

APPENDIX 5.16

EXAMPLE OF A DETAILED ROLE

WRITE-UP

PD6 – Peter Vaughan – Role Repertoire

Summary

Peter was unwilling to do these sorts, saying he did not like doing them and they did not reflect the way he saw his life. Data is fragmentary in consequence. He did not do a frequency or satisfaction sort, but he did do a spontaneous self identity sort. Although I have a clear memory of taking a photograph of the meta-role sort, I do not have one. He was playing around with my camera, so it is possible he inadvertently erased it. The meta-role sort information is taken from the transcript. In consequence there are four roles (Rotarian, Mediator, Church member, and Friend) left off because they were not mentioned by name on the transcript. The role of Son was left out of the self identity sort.

Taking the self-identity sort and the value sort together, there was a clear focus on Productivity. There was also the meta-role with the largest number of roles (5).

Productivity

Two major roles were sorted under this heading – Father and Businessman. The other roles were rated in the lower half for both self identity and value. Father was his top role for both parameters. Businessman was second in the self identity sort and third in the value sort.

Self Maintenance

This ranked second for both self identity and priority. Two roles (Health Manager and Home Manager) were sorted here. Home Manager ranked around the middle for both sorts. Health manager was sorted second for value, but only 6th for self identity.

Socio-cultural

This ranked third for self identity and fourth for value. Two roles, tennis player and water skier were sorted here. Tennis player was not particularly valued, but ranked fourth in terms of self identity.

Leisure

Only one role was sorted here. This was Pilot. These sorts were done before Peter got his pilot's licence back. He sorted this role low (2nd last) for self identity (in terms of who he was at the time of the interview) and much higher (5th) for value.

Rest

No roles sorted here

Role Map and Role Clusters

He sorted three complexes that were not linked: Home Manager, Health Manager and Businessman; Water skier, Tennis Player and Pilot; and the rest. The third complex (Son, Father, Brother Grandfather, Friend, Church Member, Rotarian and Mediator) seemed to contain roles that are relationship oriented. The first complex could be seen as a self maintenance or survival complex, whilst the second could be seen as leisure or relaxation. Three major role clusters were identified. Principally, there are the **Family** roles of Father, Son, Brother and Grandfather. Closely linked to this is a second cluster of **Caring** roles: Health Manager (care for self), Businessman (providing for others, particularly Son), and Home Manager. The role of Mediator links into this caring cluster and also relates to Friend. Church Member links to the Family cluster (instilling proper values into children). Rotarian also seems to link to the Family cluster but I am not sure why. The last cluster are roles **for himself** (Leisure? Self expression?) – Pilot, Water Skier, and Tennis Player.

Meta-role sort

No photo of this although I took one. This is taken from transcript. Roles not mentioned on transcript are Rotarian, Mediator, Church member, and Friend.

Productivity	Leisure	Rest	Self maintenance	Socio-cultural
Businessman	Pilot		Health Manager	Tennis Player
Son			Home Manager	Water Skier
Brother				
Father				
Grandfather				

The following sorts were done before he got his pilot's licence back

Self identity sort

Roles that are most part of who he is at present

12	Father	6	Rotarian
11	Businessman	5	Church member
10	Mediator	4	Grandfather
9	Tennis Player	3	Water Skier
8	Home Manager	2	Pilot
7	Health Manager	1	Brother

Value sort

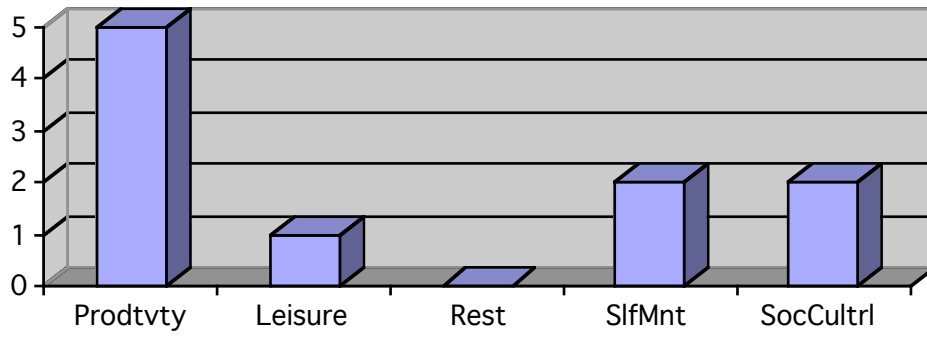
14	Father	9	Pilot / Mediator / Grandfather
13	Health Manager	6	Rotarian / Church Member
12	Friend / Businessman	4	Son / Tennis player / Brother
10	Home Manager	1	Water Skier

Individual role score (adding Self identity and Priority together)

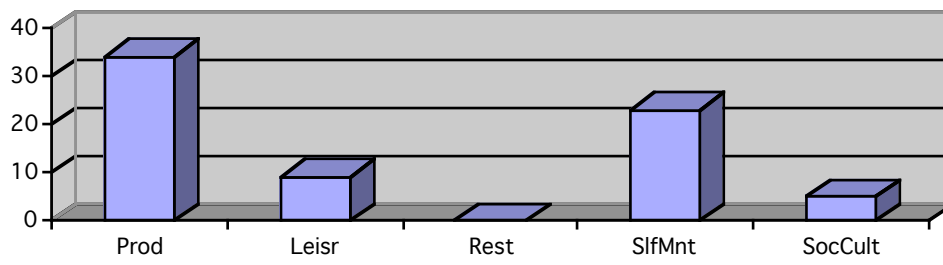
Role	Self identity	Value	Total
Father	12	14	26
Businessman	11	12	23

Health Manager	7	13	20
Mediator	10	9	19
Home Manager	8	10	18
Grandfather	4	9	13
Tennis Player	9	4	13
Rotarian	6	6	12
Church member	5	6	11
Pilot	2	9	11
Brother	1	4	5
Water Skier	3	1	4

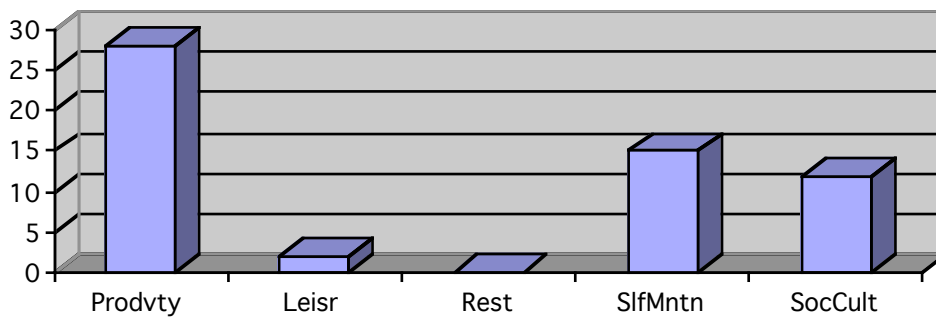
Meta-role



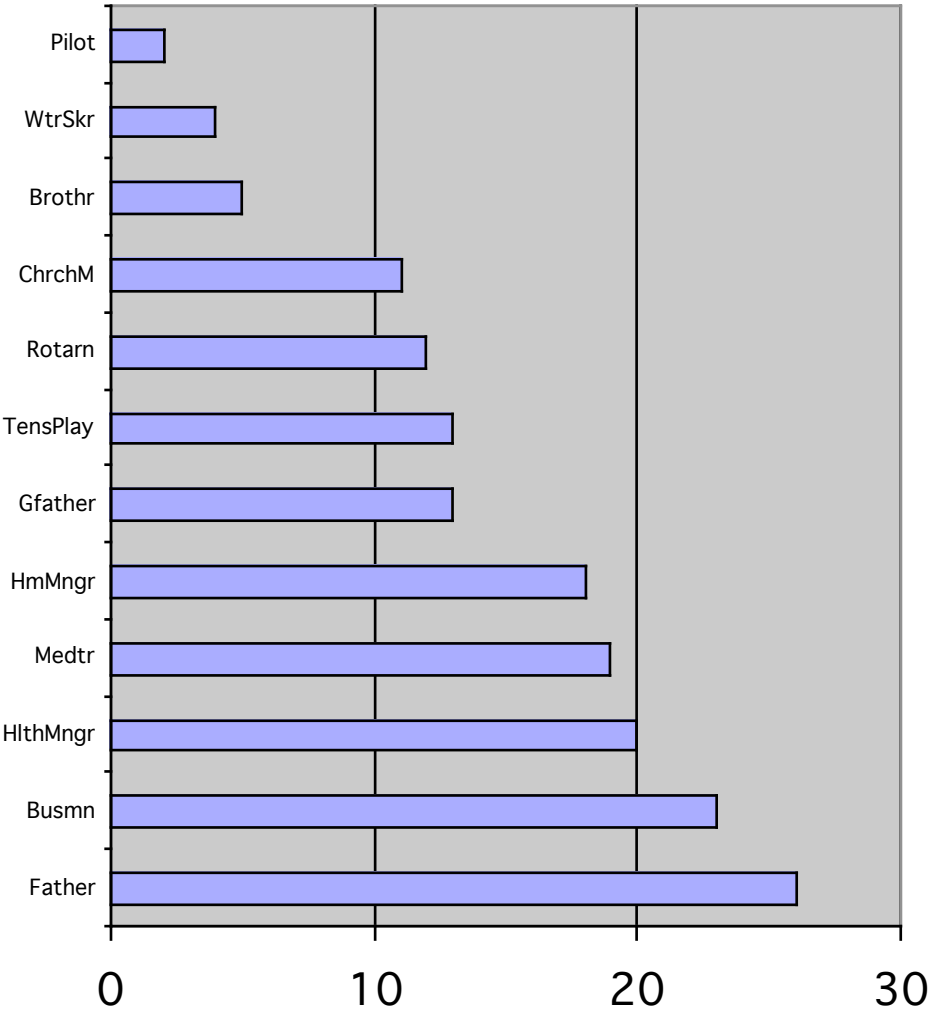
Priority



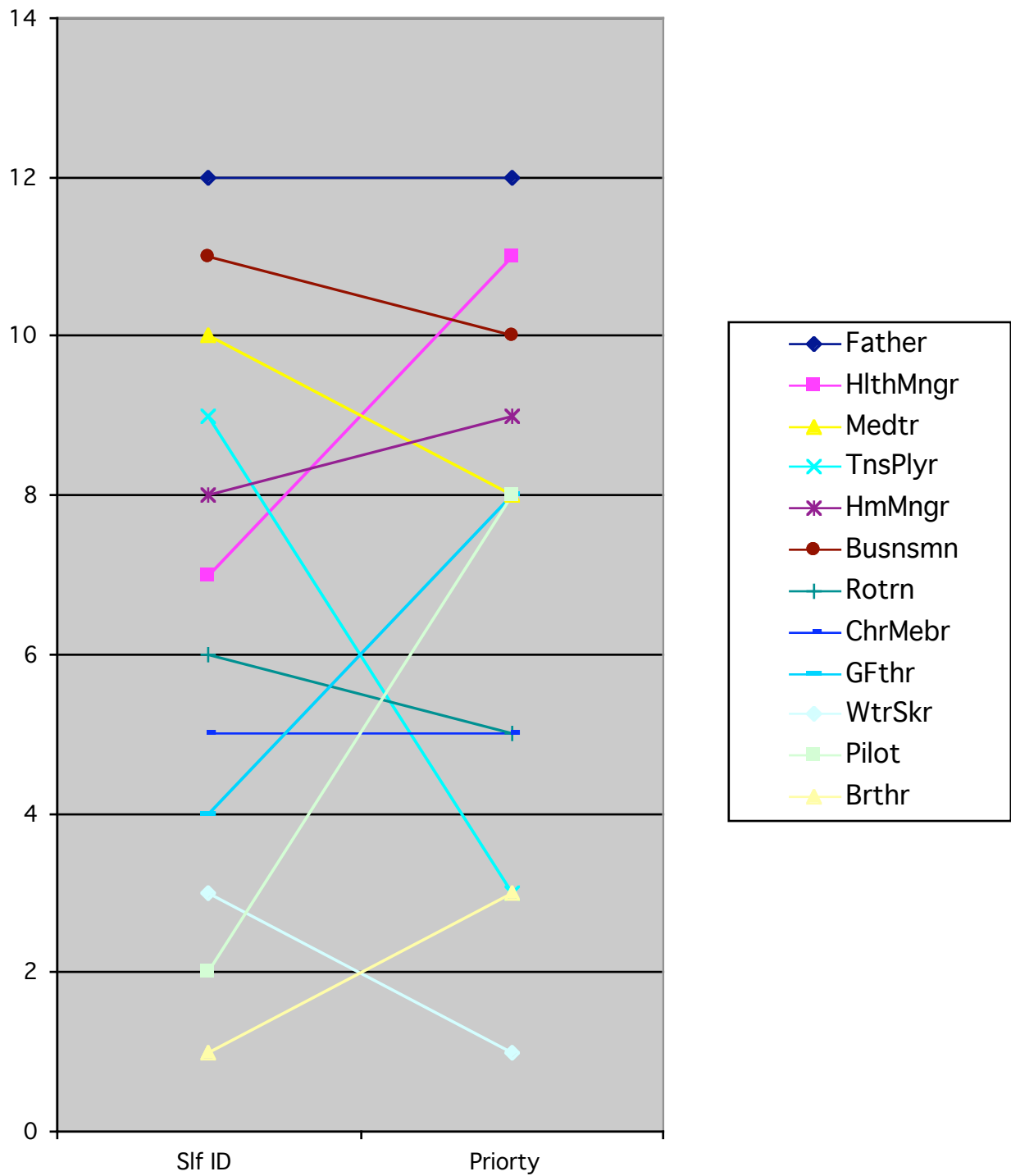
Self Identity



Individual roles with self identity and priority totalled together

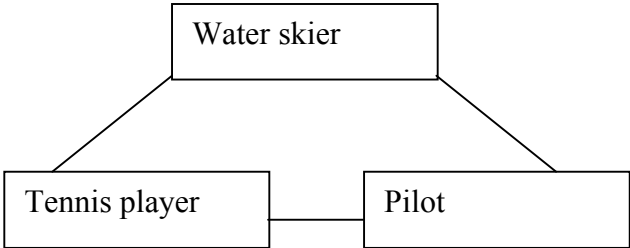
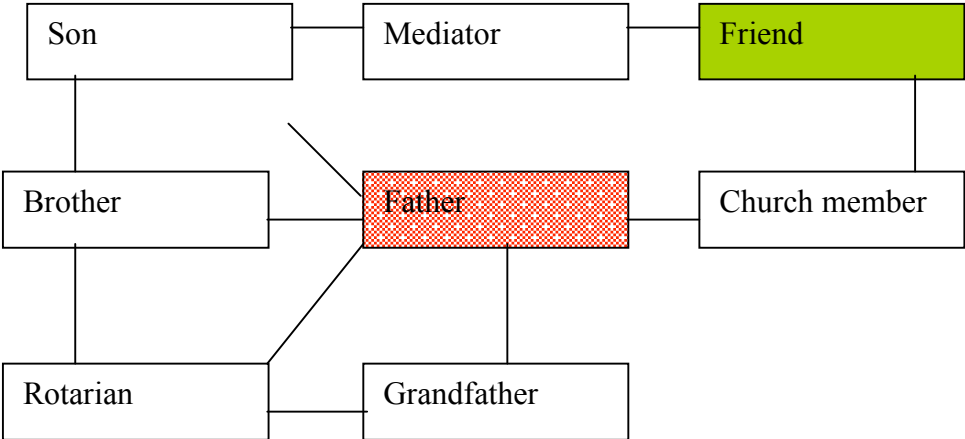
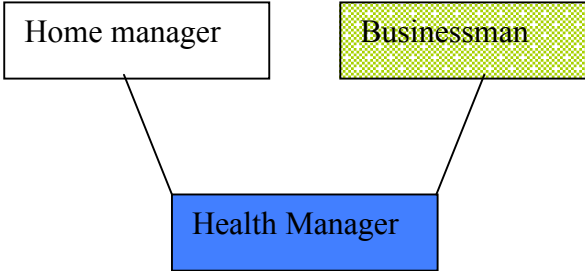


Self Identity Vs Priority



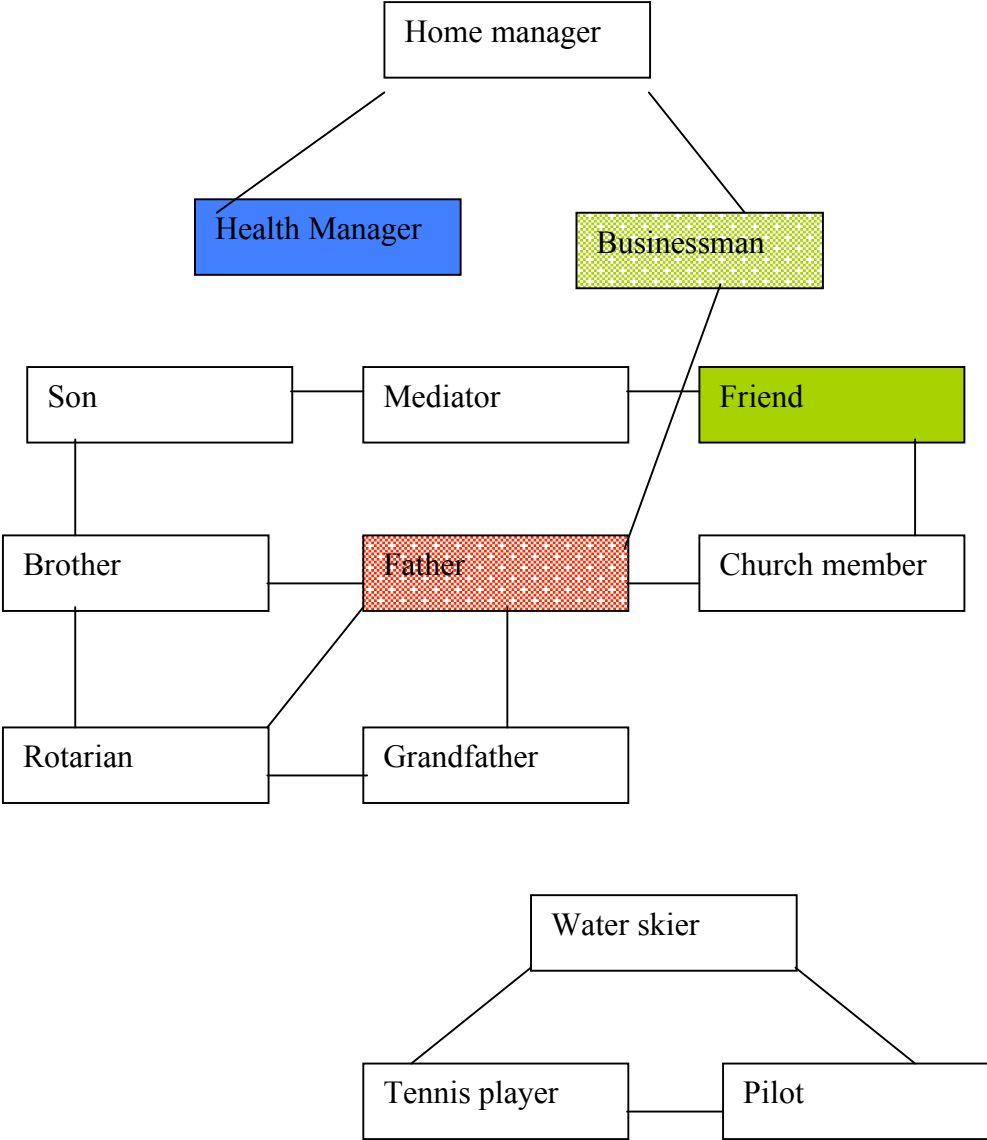
Role map

(this is what he did on the board)

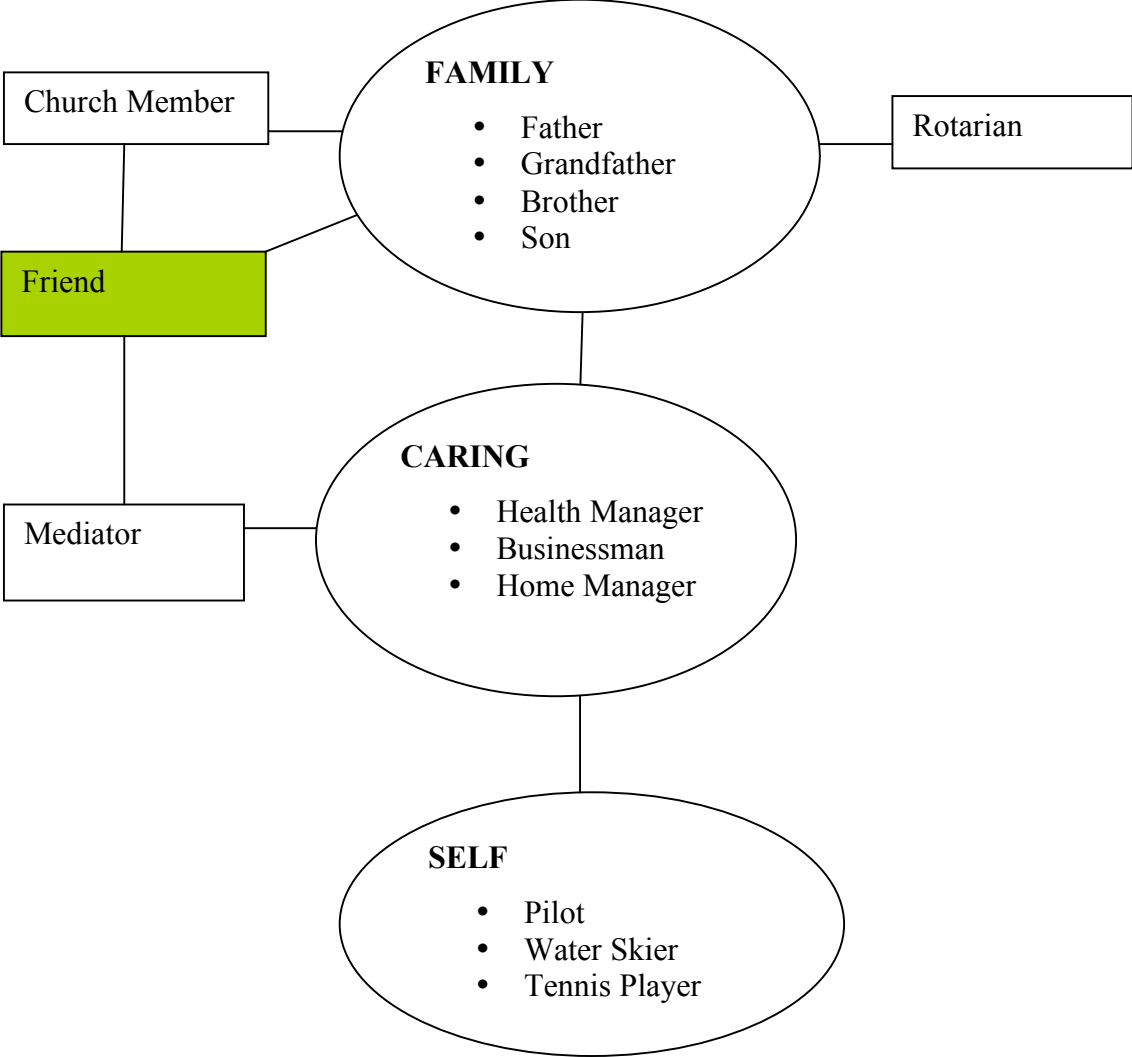


PD6 Role Map

(this is what it seems it should be like from the transcript)



From what he says, there seem to be clusters of roles. Principally, there are the **Family** roles of Father, Son, Brother and Grandfather. Closely linked to this is a second cluster of **Caring** roles: Health Manager (care for self), Businessman (providing for others, particularly Son), Home Manager. The role of Mediator links into this caring cluster and also relates to Friend. Church Member links to the Family cluster (instilling proper values into children). Rotarian also seems to link to the Family cluster but I am not sure why. The last cluster are roles **for himself** (Leisure? Self expression?) – Pilot, Water Skier, and Tennis Player.



PARKINSON PARTNERS - THEMES

Level 3

Mrs. Helen Adams husband Phillip (HM1A)

Age:

71

Functional Performance

No problems reported

Health

I mean I don't think I've got much wrong with me. I've got plenty of old age diseases – arthritis and hiatus hernia. ... I'm a coeliac, I can't eat lots of food. But none of those things - and I've got a crook valve in the heart so they've now told me ...

Living status

Own home with wife only

Time Use

Does not seem to have a weekly routine in the same way as some of the level 1 and level 2 men do.

Role Repertoire

Lists Carer as a role and places it first, with husband second, followed by shopper and then home maintainer. Then family roles, followed by gardener, and finally his own roles: computer user, organ player, and Masonic club and RSL club members. Sees carer as a productivity role and husband as socio-cultural.

He was asked how living with someone with PD affected his everyday life:

Well, you know, up to this point of time it hasn't been too bad because it's been fairly [possible] to sort of have a useful day. But I suppose probably ... for over the past 15 months, she's been really bad. And my part's almost a 24 hour job. I've given up most of the things that I used to do by myself, not that there was a lot, but there were things that I used to do and I don't do because I don't want to go out and leave her by herself for very long, or longer than 2 hours any rate.

There's not a lot of good times in our future.

I've got enough activity at the present time.

But you know, as far as I'm concerned my role is here.

Carer

He does housework, assists with toilet hygiene, sometimes with toilet transfers, all dressing (on and off), transfers in/out of bed [& chair (?)]. Manages her medication, provides drinks when needed. He says some days she can do it herself, but the majority of the time she needs help now.

When asked how he felt about the role he said:

I don't have any problem but I mean it's something we've got to do. We're not, there's no way that, like while we're able, whether it be here or in a retirement village or whatever, I mean we've got to be together and the work is much the same. So I don't have any problem with it at all. But I haven't been doing it for all that long.

Even when wife has a rare social occasion on her own e.g. meeting friends she used to work with, he has to remain nearby & *on call* in case he is needed.

Keeps up with information about PD through the support group. Says that what works for someone else does not necessarily work for them. Has learned not to get too excited about *cures* etc. He felt medication most useful because can be adjusted to suit the individual, although it can be difficult.

The role is his major priority

Oh I can't do anything without, you know, having that, seeing what's in front of me in that role before I do anything else. That's the number one thing. There's nothing that I can do. Like I can't do anything unless Helen's settled so, you know, it's just got to be, it's virtually her food – like making her comfortable, her food, taking her to the doctors – all those things have preference. And taking her to see her friends if she happens to feel like doing that. I mean I'm just taking second place. She says it's, I shouldn't do that but that's what, that's my method of approaching it, the problem. So I don't know what else I can say. You know, it's constant, it's, it's, it's there all the time. It's there all the time.

Attitude to wife

I Mm. How do you feel about that idea of putting yourself second all the time?

R I don't have any problems with it.

He went on to say that he had always been someone who tried to support his wife and not be too ambitious or expect her to just cope with the children on her own.

He was asked what he thought his wife expected of him as a carer:

Well nothing I suppose. She probably, she's probably sorry that, that it's worked out this way, but, but I don't really know.

- **There are things that have got to be done and now that means he has to do them.**
I do it, yeah, I do most of the shopping. I do most of everything at the present, now.

Limiting

She limits what he can do. She needs to be cared for. He does not feel able to leave her for more than 2 hours.

But, you know, Bette does a bit of night cooking at times. But a lot depends on how she is. She hasn't been good for a long while. So ...

b) Understands it is not much fun for her.

Belief that she has cognitive problems

This leads to a sense that she

□ **Can't be trusted**

He believes she is cognitively not managing all that well

Because I believe that her thinking is such that probably she doesn't know the full implications of what's going on.

Like you can't stop her from doing, even just medication. You know, I believe it's got to be watched at all times.

□ **Worries about their joint safety**

All sorts of things that happen because she doesn't know, like she does a lot of things at night. She has this restless sleep problem so like she's probably asleep now but by 11 o'clock she'll be out of bed walking around the house. And so then she'll sit down and watch some TV, she'll go and put something on the stove, boil some milk or whatever. Now if I'm asleep, you don't know, like if I hear her up, if I'm asleep if I hear her up, if I'm asleep she can do anything, but you know, somewhere, at some time during the time she's moving around I seem to always wake, so then I'll get out and just walk around to see what's, what's happened. It may not be necessary, but I feel that it's necessary just to, we've had a couple of fires. He tells a story about a fire that happened before she was diagnosed with PD.

(b) Worries about her safety

At this point in the interview he started talking about *they*.

But they have falls.

So there's all sorts of things that I think of that, that I feel you'd have to keep track of or keep in your mind that's going to happen or, not going to happen, may happen. And try and provide a safe environment.

d) Worries about her health

Cause I know everybody that has a complaint considers that it's not catered for. But like if somebody with Parkinson's is required to go to hospital for something else they're in a terrible mess. Nobody knows how to nurse them

c) Unable to just take over or control things that worry him out of respect for her

And I mean if you were to say – I don't want you to use the stove; I don't want you turn, you know, the bathroom heater on or something – they say – What do you think I am, stupid or something? But, so I don't think she, and I believe that it's necessary because, well we had a smoke alarm that was always going off.

He told a story about heating milk in the middle of the night and setting off the smoke alarm.

□ **Suspicion that he might be being taken for a ride by his wife**

He gave this example in relation to getting support from PD support group. He may have been woken up to take his wife the toilet and then the next thing he knows she's up and down the passage on her own making herself a cup of tea. He used to wonder if she was *having a bit of him*, but found talking to others that they were having the same experience.

There's always this thought that you have, as I've had them at times, that you know, it's some form of sympathy or something, attention I mean. Sometimes I look at it and I say – You're going on like our kids did when they were young. Like they cried and they wanted you to do this and they were always calling out for you. And, because they wanted attention. But you know, in an adult person or an elderly person, as we are, I can't think that that's the mental pattern, considering, you know, that most people have the same sort of problem. So you know, it's not one person's personality, it seems to affect them all in some manner.

□ **She is demanding**

This is said indirectly

His Needs

- **Time away from her that he can use - "good time"**
- **Opportunities to do something for himself**
- **Better understanding of what is happening**
- **Sleep**

Strategies for meeting his needs

- **Escape**

Has an intercom which means he can go downstairs to the garage and laundry and she can call him if she needs him.

It sounds as if he spends quite a bit of time down there. He washes and polishes the car, does the laundry, is nice to the dog who lives down there and gets scared, moves the summer stuff in there when winter comes on and moves the winter stuff out and vice versa when summer is coming on.

So it's just all the things of the normal, what we do normal running of the day, you know, jobs during the day. It's very hard to spend, you know, all your waking hours with a person in the same room. Sometimes Bette nods off or, but she doesn't sleep very long, that's the problem.

- **PD support group.**

- support - the strength to keep going?

And you get a little bit of strength out of that I suppose.

Describes how talking to other carers helps to get things in perspective and understand the way the disease affects people better.

On the other hand, people advocate things that he doesn't see much value in e.g. Tai Chi. He says whether you can do it or not is just a measure of how far the disease has progressed, not whether it is a cure or a panacea.

So, you know, everybody's got a cure.

2. Opportunity to talk to people who understand.

When asked why he went to the PD support group he said:

See you go and mix with people of the same kind I suppose more than anything. I mean you go with people and, normal people, and they don't really understand

- **Respite care.**

She has had one spell so far. He didn't go away and she wanted him to visit her each day and she wanted him to do shopping for her, so it wasn't as much of a break as it might have been. The children are trying to arrange some respite for her near them and he feels this will work better for everyone.

I mean I'll be able to visit people any rate, cause we have, no a fair, some people up there, and probably go to a Lodge meeting or something up there. And the children will

be able to take my, do what I've been doing by helping out at the Nursing Home where she's having a respite, by calling and seeing her and, you know, occupying. Because they're not very good places. I mean you can't do any, there's no other way that they can, well I don't know of any other way that they can handle caring for people who have disabilities. But most of them are a lot older and they have their funny ways and they don't mix very well and, you know, you're on your own virtually.

- **Shopping provides a break**

Well it's a break away. Like it is a break away, but I can't be away. Like I'm conscious of how long I'm away. And like Tuesday some friends said, she is doing, what do they call it, one of those things run by Mona Vale Hospital, and she goes up here to Allan Walker Village to the swimming pool. And she was trying to get [wife] interested in that, so they took her out. Well I went up to do the shopping and when I was up there I remembered well they were only away for 2 hours and[wife]e may have had, not had her keys and, you know, she mightn't have been very good when she got back so I felt that I should have been here, which I did come back early. And then I went back to the street again. So you know, you've got to be confident that whatever she's doing is comfortable for her. And it's best in the home. Like my best support would be somebody in the house with her like for a few hours while I went out.

Strategies for getting things done

- **Be flexible**

I can't make any, no plans or predictions. I just wait and like if she happens to be looking pretty good say well now's the time to whip down the street and, or to race out and mow the lawns or whatever, you know. You've just got to take it when she's feeling alright and, you know, have the things that you've got to do and go and get them done in those good times.

Barriers to Carer Role Continuity

- **She doesn't sleep for very long**
- **inability to make plans because of her fluctuations**
- **A suspicion that you might be being taken for a ride.**
(see attitude to wife)
- **Health Professionals - understanding and communication**

Finds professional advice a bit confusing and unhelpful at times:

Equipment:

Talking about getting a chair she can transfer in and out of herself:

I say to her that, like while I'm helping her in and out of chairs I can't be doing anything else. It's not that I don't want to, like I'll stand here for 24 hours a day and just say – Yes dear, no dear, yes dear – but that's sort of, it's going to kill me and ruin all my good time. I mean even if I get an hour or half an hour it's something.

She chose an electric chair that will stand her up, but finds she can't always operate it herself, so he has to help her anyway.

He did not appreciate the attitude of the OT about this.

Now, see the Occupation, yeah OT, Occupational Therapist down there promptly said – Oh don't get, no, you don't want them, they need the exercise, to get in and out of the chairs.

Medication

He also gets conflicting advice about medication from different medical practitioners - either just take another pill whenever you feel the need or keep your dosage to a minimum.

He complained that they don't explain things enough. He had read that you should not take vitamin B6 with PD drugs, but he says not one doctor has ever explained that.

But one of the things that it did say is you shouldn't take B6 with Levidoba, so I just said to Dr X, I said – Is B6 alright to take? Oh no, no, you shouldn't take B6, but she never explained it. And those sort of things, you know, I think they're very casual about, but probably they don't expect you to be doing it. People do, these days, you know.

Important to communicate with the GP and the specialist about her medication so as not to get in a mess e.g. GP wanted to prescribe Valium so she manage a long car trip but specialist was not happy when he contacted her. Have the be careful with the anti-depressants as well.

He said quite a bit more about health professionals and OT - not happy with the home visit that was done etc.

- **He no longer feels the same way about his wife (see attitude to wife)**
- **Lack of understanding of others**

In relation to the chair:

And so they [OT] advised us against it, but you know, I encouraged it and Helen I hope was happy with it because, I encouraged it because I reckon that, you know, if she can do it well it's going to relieve me.

Tells story about grand-daughter who came to a PD meeting where the OT was talking about cuing. They got home and wife asked to be helped out of chair. Grand-daughter did not help but cued her and it worked. He said:

Like who's going to train me to see the situation and say, I mean Sue, some other time like if she'd had of said it well Helen would just have said, you know, I can't get out. But Sue was there and Helen'd been out and probably there was things that were stimulating and she just got straight out of the chair no trouble at all.

Husband

He was asked whether he saw his role as a carer and as a husband as one and the same. He said:

Well the husband part is sort of gone. ... Like we've been married nearly 48 years. So like we've had a relationship that's been pretty good right up to the time that she got bad with Parkinson's.

... but as we are now we're partners and, you know, interested in our family and ourselves and friends whenever we can be. And we're sort of limited as to how much enjoyment we can get out of those things. No I don't have any problems with it.

Ageing Issues

Confusion about how much is ageing and how much is PD

He is not sure how to compare their situation with others of the same age.

And, you know, you don't do the same sort of things as what you did back in those days, what with having children and

(Side 2 of tape)

and I don't know what an older person, without the Parkinson's, you know, what older people look at out of life. ... Like I don't know how other husbands feel about their wives, I don't know. Some of them like at 71 and 75 look at their wives as sex objects ...

But like you don't, can't, you haven't any ambitions. Like your usefulness is almost over. I mean that might be a defeatist but I'm 71, like if I get to 81 I'll be doing, like my father died at 47 at 57, my mother died at 42.

Productivity/Making a contribution

So like I've had a far more useful life than what both of those did. And if I can be of help to anybody, but like in this case I'm a help to my wife or partner or whatever, and like that's as much as fulfilment as what I can get out of the relationship. ...

Worries about the future

I have problems with, with concern that if I should get sick or whatever. That's probably my biggest concern.

But like our future doesn't seem very bright at this particular time.

Strategies for Role Continuity

None identified

Barriers to Role Continuity

Concerned what would happen if he got sick

I'm just looking forward to being able to look after Helen, you know, for a long period yet, for a long time yet. But I couldn't, I wouldn't think that she'd be able to do the same for me should I get chronically ill.

Impact of Parkinson's Disease on Role Performance

Losses

Community roles:

But no, I don't do anything in the community

Fishing.

Doing things with friends.

Dancing:

Like ... we used to go dancing and like 2 or 3 nights a week, or an afternoon and a couple of nights, which we don't do now.

Travel:

Wife can't travel on buses which means he misses weekend trips and day trips organised through the Masonic Lodge. Confirms that she can only last about 2 hours.

Probably the biggest problem is getting a couple of weeks away because, you know, she has trouble travelling and so we can't, it's hard even to go for a drive somewhere, just wherever, if you went to the Mountains or ...

Mason:

Gave it up about a year ago after she deteriorated.

Member of Senior Citizen's Club:

He still goes to play snooker. Goes alone. Club is nearby and he feels able to leave his wife for a little while.

Well Bette's better of a morning than she is of an afternoon, so and like we don't go all that much because she hasn't been well enough to go. But it's just around the corner and, you know, I can get up there for a couple of hours if she's alright and she doesn't want to come. So, oh no, I've got enough activity at the present time.

Father/Grandfather:

I can relay information to them, that's about all I can do at the present time.

Helen is unable to travel to see the children (they all live elsewhere). Children are pretty busy with their own lives. See them occasionally only.

Barriers

His wife

Has difficulty watching TV or playing his organ because his wife goes to bed early. She is sensitive to sound and finds it too noisy. He has tried using headphones, but then he cannot hear if his wife needs something.

In relation to fishing and doing things with friends he said:

Like well sometimes Bette used to come but she can't come any more and nor can I go. So, you know, all in all we're pretty well both confined to the house most of the time.

Going out into the community (movies/shopping)

If they go to a film she may only be able to last half-way through the film and then they both have to leave. He described it as like a panic attack - same as with shopping.

He does not get enough sleep:

So as I say it's a 24 hour job and there's times during the night that she can't cope and so, you know, it's hard to get a full night's sleep, so you're sort of sleeping a bit of the night and a bit of the day and trying to do some work. So that's about the, the run down on the daily routine. So, you know, there's almost nothing that you can, that we can undertake.

Getting help is problematic

But I mean, some friends have offered, mostly lady friends, but they, sometimes when Bette gets bad, you know, she needs a lot of assistance and they say they wouldn't be able to manage, manage her by herself. So it's a bit hard to find the right help or the right assistance, from friends anyway. Sorry, I haven't tried any professional stuff at this point of time. Because I suppose in the end, you know, money comes into it and we'll need more help later on if she gets any worse.

Mrs. Jenny Morgan's husband Arthur (HM3A)

Age:

75

Functional Performance

No problems reported

Health

None reported

Living status

Own home with wife only

Time Use

Attends bible study group and church on a weekly basis. No other regular commitments noted.

Role Repertoire

Carer top priority with husband second.

Attitude to wife

He worries about her. He feels she does too much herself.

Too independent I think which is partly why she falls.

She has a history of bad falls with consequent ongoing surgery.

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.

I'm anxious. Every time I hear a thump outside I think [wife] has 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, when she was still, while she was independent, she walked up the street on her own without walkers or anything, and 2 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.

Oh I go up the street and do a bit of shopping for half an hour. But I wouldn't go to town. 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 [wife].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. For instance I had to go to the hospital myself for 2 nights and one of our friends came and stayed in the house at night with her to help her. I don't like, ... [wife] doesn't like [?]. That's the bind you get caught up in.

Yes, oh yes. She's very aware of how she's hindered life. Very self conscious of it.

Is that something that she talks about or expresses a lot? Or it's, you just know that she feels like that?

Oh no, 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.

Because [wife] 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.

Actually [wife] 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.

Family, Speech and Cognition:

Do you perceive that your wife with Parkinson's Disease, does that affect her ability to interact with family and the grandchildren and with people in general?

Well it certainly, it does. 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. 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 2 grandchildren from Wales, who are 5 and 3, 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

Note isolating use of 'they'.

Carer

He identifies himself clearly as a carer:

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

He helps her:

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.

Well my day starts - I wake at five and I get up at a quarter to six and I make the morning tea and the breakfast and bring it to bed and she takes the first day's tablets about half past six and she doesn't become mobile until about half past eight as a result of that.

If something has to be done, then he is the one that does it

And at the present moment I'm picking my grand-daughter up at a quarter past seven and my son and taking her to day care, and so I get home from that at eight o'clock and [Jenny] is still in bed. And then I do the washing up and make the bed and do the washing and do various chores that are involved in running the house.

I don't enjoy ironing. I love washing up, I don't mind that at all. I'd rather if [wife] 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 unironed shirts. And a lot of materials are damned hard to look after I think. Men's cotton shirts are a disaster. ... And you get given these things by your children and they don't ask if something's easy to maintain.

They do not go out at night:

Because after about 8 o'clock she's wiped out. And she's in bed by half past 8.

He takes her out a lot during the day.

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.

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 labor. 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.

He drives her

Well chauffeur would be the next most important thing, because wherever she goes I take her.

Qualities needed by a carer to do a good job

Emotional stability, unqualified love, empathy, and skills.

His needs

Time to himself?

Referred to his *bad temper*

Community involvement - going out.

Sleep:

And yes, I very rarely have a rest, a restful night, because she's up to the bathroom 2 or 3 times a night.

And you're up with her, or you're just aware that she's up?

Well yes, aware. Oh well you wake. And so I think I'm lucky if I get 6 hours at night but [?] if I occasionally get 7 or 8, that's fabulous.

Acknowledgment from wife:

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.

The need to do well:

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

Oh yes. Too definitely right. ... Yes, I think so. 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.

Strategies for meeting his needs

Asks friends to sit with her sometimes so he can go out.

Gardening is an outlet for him (see under role).

And 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.

The PD Support group runs regular sessions for carers and he finds them helpful (see under role).

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.

He describes going on a course for his church one night a week as helpful too - particularly as it allows him to have a relaxed meal (see under role).

Strategies for getting things done in carer role

Equipment and Home Modifications

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.

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

Barriers to Carer role continuity

He found the carer support group helpful but could no longer leave wife.

But I found that took me out for two hours and I didn't feel that was justified any longer. So I gave that up about 18 months ago. ... And I worry too much when I'm away.

His anger and frustration:

Mm. The only thing is, and I regret this very much, it does make me tired and it makes me irritable. And I'm more irritable than I should be.

He would rather do household things by himself than share with his wife, but he recognises her need to still do things.

Eating

I find that difficult, by the time I get the meal. (I think he is talking about at home) 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. (I think he means indigestion?) And the interesting thing is I used to find that I enjoyed my couple of glasses of wine at night, and now I find that one knocks me and I'm asleep by 8 o'clock.

Husband

Sees carer and husband as different aspects of the same thing.

It's a lifetime role I took on.

It affects their relationship:

'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. It does - although as I said, 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?

Oh she knows that. Oh yeah. Oh yes. I'm pretty bad tempered.

Yeah? How do you deal with that together?

Well I just sort of don't talk for a while. For a time I withdraw and [?] Yeah. 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. Yes.

I don't think I'm always a good husband, no.

Strategies for continuity of husband role

Ageing issues

Talks of the need for exercise.

He is concerned he will run out of time to finish his book and other scholarly pursuits (see under impact of PD on roles) - not just through death, but also through failing cognitive abilities.

Time is short. Particularly at 75. Yes, they say mentally active. You don't lose your marbles up top. But I'm losing mine fast. My memory's - varies a lot in the last 12 months. Well I went through this, you know, the research centre at Prince of Wales Hospital when I was doing the research into Parkinson's and I went through as a control, and I wasn't very pleased with my performance in the psychological testing.

Impact of PD on role repertoire

Losses

Political party member:

Feels unable to attend night-time meetings because cannot leave wife.

Holidays:

But it means we haven't been for a holiday for 18 months, except for these 2 quick dashes up to [place] to see my brother. We're actually doing that Monday. And I don't like making [wife] 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. ... the one thing I really resent is hearing people talking about their overseas travel, or holidays. We're [?] Don't want to hear about it. Because that's something we were denied. We always, as you make the mistake, when you retire you're going to do these things. It's too late. And at some stage the neurologist said Don't contemplate going. I don't know what was on at the time and I asked him later and he said, Oh it must have been something. But 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. ... I didn't feel like I could take a prolonged period of absence. ... The longest holiday I think was 3 weeks. And that was difficult to organise because I had to organise my relief. And I felt responsible being away anyway. And so it was very much something that we had hoped to do when the time was right. It never happened. ... And I went through a very resentful period. But there are no worries now. With good grace.

Student

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.

Chorister

I used to sing with choir and I'm, 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.

Role Maintenance

Committee member of their PD support group.

They go to the monthly meeting and he is also on the committee.

And there's a committee meeting once a month also.

Which you also, you both go to?

No I go. I leave [wife] for the 2 or 3 hours. That's of a morning.

**Not sure if this is an aspect of the carer role or a separate role.

Strategy: they go together. I guess someone sits with her for committee meetings.

Still a member of Probis Club but has cut back involvement a lot. He was President, he used to bowl with them and also go bushwalking. Now he just attends meetings.

And so yes, it's had a severe impact on me.

Strategy:

And I go to the monthly meeting because that happens to be the morning I'm taking her to the church. So that works very well.

Family:

Still able to visit family sometimes:

They've got 5 acres out there and there's gardening and swings to build and I take great pleasure in doing that and [wife] comes with me and sits on the balcony. Yes, she likes that.

Theatre-goer

What we do do, we have the social outing and we subscribe to the Theatre sessions at Marion Street and Glen Street.

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 Beth 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. I'm anxious about so many things

Strategies for Role Continuity

They go to matinees.

But those are afternoon matinees cause [wife] can't go out at night.

Barriers to role continuity

Anxiety.

Author:

He has been writing a book about his family. It has taken three years and is nearly finished.

Historian:

I would have five or six hundred postcards dating back from 1902-3-4, all with history on the back of them, like all written on, and that is my next project, to get all that history off. I started out and then I realised I was getting side tracked. Away from the main book. And then my wife's got some documents there. Her mother was the campaign manager for Billy Hughes. And there are some interesting things there. Oh yes

Collector:

And also I would have a collection of many hundred cigarette cards dating back from the 1900-1-2, which I've now got sorted. But there all these things that need to be. You put some pleasure in it. I've got to get this[book] finished so I can get on it

PD is a barrier

Is it something that you would have, you'd like to do more of if you had the opportunity?

Oh yes. Twelve months I didn't do any last year. And so I'm 12 months behind. And I'm nearly 75. I might snuff before it's finished. (Laughing). I wouldn't like to leave it to anyone else to finish.

Attitude to PD

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 Future

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 [wife] is in her 15th 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 So, you know, I don't look too far ahead.

When you say a honeymoon period, what do you mean by that? At the moment you ...

Well where the disease isn't catching up on her. She's, I look at other people and, in our support group, and [wife]'s done extraordinarily well. Other people have gone down very much more quickly than she has.

Are there any reasons why you can see that might ...

No. 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 [?] state now. So I think honeymoon period inasmuch as you haven't progressed from a stage 4 which [wife] is in now into stage 5 where you're totally dependent. So for me that's a honeymoon period.