The dynamics of dementia: working together, working separately, or working alone?

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Introduction

There has probably been more research into the needs of family members caring for a person with dementia than in any other field. As with the wider literature, a stress/burden model has been the predominant theoretical frame of reference but other, more positive and holistic orientations have had their roots in dementia care. So, for example, Hirschfield's (1983) important contribution was to develop the concept of mutuality, defined as: ‘the caregiver’s ability to find gratification and meaning from the caregiving situation’ (p. 26), and to demonstrate that in situations of high mutuality, caregiving was less stressful and more likely to be sustained. This early work highlighted the importance of the quality of prior and current relationships in providing a context for caregiving. Later Motenko (1989) explored further the delicate interplay between the frustrations and gratifications of caring for someone with dementia and his work further belied the belief that caring was necessarily all ‘bad news’.

Other important insights have also been gained from research in the field of dementia. For instance, Bowers’s (1987, 1988) exposition of the differing types of care that daughters provide for their mothers with dementia moved the focus away from an ‘instrumental’ or hands-on caring role and suggested that other, often invisible types of care were seen by caregivers to be both more important and more stressful. Bowers (1987, 1988) argued that it was not so much what carers did that mattered but rather that the important consideration was the motivation or purpose underlying differing types of care. Building on this she identified several types of care that developed over time including: anticipatory care; preventative care; supervisory care; instrumental care and protective care (Bowers 1987). In a second study she began to explore the interplay
between family and professional carers following placement of the person with dementia (PWD) in a care home. On the basis of this work she identified a further type of care, ‘preservative care’, by which the family tried to maintain the PWD’s family connections, dignity, hope and sense of control. She argued that the family wanted to collaborate actively with staff in ensuring that the PWD’s needs were met. However, staff were often not conscious of, or did not respond to the families’ efforts to work together.

Hasselkus (1988) similarly suggested that family carers considered that they had expertise and knowledge that they wanted to share with professionals. Once again, however, such knowledge was often overlooked or ignored, which frequently resulted in families rejecting the support they were offered.

These differing but complementary insights provided a wider perspective on family care, and each in their own way has been influential in the evolution of our own approach to ‘understanding family care’ (Nolan et al. 1996a). However, in the present context it is the development of the six-stage temporal model of care (Keady and Nolan 1994a; Nolan et al. 1996a; Keady 1999) that is the primary focus of this chapter.

Several temporal models have emerged to help identify and better understand the changing experiences of families providing support to a PWD (see, for example, Kobayashi et al. 1993; Wuest et al. 1994; Aneshensel et al. 1995), but our own work was most influenced by the model developed by Wilson (1989a, b). The purpose of this chapter is to outline briefly the way in which Wilson’s model was further elaborated upon by Keady (Keady and Nolan 1994a; Keady 1999), and then to focus on the early caring period, particularly the process of ‘recognizing the need’. However, we will not concentrate solely on the views of carers but also incorporate those of the PWD, and in so doing map out the ways in which these two key figures interact and help to shape the nature of caregiving. This interaction largely determined whether carers and PWD ‘work together’, ‘work separately’, or ‘work alone’. We will highlight in particular the often prolonged, subtle and sometimes divisive interactions that both carers and PWD engage in during the period before a formal diagnosis of dementia is provided. In order to portray an accurate sense of the temporal sequence in which Keady’s (1999) work unfolded, this chapter will describe the carer’s perspective first, then add that of the PWD before seeking to integrate the two.

In order fully to acknowledge the influence of Wilson’s (1989a) work, and to provide a context against which to consider our adaptation of it, the chapter begins with a quite detailed summary of the published work that informed our own. For the purposes of this chapter the greatest emphasis is placed on the first of her two studies (Wilson 1989a).
A temporal model of caregiving in dementia

Wilson (1989a, b) used a grounded theory method to explore the experience of living with a PWD and to interpret the processes and coping patterns of family carers. She adapted an analytical approach first described by Hutchinson (1986) to outline an eight-stage model of the course of Alzheimer’s disease as experienced by family members.

Her temporal model begins with the initial stage of ‘noticing’, where family carers gradually become more aware of the bizarre, or aberrant, behaviour of the person they live with. This stage was reported as only being recognized in retrospect and no particular cognitive deficit or behaviour was cited by family caregivers in this study as alerting them to the fact that something was wrong. Noticing, therefore, was as a result of cumulative behaviour which was initially discounted and normalized. The processes of ‘discounting and normalizing’ formed stage two of the model, and at this point carers attributed changes mainly to old age until two conditions emerged:

- the unusual behaviour worsened;
- a particular event took place which was sufficiently serious to make discounting it very difficult.

Wilson (1989a) gives an example of one family noticing changes for three or four years until one behavioural cue made it impossible to discount. This led to stage three, ‘suspecting’. Wilson (1989a) suggested that ‘pervasive uncertainty’ characterized this stage with family members speculating about what was going wrong. This suspicion fuelled a realization that something more serious was happening and prompted family carers to search for explanations. In stage four, ‘searching for explanations’, Wilson (1989a) suggests that the decision to seek confirmation of a diagnosis was undertaken ‘reluctantly’ as families were increasingly aware of the financial costs and stress involved. The discovery that the person had probable Alzheimer’s disease led some families to avoid further medical investigations, fuelled by the belief that nothing could be done anyway.

Stage five, ‘recasting’, describes how, once the diagnosis had been tentatively confirmed, families engaged in a range of tactics which involved reappraising, retrospectively, various experiences with their demented relative; that is, they reflected back on their experiences to date within the context of the diagnosis. In stage six, ‘taking it on’, ‘recasting’ provides the basis for making informed decisions about whether to ‘take on’ care. Wilson (1989a) describes this as being a decision taken without full knowledge of the likely demands and implications of the role. Rather, the decision to take on family care was motivated by a sense of moral duty. Stage seven, ‘going through it’, describes how dementia presents the family caregiver with a ‘seemingly unending list of problems’ (Wilson 1989a: 43) which require resolution. These are tackled on a trial and error
basis, with little or no practical help, support or respite. The experience is characterized as ‘living on the brink’ of the family carer’s tolerance, with carers being continually confronted by negative choices in which decisions must be made, but without desirable alternatives. Wilson suggests that most family caregivers then come to terms with the erosion of their own physical and emotional well-being and start to consider institutionalization. This leads to stage eight, ‘turning it over’. At this point family caregivers consciously and reluctantly let go of the direct care of their relative and entrust that care to an institution. Wilson (1989a) suggests that carers continue their role in a less visible capacity by undertaking daily visits, taking care of financial management and ‘being there’ during crises and transfers in and out of institutions. Wilson (1989a) acknowledged that this study offered ‘a beginning knowledge basic to interpreting the meaning associated with their (family carers’) experience’ (p. 44). While she went on to elaborate upon the theory in another study (Wilson 1989b), it is the above account that most influenced our work, and the way in which Wilson’s (1989a) study was further developed is described below.

**Taking the model further**

Our interest in the dynamic nature of caregiving, the quality of relationships, and the interface between family and professional carers from a temporal perspective has been long-standing (see, for example, Nolan and Grant 1989; Nolan 1991; Nolan and Grant 1992a, b). However, it was Keady’s efforts to extend Wilson’s work further that underpinned the six-stage model upon which this book is based. As already noted, the six stages of this model are:

- building on the past;
- recognizing the need;
- taking it on;
- working through it;
- reaching the end;
- a new beginning.

(Nolan et al. 1996a)

The influence of Wilson’s work on this model is obvious. For example, we adopt Wilson’s phrase ‘taking it on’ as an explicit part of our model. Moreover, ‘working through it’ is analogous to Wilson’s ‘going through it’, but this stage was renamed and ‘going’ replaced by ‘working’ to capture the much more proactive stance adopted by carers, as suggested in Keady’s study (Keady and Nolan 1994a; Keady 1999). However, it is the prior elements of the model, particularly ‘recognizing the need’ that are explored in greatest detail here.

In building on Wilson’s (1989a, b) studies, Keady too adopted a
grounded theory methodology (see Keady 1999 for a detailed account). The original aim of the study was to explore further the temporal experience of care using the prior literature, and especially Wilson’s (1989a, b) work, not as an explicit theoretical framework, but as a heuristic device that would help to recognize ‘leads’ in the data but without ‘leading’ data collection (Morse 1994). To this end a series of interviews were conducted with family carers. During a small number of these the PWD also asked to contribute, and on this basis a tentative temporal model from their perspective was also developed (see Keady and Nolan 1994b). Subsequently further joint interviews (n = 11) were conducted that explicitly included and focused on the perspective of the PWD. This allowed for an integration of the two temporal models and a resultant grounded theory which suggested that the primary aim of both caregiver and the PWD was to try and maintain the involvement of the PWD as an active agent in the world (Keady 1999). This was best achieved by the carer and PWD ‘working together’ (ideally in concert with the formal services) but occasionally they would also ‘work apart’, or the carer was left to ‘work alone’ (Keady 1999). The nature of the ‘working’ relationship which predominated was heavily influenced by the type and quality of prior relationships (building on the past) and the interactions that occurred prior to the formal diagnosis of dementia. This is what we will focus on here.

In doing so we will draw explicitly on Keady’s (1999) original grounded theory but will further elaborate and reconsider the subtle interplay that occurs during ‘recognizing the need’, and suggest that in addition to ‘working together’, ‘working alone’, or ‘working apart’, another process, ‘working separately’, also occurs, of which ‘working apart’ is a variant. As modifiability is one of the key characteristics of a good grounded theory (Glaser and Strauss 1967; Charmaz 2000) we believe that this subtle change provides a further elaboration upon the original processes identified by Keady (1999).

**Results**

Just as with Wilson’s (1989a, b) studies, early data collection suggested that it was often a seemingly insignificant but either unusual or repeated event that caught the carer’s eye and first alerted them that something was perhaps not quite right. This ‘noticing’ took a variety of forms and often involved a daily event, for example, driving:

The first thing I noticed? His [carer’s husband] driving. My husband had always been such a careful driver and then he suddenly started to hit the kerb and drive too close to the car in front. He also didn’t seem to understand traffic lights anymore. They would turn to green and I would be sitting there waiting to move off but he didn’t go. He
would just sit there and I would have to tell him to go in the end. I just thought he was getting on and that he couldn’t see as well as he used to. That’s what I told myself anyway, but I thought it was a little strange.

Other examples included forgetting to pay bills when previously this had always been done punctually, or not being able to calculate a darts score when this had always been second nature. Wilson’s study suggested that in the early stages these events would be discounted and normalized (stage two) until this was no longer possible, when carers moved onto stage three of her model – ‘suspecting’.

However, close consideration of data from the interviews did not fully support such an interpretation. First, it became apparent that carers did not ‘discount and normalize’ but rather that they first normalized and only then discounted. These processes were therefore related but distinct and had a differing temporal sequencing than Wilson (1989a) had suggested. Initially carers would ask themselves ‘what am I seeing?’ and ‘why is this happening?’ ‘Normalizing’ the unusual behaviour usually involved finding a rational explanation, for instance stress at work, acute illness, or often ‘just old age’. This would allow carers to come to the conclusion that ‘this (the behaviour) is okay’ and could be ‘discounted’. However, as the behaviour was either repeated or became more obvious carers began to ‘suspect’ that something might be wrong and it became more difficult to ‘discount’ the behaviour. Carers then began a more active process than ‘noticing’ and specifically began to ‘keep an eye’ on their relative, in some respects a process akin to the preventative care described by Bowers (1987). This could often go on for a prolonged period of time:

What did I first notice about Mum? Well, the first nine months I was down there [her mother’s house situated a short walk away] virtually from the time I got up in the morning to the time I went to bed. I’d run home, get a quick snack, and I would have to spend more and more time down there because... I think it really started that we noticed... I mean I noticed there was things she was forgetting and I put it down to old age and she, I mean my sister, she came up once a year. So the first year she came up she was fine, the second year she started to say that ‘Mum is definitely forgetful, isn’t she?’, and the third year she came up I said, ‘Yes she is.’

As will be highlighted later, the extended nature of this process of ‘suspecting’ was in part due to action on the part of the PWD (undiagnosed at this point) to ‘cover their tracks’. However, carers eventually began to realize that ‘this might be serious’ and therefore ‘increased vigilance’ (Keady 1999), and began to observe their relative far more rigorously. However, despite the increasing severity of the symptoms several carers still hoped to find another explanation for their concerns:
In the early days I wanted my mum to be better. I knew it was not getting any better, but I wanted her to, if that makes any sense to you. She was so forgetful by then. Calling me the wrong name all the time, not doing the shopping and the like. It was so unlike her. And her temper! I knew then I had to do something, but early on I always hoped that she would come back and be my mum again.

The data also suggested that ‘noticing’ was not a stage in caregiving, but rather a process that was not confined to the first episodes of odd behaviour but occurred throughout the caring trajectory, that is, carers continued to ‘notice’ things even after the diagnosis. This strategy was used to alert them to yet further changes in the PWD:

...isn’t it funny. Just this morning I ‘noticed’ [emphasis added] that he [her husband] didn’t dry his face with the towel. He just sat there with it in his hands and looked at me – he didn’t seem to know what to do. I always help him in the bathroom, with his shaving and that, but he has always dried his face afterwards. Normally, I just hand him the towel and he gets on with it. So this morning when he didn’t do that I thought it was a little strange.

Prior to diagnosis the time would come when carers could no longer sustain a belief that ‘this is okay’ and moved from the notion that ‘this might be serious’ to ‘this probably is serious’. Prior to this, children in particular often tried to get external confirmation for their concerns from siblings, but eventually carers’ concerns were such that they sought more concrete confirmation. This tended to happen in one of three main ways:

- they might raise their concerns directly with their relative – ‘have you noticed anything?’;
- some event would occur that was so bizarre or unacceptable that the carer’s patience would ‘snap’ and they would directly confront the PWD – ‘bringing things to a head’;
- they would seek medical confirmation – ‘asking the experts’.

As we will discuss later, ‘working together’ began much earlier and was more successful when: the PWD agreed that they too had ‘noticed’ something; both the carer and the PWD ‘asked the experts’ early, and the expert (usually the GP) was receptive and well informed and acted upon the concerns that had been raised. Unfortunately this was not the usual pattern of events.

In instances when the carer asked their relative ‘have you noticed anything?’ (originally termed ‘open confirmation’, Keady 1999), this was often denied, thereby effectively closing off further discussion:

I tried to tell my mother about what she was doing and ask her if she recognized it too, but she didn’t want to know. I thought I had done all the right things, you know, planned what I was going to say and I waited until there was no one else in the house. She seemed happy
enough at first but I couldn’t get through to her. She just stopped me stone dead and said there was nothing wrong with her . . . [pause], but I knew there was.

In such instances the ‘issue’ might not be raised again until an event occurred that ‘brought things to a head’ (originally termed ‘confrontation confirmation’):

Carer: I remember coming home from the shops to find my husband on his knees trying to put soiled toilet paper into a plant pot. At the time I felt sick and disgusted, I was just so tired of having to chase after him all the time. I remember shouting at him, ‘Why don’t you flush it down the toilet like everyone else?’ I then said something like ‘You’re a grown man’ and ‘You’re not normal’.

Researcher: What happened after you said those things?

Carer: Nothing much, he just sort of looked at me strangely and started to walk away.

Researcher: Did you chase after him?

Carer: Yes. I went running after him. I remember I was still shouting at him, things like ‘You’ve ruined my life’, that sort of thing. I feel terrible telling you all about this now because he [carer’s husband] really isn’t well. But it is what happened. When he didn’t answer me I told him I was ‘going to do something about it’, so I remember leaving him by himself and I went straight to the doctors. I couldn’t cope any more. I felt so angry and I knew something had to be done.

When something like this happened carers usually felt very guilty afterwards, but at least this unexpected event highlighted the need to ‘ask the experts’.

Of course, not all carers had their first contact with their doctor following such a dramatic event. Nevertheless, in many instances, initial medical contact was made without the knowledge of their relative, either because they had not responded to the carer’s question, ‘Have you noticed anything?’, or because the carer wanted to talk things through before raising it with their relative. As already noted, ‘working together’ began earlier and was more effective when both the carer and the relative went to the ‘expert’ together and he/she responded appropriately. All too often, however, and irrespective of the events prior to the consultation, the medical response was inadequate:

I went to the doctor because my wife was doing things that I just did not understand. I knew she was ill but nobody would believe me – she couldn’t go with me you see and they had to go on what I said. All the doctor said to me was, ‘Come back again in six months if things have not improved.’ Some help that was.
Carer: All I knew was that he would do funny things and fiddle with things in the house. It was when he started to put the gas on and forget to light it, that I knew something had to be done. We discussed it as a family and we all agreed. 

Researcher: When you say you discussed it as a family, did the discussion include your husband? 

Carer: No. 

Researcher: So it was when your husband began to be unsafe in the house you felt you had to do something? 

Carer: Yes, that’s it. I went to the doctor then and he gave me a booklet – one with a black cover. He asked me to read it and come back again if I was having trouble managing. He also gave me a booklet telling me who to contact and, you know, that’s just about it until I went back again to see him. 

Researcher: So how long did you live with this knowledge, and your husband, before you returned again to your doctor to ask for more help? 

Carer: About two years. 

Ironically many of the encounters with GPs resulted in the family doctor adopting the same tactics as the carer had earlier, and both ‘normalizing’ and ‘discounting’ the carer’s concerns, usually by attributing the behaviour to old age and telling the carer that it was ‘okay’. By this stage, of course, the carers were usually quite sure that it was not okay but their belief that ‘this might be serious’ was discounted by the ‘expert’, thereby adding to their stress and the emerging feeling that they were ‘working alone’. 

Eventually, however, a diagnosis was provided and the carer’s ‘needs’ were recognized by the ‘experts’, leading to a situation where the carer had to decide if they wanted to ‘take it on’. 

The decision-making processes involved in choosing to become or not to become a ‘carer’ at the time of the diagnosis constituted the next stage of care, one Wilson (1989a) had previously named ‘taking it on’. While the time dimension for this stage of care is brief, it is, nonetheless, a crucial phase of the caregiving experience. The data suggested that this stage was not particularly well understood by carers, and it was a period in which professional intervention played a major role in the life of both the person with dementia and also the carer. Formal (medical) explanation of the cause of the person’s behaviour/actions marked a critical juncture, leading the carer out of ‘recognizing the need’ and into a stage that propels the family member towards the more formally recognized role of ‘carer’. The data would suggest that this period of further decision making confronts the carer with a number of questions, such as: 

- Is this for me? 
- Can I do it?
What will it mean?
Should I ‘go through with it’?

The decision to take on the caring role is a result of a number of complex dynamics, which are related directly to the context of previous relationships and to the opportunities provided by professional care agencies. How carers weigh up the options at this time is crucial, and yet there was not one carer in the sample that had been made aware of potential alternatives to them ‘taking on’ the caring role. From the perspective of helping agencies, it was expected that caregiving would continue and that, when offered, professional support would simply assist in this process; it was through this narrow and circumscribed view of the world that carers took on their role. From the data it appeared that Wilson (1989a) had accurately represented and named this stage as ‘taking it on’, and it seemed inappropriate to change the title simply for cosmetic purposes.

To a significant extent ‘taking it on’ was shaped by ‘building on the past’ and the length of time it had taken to work through the stage of ‘recognizing the need’. For some carers, reaching the point of a diagnosis was a relief as it validated their concerns about the relative and put their future into some form of context. Conversely, other carers approached ‘taking it on’ with misgivings, uncertain about the future and their relationship with the person with dementia.

Adding another perspective

As we noted at the start of this chapter, in four of the later interviews with the family carers the PWD had also asked to be present and gave their account of their experiences to date. Based on these, and a consideration of the literature, a tentative temporal model from the perspective of the PWD was published (Keady and Nolan 1994b) comprising nine stages:

- slipping;
- suspecting;
- covering up;
- revealing;
- confirming;
- surviving;
- disorganization;
- decline;
- death.

It is the first five stages that are particularly relevant here, and these are described more fully below.
Slipping
The process of dementia was seen to begin with a stage of slipping where the person gradually became aware of minor and seemingly trivial ‘slips and lapses’ in his/her memory and/or behaviour. These ‘slips and lapses’ were initially ignored, but as they became more frequent could no longer be so easily dismissed. At this time emotion-focused coping behaviours such as ‘discounting’ and the ‘normalizing of events’ were used to deny the significance of the symptoms. The stage was then seen to shade into:

Suspecting
Here the incidences occurred with greater frequency/severity so that they could no longer be rationalized or ignored. The ‘discounting’ and ‘normalizing of events’ became less successful coping strategies and the individual began to suspect that something could be quite seriously amiss.

Covering up
This strategy was employed when the person made a conscious and deliberate effort to compensate for his/her difficulties and actively to hide them from family members, friends and colleagues. As the condition progressed and covering up became more problematic, the person began to restrict activities in certain areas where his/her competence was difficult to sustain. If they had not noticed before, it was often at this point that the individual’s partner/family may have begun to notice changes in the behaviour of their relative.

Revealing
A stage of revealing is then reached where the individual’s difficulties are revealed to those closest to him/her. This may be as a result of a conscious decision, or as a result of being confronted with patterns of loss. At this point shared knowledge might still be kept within the immediate family and a formal confirmation of suspicions may be delayed.

Confirming
Next is a stage of ‘confirming’ where open acknowledgement of the problem is made and the process of diagnostic conformation begins. This is usually the first point of contact with formal services.

It was the desire to explore these stages in greater detail that resulted in interviews being undertaken with ten people with dementia (PWD) and their carers. This provided a number of methodological and ethical challenges (see Keady 1999 for more detail) but also produced a rich source
of data that allowed for a far more detailed understanding of the caring dynamic to emerge.

**Hearing the voice of the person with dementia**

Analysis of data from these interviews indicated that while the initial stages of slipping, suspecting and covering up were broadly descriptive of the early experience of dementia, they failed fully to capture the subtle and proactive actions taken. It emerged that during the stage of ‘slipping’ the PWD ‘noticed’ something unusual in their normal behaviour and, as with the carers, initially normalized and discounted such events. Only when the behaviours or events reoccurred, increased in severity, or new lapses occurred did the PWD begin to suspect that something quite serious might be happening. However, at this stage people generally kept their fears hidden:

> At the beginning it was so dark. I couldn’t believe I was doing these things. I felt so stupid and didn’t want to share it with anyone else. I had trouble getting the right word out and forgetting people’s names. It was awful.

Therefore none of these early experiences were shared; rather the PWD began to engage in a ‘secret’ process of ‘testing’ themselves out to see if their performance would return to normal. During these early stages they therefore actively ‘worked alone’ to try and maintain a veneer of normality. However, this could not be sustained indefinitely and, as the PWD feared that they would be ‘discovered’ they began a process of ‘closing down’ (Keady 1999) in order to ‘keep it (their suspicions and failing memory) hidden’. ‘Closing down’ was a prolonged process that could go on for several months and allowed for two main things to occur. It gave the PWD:

- time to adjust to their situation;
- space to reflect and try to make sense of what was happening.

‘Closing down’ can therefore be seen as a protective mechanism aimed at maintaining the person’s integrity and sense of ‘who they are’. It was also an intensely private experience, often accompanied by a lowered mood and feelings of depression. ‘Closing down’ comprised a number of tactics, all of which were designed essentially to limit exposure to ‘threatening’ situations where the PWD might no longer be able to cope. Two broad categories of activity could be identified, termed here:

- playing it safe;
- making excuses.

‘Playing it safe’ involved sticking to a limited number of behaviours and activities that the PWD felt that they could complete effectively. Hiding
their failing abilities, or ‘making excuses’, is descriptive of the PWD’s need to justify why they were not undertaking activities that they would previously have completed with no difficulty. It was often at this point that carers began to notice the increasingly limited social world of the PWD, as it also began to impact on them. The following interchange illustrates this well:

**Person:** Well, it was the simple things really. I couldn’t remember where the shopping went in the cupboards so I said something to [my wife] and would let her do it [playing it safe]. She used to get angry with me about that. I also got scared driving as I couldn’t work out the way to the shops, so I told her my eyesight wasn’t good and I stopped [making excuses].

**Carer:** [to researcher] That’s true. I used to think he was doing it on purpose. I never stopped at the beginning to think that something was wrong with him. I just thought he was trying to annoy me all the time, and that he had lost his confidence.

Eventually as the PWD felt certain that things were not going to return to ‘normal’, they began a brief process of ‘regrouping’, which again was an active process of seeking to maintain their involvement for as long as possible. Several tactics were adopted, for example:

- taking things one day at a time;
- keeping any further memory loss to myself for as long as possible;
- engaging in mentally challenging activities such as puzzles and crossword;
- using lists and other memory aids;
- constantly repeating things to myself to help me remember;
- keeping my real fears and feelings secret;
- trying to keep calm and relaxed at all times;
- making up stories to fill in the gaps;
- fighting the memory loss and trying not to let it get the better of me.

At this point the PWD used a variety of adaptive and creative coping tactics, such as writing down significant matters of concern such as: important birthdays, ages of (your) children, date of (your) anniversary, directions to the local shop, where important keys are kept and what they are for, a pictorial representation of the value of money and so on. These lists were usually secreted in places of as near absolute safety as possible where their chances of discovery were minimal; although, even in this scenario, there was an associated fear that their discovery could reveal the depths of an individual’s loss and perceived sense of failing. Interestingly, in carrying out this adaptive coping strategy, there were gender differences in places of concealment. For men a common hiding place for the lists was usually outside the house in places such as the garden shed or inside the
car, while for women inside a handbag or inside clothes hanging in a wardrobe were frequently cited as ‘secret places’. Wherever it was hidden the purpose of the list was to maintain the veneer of normality and to preserve feelings of self-worth, identity and control.

The active nature of such activities was termed ‘covering your tracks’, and this could go on for months or even years, and eventually, in some cases, was even accepted as ‘normal’ by the carer:

After a while I began to think what he [her husband] was doing wasn’t a problem. He wasn’t doing any harm, you know. I got frustrated at first not being able to go out as often as I would have liked, to get the shopping mainly, but I just thought he had gone off the idea of driving. That’s what he told me anyway, and there are worse things in this life than not going out in the car, don’t you think? I picked up some old interests of mine and life just went on.

How long ‘covering your tracks’ could be sustained depended on whether it was questioned by carers. In some cases carers unwittingly began to collude with the stories and behaviours of their partner, thus twisting their meaning and making a seemingly abnormal situation ‘normal’ again.

Eventually, however, ‘covering your tracks’ became an increasingly fraught and difficult process to manage. In time the PWD started to react to events rather than shape them, and others then began to ‘notice’ the ‘slips and lapses’ and note their frequency. For the individual with dementia, long-held coping mechanisms aimed at concealment also began to break down and their cognitive skills were not sufficient to reshape them successfully.

Eventually the PWD needed to ‘open up’ to the fact that something was wrong and, as noted earlier, carers often initiated this process themselves, or alternatively the PWD raised their concerns with the carer. Paradoxically, reversing the situation described in the carer interviews, in two cases when this occurred the carer initially denied that there was anything wrong, and when the PWD asked, ‘Have you noticed anything?’, they said no.

However, from the interviews conducted with PWD, in three out of ten cases the carers made the initial contact with the GP, and in seven out of ten cases it was a joint approach. The data from the larger set of carer interviews would suggest that this pattern was not typical and that fewer couples make an initial joint approach. The greater numbers approaching the GP together from the second set of interviews may well have been an artefact of the sample, as by definition these couples were willing to discuss their situation openly. Clearly there is a need for more research in this area.

However, in the situations where there was mutual acceptance of the situation, the PWD entered a new and less stressful phase termed ‘sharing the load’ (Keady 1999). This meant that the PWD and their carer could begin to ‘work together’ in making sense of, and responding to the future:
I know I have Alzheimer’s disease, but what can anyone do about it? I do silly things now but we just try and laugh about it. We have a saying, ‘Pick up the pieces and start again.’ It’s the only way we manage. However, even now the PWD would still keep their deteriorating abilities ‘secret’ for as long as possible, but the motivation was usually one of wishing to protect the carer for as long as possible from knowledge of their worsening condition. Interestingly this seemed to be a reverse of the ‘protective’ caring described by Bowers (1987).

Mapping experiences: when do trajectories cross?

A comparison of the early experience of the signs and symptoms of dementia from a carer’s perspective, and that of the PWD, clearly indicates that this is a time of great uncertainty for both parties. Moreover, this uncertainty can be prolonged and is often not helped by the ways in which behaviours are kept hidden, particularly in the early stages. Furthermore, even when professional support is sought the reaction is often not particularly helpful thereby further prolonging an already difficult period.

As the focus of this book is on how partnerships can be created both within dyadic (carer/cared-for person) and triadic (carer/cared-for person/professional) relationships, the ways in which these early experiences unfold is very important. Within the context of the situations described above we have adopted the term ‘working’ to capture the largely proactive, but frequently covert, strategies adopted by both PWD and their family carers. While ‘working through it’ is an explicit stage in our temporal model it is apparent that several types of ‘work’ also occur during the ‘recognizing the need’ stage. We would suggest that, depending on the extent to which carers and PWD experience a shared early trajectory, then four main types of ‘working’ can emerge. These are:

- ‘Working together’ – describes the ‘best’ case scenario when there is shared and early recognition of the symptoms and help is sought jointly. Fears and concerns are recognized by the GP, and appropriate specialist advice is taken.
- ‘Working alone’ – occurs even when there is a shared and early recognition of the difficulties that the PWD has, as he/she is likely to have kept his/her initial concerns secret for some time and will have been ‘working alone’ to hide them. Furthermore, both carers and PWD are often left to feel that they ‘work alone’ when their efforts to seek professional help do not get the appropriate response.
- ‘Working separately’ – describes the instances where the PWD is working alone to ‘keep things hidden’, and the carer is also actively ‘increasing vigilance’ so that a situation occurs where both parties are investing considerable effort but are ‘working separately’, each trying to...
make sense of and respond to their circumstances. When the PWD is very adept at ‘keeping it hidden’ and carers accept this behaviour as normal, then this period of ‘working separately’ can be prolonged.

- ‘Working apart’ – usually occurs when prior relationships between the carer and the PWD have not been good, or when difficulties in the ‘working separately’ period lead to strained interactions. Consequently the carer and the PWD can ‘work apart’ so that their relationship deteriorates and the carer feels increasingly trapped in his/her role:

  We’ve been married over 60 years. I took her on for life and we made vows to each other. That meant everything to me and no one is going to take her away from me. I would have to be dead first. I’ll put up with all this because I love her and she’s my wife. I take everything day by day and I thank God for every day we are alive. As long as I get someone to help me with a bath for her, I don’t need anything else. Ever.

This obviously represents a particularly fraught set of circumstances and provides testimony to the importance of prior relationships, ‘building on the past’, in framing the early caregiving context. Clearly the goal should be to try and ensure that all parties ‘work together’ as soon as possible, and we would suggest that certain conditions are likely to determine this. These are:

- a good prior relationship;
- a willingness by the person with (undiagnosed) dementia openly to disclose their fears, concerns and coping behaviours with a trusted person;
- a willingness by the trusted person (carer) to hear these concerns, validate and act upon them;
- a mutual decision to do something about it, where both parties recognize and agree that ‘this is (might be) serious’;
- a reasonably quick decision to seek a medical opinion;
- primary health care teams taking the reported signs and symptoms seriously, and having the necessary knowledge and skills to facilitate an early diagnosis of dementia. Alternatively, the primary health care team response may be to refer the person/couple to more specialized support services, such as a memory clinic, for a more detailed assessment;
- an early diagnosis being made and the person with dementia and the carer being informed of the diagnosis and prognosis;
- An understanding by the person and carer of the implications of the diagnosis;
- an explicit willingness by the person/carer/family to work through the processes involved in living with the experience of dementia in a supportive manner;
- specialist services being available on a continual basis to help support ‘the partnership’ – and the family – through this transition;
• ability of the carer to ‘maintain involvement’ even when the person with dementia reaches the time when he/she can no longer play an active role but the carer is still able to gain satisfaction and meaning from the act of caring itself (mutuality).

**Discussion**

The purpose of this chapter has been to explore the early stage of caring (‘recognizing the need’ in particular) from the perspectives of both family carers and the PWD. Using a grounded theory method, ‘working’ has been identified as one of the key processes, with the PWD and the carer often being proactive in terms of both trying to hide and to make sense of their early experiences. As a result much emotional and cognitive energy is invested, particularly by the PWD in ‘keeping things hidden’. Consequently, they are often working alone in the first instance. Later, as carers begin to suspect that all may not be well, they too engage in an initially rather passive, but eventually more active process of noticing and becoming increasingly vigilant. At this point both parties are working hard, but ‘working separately’.

The point at which PWD and their carers begin to work together, or even if they do successfully work together, depends in no small measure on the way in which they ‘open’ up the discussion and both acknowledge the difficulties they are facing. As we have indicated, in the best cases people begin to work together at an early stage, but all too often working separately is prolonged, and in the worst situations this can lead to a process whereby the caring dyad ‘work apart’.

Much of the above would seem to turn on the extent to which there is open discussion and a willingness to share concerns and fears. In many instances our data and results resonate with those of Hutchinson et al. (1997) who carried out a similar study involving both carers and PWD, but who used Glaser and Strauss’s (1968) concept of ‘awareness contexts’ as a heuristic to explore and interpret their data.

‘Awareness contexts’ were initially developed as a model to help understand awareness of death in hospitals, with Glaser and Strauss (1968) identifying four differing awareness contexts:

• open;
• mutual pretence;
• suspected;
• closed.

In an open awareness context all parties are aware of the situation and discuss it openly. In a mutual pretence context all parties are similarly aware but ‘pretend’ that things are different. A suspected awareness context refers to circumstances where parties only suspect that something is wrong. A closed awareness context does not relate simply to whether all
parties have knowledge of the situation, but also requires that they are all willing to discuss the matter openly. Hutchinson *et al.* (1997) argues that the idea of awareness contexts relates equally, but in differing ways, to Alzheimer’s disease, and our data would support such a conclusion.

As we have described above, during the early stages the most common and most lengthy form of awareness context was a ‘suspected’ one. This reflects the diffuse and difficult nature of early symptoms. Similar to our own conclusions, Hutchinson *et al.* (1997) argue that if a suspected context is prolonged then it can result in a competitive situation whereby the PWD is working hard to ‘keep it hidden’ and the carer becomes ‘hyper vigilant’ (Hutchinson *et al.* 1997) in trying to find out what is wrong. As Hutchinson *et al.* (1997) contend, this is not conducive to ‘interpersonal closeness’ which, as we have noted, can result in carers ‘working apart’.

We were also able to discern ‘mutual pretence’ contexts when, for example, spouses will pretend that everything is normal for their children. However, more often than not closed contexts exist either because the diagnosis is kept from the PWD or one or other party (PWD/carer/professional) ‘discounts’ the knowledge/concerns of the other, thereby maintaining a closed dialogue.

Clearly then the extent to which carers, PWD and professionals can ‘work together’ in the best relationships mandates an open awareness context and establishing this should be one of the priorities in the ‘recognizing the need’ stage, if during ‘working through it’ the PWD is to maintain involvement as an active agent for as long as possible.