoys being able to give the families things she wins at the weekly raffle and her sons all help out with home maintenance, to the extent that she never has to get anyone in to do work on the house. She is also close to her daughters-in-law.

Mrs. Allen gets on very well with her **neighbours**. One neighbour is like a younger sister to her and keeps a firm eye on her to make sure she is OK. Her grandchildren also visit, and Mrs. Allen enjoys having small children around now that her own grandchildren have grown up.

She is a very keen supporter of **Parkinson's** NSW and Parkinson's Australia's activities. She attends a support group and an exercise group regularly. She fund raises by donating stamps, knitting and baking for fetes and other fund-raising events. She regularly takes some of her baking to the support group meeting. She also offers support and spends a great deal of time talking to people with Parkinson's disease and to their partners, either on the telephone or in person.

Mrs. Allen **reads** more now in the summer when she does not knit. She loves to read anything about Parkinson's disease.

She does not watch very much television, but she does love to watch sport. She watches football, soccer and cricket. Her favourite is soccer. She is watching more sport at present because the son who is staying with her watches it a lot. She finds it is a good way to relax.

One of her **sisters** visits every week to play Yahtzee. She goes to the weekly raffle with some of her sisters. Her youngest sister rings every second day and has been very supportive since she lost her husband.

As a **widow**, Mrs. Allen is grieving for her husband and learning to deal with his death. She is supported by her family in this. She visits the cemetery once a week.

She plays **Yahtzee** on her own and with her sisters. She finds it an enjoyable time-filler and she and her sisters compete for high scores.

Summary of how Rex Irwin experiences life - Being

Background

Rex and Enid still live in the same house they have occupied most of their married life, having built it at a time when the area was mainly bushland. They watched a suburb grow up and develop around them while they brought up four sons.

Rex himself was the youngest of three. Their father was a dentist, and the family had good standing in the community in consequence. He remembers fishing trips with his father, but his mother always stayed at home. She was a very straight, strong person and the children had to answer to her rather than their father.

Rex went right through school, but chose not to go to university. He worked initially as a footwear salesman, then moved into a career as a wholesale butcher. He worked for three different companies and retired from his last job, where he held a very responsible position,, eleven years ago. He feels that he and Enid are comfortably off in relation to their current modest needs.

Significance of roles and activities

Rex sorted his roles in order of their importance to him as follows: Carer, Husband, Friend, Home maintainer, Father, Grandfather, Neighbour, Mechanic.

When asked to identify the principle reason for doing specific roles, given certain headings, he sorted them as follows:

Productivity	Leisure	Rest and Relaxation	Self Maintenance	Social and Cultural	Other
Carer	Mechanic	Grandfather	Home maintainer	Friend	Neighbour
		Father	Husband		

When asked to sort his roles in order in terms of his satisfaction with his own role performance, Rex sorted them as follows: Carer, Husband, Home maintainer, Father, Grandfather, Friend, Mechanic, Neighbour.

The role of **carer** is the most important to Rex and he sees himself as supporting Enid and himself in their home. He described a number of problems Enid is now experiencing with performing everyday tasks. He is concerned for her safety and feels he must watch her constantly to try and prevent accidents and to ensure the smooth running of their daily life. He spends much of his time worrying and trying to anticipate problems. He has taken over much of what Enid used to do and has largely assumed responsibility for both of them. At the same time he is acutely aware of how things must be for Enid and frustrated that he cannot help her more - particularly with her communication problems. He is in a dilemma between letting her do things around the house and protecting her from possible injury.

He feels happy and satisfied with his role as a carer when Enid has a good day, but these are happening less and less often. He is finding the twenty-four hour care and the four-hourly medication routine wearing. Rex believes he does a very good job as a carer. However, he is concerned that he is starting to get testy with her and feels that the time may come when he can no longer deal with the situation as effectively.

He is looking to the future. In the short term Enid will require admission for respite care while he has a hip operation. He feels the family, while keen to help, do not have the resources or understanding of the situation to be able to hold the fort effectively while he is away. He feels their support will be much more effective if directed to visiting her as often as possible while he is in hospital. He and Enid are also currently exploring day care options, to give him a break. Enid needs lots of support from staff to accept this new situation. In the longer term Rex can see a time approaching when it may be necessary for them to sell their house and move into a fully serviced unit.

The role of **husband** is still there for Rex, but it is getting a bit swamped by the role of carer, which has to come first. He still loves Enid very much and they are friends to each other, which he feels is an important part of marriage. As a husband he sees himself as managing their joint survival at home in their house.

As a **father** and **grandfather**, Rex enjoys his family and feels pretty good about them all. He finds their company very relaxing and enjoyable. He spoke of a very happy evening recently to celebrate his birthday.

As a **friend**, Rex feels he has excellent support from their friends, although he no longer gets many opportunities for a good talk with anyone about how things are because Enid is always there.

Rex spends time in his role as a **mechanic** in the garage under the house. He finds this is a great circuit breaker and relieves his tension when he finding things a bit difficult. It gives him some time away from Enid, but allows him to remain within call. When he is working on something in the workshop he is able to focus entirely on what he is doing and screen out other issues that may be worrying him. He talks about playing with his toys and sees it as fun. He gets a lot of satisfaction from being able to meet a challenge and fix something himself. His role as carer limits the time he can spend on this - not only in terms of total time, but also the blocks of time he needs for some tasks.

As a **Neighbour** Rex actively discourages close daily interactions. He is happy to be a helpful neighbour, but has no desire to become friends with his neighbours. This policy seems to work well and he is happy with the relationships he has with his neighbours.

APPENDIX 5.12

EXAMPLES OF INTERVIEW

FIELD NOTES

Field Notes for Partner 3 (Mr. Irwin): Doing – 3.2.03

I arrived a little early, so I drove around the neighbourhood. They live on one of the lovely promontories in Sydney harbour, with water around three sides and beautiful views. Considering the outlooks, it is not a very expensive suburb and there appeared to be a lot of retired people living there. However, it seemed to be undergoing change, with large expensive houses and units being built next to the original housing which looked post war.

When I arrived both Mr. and Mrs. Irwin were sitting in their front balcony in the sun. The house is built on the side of a hill and from their balcony they have extensive harbour views. They (Mr. Irwin mainly) told me how when he had built the house it was the only one around, with the exception of one other down by the water. There was bush all around and their children used to run wild through the area. They used to have huge bonfires right where the suburban street runs now. Then gradually the houses had popped up around them and now the prices were going up and up.

When we went inside, there was some discussion about where we should sit. Mr. Irwin suggested the back patio, or inside at the dining table. The second choice meant competing with the radio and having Mrs. Irwin sitting close by watching TV. I opted for the back patio. This turned out to also be a bit noisy, as a neighbour was mowing the lawn and large planes flew overhead regularly as we were under a flight path. Several times during the interview Mr. Irwin jumped up to see how Mrs. Irwin was getting on. Each time we both forgot that I had suggested he clip the microphone to his clothing to overcome some of the noise hazards mentioned. This meant that each time the tape recorder hit the deck (must have happened three times). It is still working!

He is fit and well, apart from osteo-arthritis. He has had his right hip done with great success and is waiting to have the other one done in about three months' time (he is in a long queue because he does not have private insurance). He mentioned later on that he had already found out about respite care for Mrs. Irwin while he is in hospital and then getting mobile again.

He felt he spends nearly all his time caring for his wife. He is frightened to leave her alone for too long because she can do some strange things. Once he nipped down to the shops (which are just at the end of the road) and left at home on her own. When he

got back, she had taRex fright at his not being there and had gone out into the street, where she was found by the postman. She was waving her arms around and seemed confused. The postman rang the police and for an ambulance and he and a neighbour got her back inside before Mr. Irwin got back about five minutes later. He was clearly concerned and I felt that underneath, although he didn't say so, he was embarrassed and concerned that people might think he was not looking after her properly. Now he always takes her with him.

As we spoke, Mrs. Irwin appeared two or three times in the distance wandering through the house. She nearly came out once or twice, then put her hand to her mouth and made a face as if to say 'Oh, she is still here, I must not disturb them'. I could see this because I was facing that way. Mr. Irwin had his back to the house.

He described how they had gone to her specialist the other day and he had given her an extra half tablet, because she was really having a bad day. By the time they got there she was in great form. He was pleased because he wanted the doctor to see what she could be like. The consultant changed her medication slightly, which has seemed to help.

He said he feels cheated because they are not able to do the things he would like to be doing at this stage of their lives. They have a caravan that Mrs. Irwin refuses to go into. He feels she could if she really wanted to, but she won't. So the caravan sits in the back yard, when otherwise they might be doing some travelling. He has always been a keen sailor, and still has a boat. He said his wife is scared to go on the boat now because she is frightened she will fall. So the boat sits there too. He has a workshop under the house and he goes down there to tinker with an engine he is rebuilding. He says he spends up to an hour at a time down there and pops up to check that Mrs. Irwin is OK. He feels that if he could go sailing again it would relieve some of the stress he feels. He has also given up golf. They both used to play a lot of golf. He has had hip problems that interfere with that as well as the fact that he does not feel able to leave Mrs. Irwin. He has looked into respite care however, and said that if his left hip operation works well, then he might think about going back to golf and getting someone in to sit with Mrs. Irwin while he is gone.

He does all the cooking, although she makes cups of tea etc. He is frightened to leave her alone in the kitchen because he feels it is too dangerous. She occasionally does strange things like pour boiling water in the tea bag container rather than the teapot. He

said he also has to check if things go quiet, because she can get cognitively and physically stuck and will just stand there.

They have four sons, all married. One drops by every two or three days with his grandsons (pre-teen and teenagers) and phones most days. Another phones often and they see him about once a fortnight. Another is not speaking at present and undergoing a marriage break-up and the fourth lives further away and phones occasionally.

They also have one or two friends who ring nearly every day.

**Question for next time - do any of them give you a hand with anything? Could you ask any of them to sit with Mrs. Irwin while you went out for a bit?

They go for a walk together every afternoon, for about twenty minutes, and he feels it does a lot towards keeping her mobile. It is a hilly area and they go up the hill and down to the shoreline.

She now needs medication every four hours. He gets her to bed about 8.00 and goes himself around 10.00. He wakes up at 12.00 and at 4.00 to give her her tablets. If he sleeps through he said she usually wakes him because he can feel her starts to shake and she wakes up aching. Then it can take her a while to get back to sleep. If he catches her at the right time, he can give her the pills and she goes straight back to sleep.

He used to be a wholesale butcher. In his spare time he used to coach boys in football. Some of them still pop round to see him or ring him up. They also have old golfing friends and friends from the sailing club. They go out for meals with a group of friends every now and then, but not at night. Also, Mrs. Irwin is becoming shy of crowds and finds larger social events stressful. She finds it difficult to speak and it upsets her he said.

His roles are:

Carer, Home maintainer and husband (all different aspects of the same role); Father; Grandfather; Friend; Neighbour. Then it starts to move off role to things he does (see transcript - some useful discussion about this); Mechanic, Boat owner and Gardener.

Sort 1

I think I asked him to sort most important roles first (see transcript).

Carer/Home maintainer/Husband. Father, Grandfather, Friend, Neighbour, Mechanic were arranged across the top of the board. Then he went down the right hand side under Mechanic for Boat owner and last Gardener. He didn't feel that Gardener was a role

because it was just something he did to keep things tidy. The Boat owner role used to be an important role to him and he described a typical Saturday - very busy boating day. However, now he felt that really all that was left was tinkering with the boat engine - the Mechanic part. He seemed to be a bit equivocal about whether Mechanic or Boat owner were roles or not - perhaps because he felt they had been in the past.

Sort 2? (second photo) I asked him to sort in terms of time spent in each role, most to least.

Carer/Home maintainer/Husband; Father; Grandfather; Friend; Gardener; Mechanic; Boat owner. Then he put Neighbour to one side. He said that he sees his neighbours often, but not for any length of time.