

Sharing the Lived Experience: Case Studies of Two Families Living with Alzheimer's Disease

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Introduction

I have been meeting with two families once a week for five weeks. These families are living in the Victoria community. Both families are caring for individuals in moderate-to-late stage Alzheimer disease in the nursing home setting. *Family A* is caring for a person with late-stage Alzheimer disease, whereas *Family B* is caring for an individual in moderate-to-late stage Alzheimer disease. During these meeting times I have focused on listening skills as opposed to direct questioning. This has provided an opportunity for the family members to share their lived experience and reflect upon perceived needs. As a result of this reflective listening, I also have a much clearer understanding of how Alzheimer disease is impacting on these families. Also, this understanding has enabled me to identify three emergent themes: structural data, relationship issues, and preparing for the next stage.

This paper will address these emergent themes and discuss the relevant literature according to these themes. The paper embraces the importance of attaching significance to the family interpretation, surrounding the impact of Alzheimer disease on the family. As well, the paper identifies the need for formal and informal support for the family. Finally, the paper recognizes some of the ethical issues involved in caring for these individuals.

Structural Data

Alzheimer disease (AD) is a progressive degenerative neurological disorder for which there currently is no known cure. This disease develops insidiously. The first symptoms are usually memory problems or disorientation in familiar surroundings. However, some patients develop mood or personality changes before their memory problems are recognized (Volicer et al, 1993; Boyd et al, 1998).

The literature identifies that in the early stages, patients are still able to care for themselves and to engage in leisure activities. In the middle stage patients require constant supervision, lose their ability to use common household utensils, and develop speech difficulties and incontinence. Late-stage AD is characterized by motor difficulties leading to inability to walk, chew, and sometimes swallow. The patient becomes completely dependent on their caregivers for all activities of daily living (Reisberg et al, 1989; Boyd et al, 1998; Volicer et al, 1986).

Because of the progressive, irreversible changes in a previously normal functioning brain characterized by multiple cognitive deficits that include memory impairment (an inability to learn new information and/or recall previously learned information), the individual faces at least one of the following cognitive disturbances: aphasia, apraxia, agnosia, or a disturbance in executive functioning. These changes may be due to multiple etiologies, for example, the combined effects of cerebrovascular disease and Alzheimer disease (Barnes, 1998; Reisberg et al, 1989).

From first symptoms to death, the average duration of AD is eight years, with large variability in the rate of disease progression. The disease affects mainly the areas of the brain involved in memory, speech and other higher functions, but does not affect the brain areas regulating basic body functions such as breathing and circulation. Therefore, patients do not die because of the disease itself, but because of its complications (Volicer et al, 1993; Barnes, 1998). As a result, individuals with AD may live for many years.

For *Family A*, other complicating health problems insidiously accompanied Barb's onset of Alzheimer disease. In 1987, life as they had come to know it, changed for this family due to the degenerative, progressive nature of the disease. Mr. C. says that this was the year Barb had bypass heart surgery, and he started to notice a decline in her. He feels this was the time when her memory started to deteriorate; "one day she was soaking the plump vegetables from the garden, somehow her mind got off the track, and she left the water running in the sink until it overflowed and leaked into the downstairs ceiling." Mr. C. says, "we laughed about these things at the time, but soon they became more disturbing." And then Barb began to lose interest in all those things she had loved to do: gardening, sewing, and cooking. Mr. C. says, "the wife, mother, and grandma who had been so creative and in control started to fade away." In 1993 the neurologist performed a Cat scan. In 1994 Mr. and Mrs. C. moved from Trail to Victoria.

It is only the past year and a half since Mr. C. brought his wife to live in the nursing home. In 1998 Barb suffered a 'stroke,' and this has set her back tremendously, he reports. "now she no longer speaks, only makes funny little sounds, I think I'm the only one who even understands her. Like, she'll cry for happy when she sees me arrive, and then she'll cry for sad when she's having pain or needs to go the bathroom." Mr. C. states that the caregivers at the nursing home were astonished that he was able to provide care at home for his wife as long as he did.

In other words, as the disease progressed, Barb was requiring more and more caregiving, and becoming completely dependent on Mr. C. for all activities of daily living. Mr. C. could no longer manage, as he had his own health to consider. At this stage, it is vital to recognize the importance of formal as well as informal support for the family.

See Appendix, visit #3 — which revolves around some of Barb's challenging behaviors.

In the case of *Family B*, Dr. M. (Mac) has other “pressing health concerns” as well as Alzheimer disease. In fact, it was actually his heart condition that brought the family to the physician initially. Prior to admission to the nursing home, he was given a series of psychological testing, with a tentative diagnosis of Alzheimer disease. The medication, Aricept was then prescribed for him. Mrs. M. reports that it did Mac “absolutely no good; I think one has to take it earlier on,” she says.

Dr. M. was admitted to the nursing home in March 1998. But Mrs. M. reports a decline in Mac “long before that.” He had loved to play the bagpipes; actually Dr. M. was part of a band, and this provided a great social time for them both. Dr. M. stopped playing the bagpipes 3 years ago, and he hasn’t once asked for them. He stopped driving several years ago and hasn’t once asked to drive the car again. And even since being admitted to the nursing home, Mac has never once asked, “to go home.” Mrs. M. says, “He has a most accepting nature of whatever comes to him.” The literature says that elderly wives may be especially vulnerable to the challenges of caregiving because of their own advancing age (Ross et al, 1997). On several occasions, Mrs. M. had commented that Dr. M’s behaviors were disturbing to her, particularly the repeated waking during the night, “because neither of us get our rest.” Although both families cared for their spouse at home as long as they possibly could manage, Alzheimer disease totally changed the family unit as they once knew it. The next section will discuss relationship issues within the family.

See Appendix, Visit #3 — which revolves around some of Mac’s challenging behaviors.

Relationship to Person with Alzheimer’s Disease

Family caregivers of individuals with Alzheimer disease (AD) have been described as an “at-risk” population. Although support needs of family caregivers in general have been recognized, no literature describes the issues and needs of families dealing with the late stage of AD (Bonnell, 1996; Cuttillo–Schmitter, 1996).

Due to the disease process, there are several resolving losses threatening family solidarity. Loss such as death is definite; clearly tangible and visible. Other loss such as deterioration associated with terminal illness can be ambiguous. Lingering, incurable illness, such as AD, is extremely painful and stressful for family members as they endure the progressive deterioration and eventual death of their loved one. In such cases, the essence of self (i.e. individual personality) ceases though the person physically remains alive. Such an ambiguous loss may be more complicated for family members to grasp, and thereby begin to resolve. As a result, ambiguous loss may constrain relationships and hamper family connectedness and restructuring. Cuttillo–

Schmitter (1996) offers several strategies for families in dealing with some of these difficult issues:

- Presence yourself and acknowledge what can and cannot be done for those experiencing grief and loss.
- Label the ambiguous nature of the illness loss, helping to clarify lost parts of the relationship as well as what still remains.
- Provide opportunities for sharing perceptions of loss as well as the meaning they attribute to the illness situation.
- Education is the key for families regarding the progression of the disease process and its effects on family members, providing guidance about resources available to lessen the family burden.

This family burden is of particular concern for spousal members who are vulnerable due to their own health concerns. Ross et al (1997), in exploring the “caregiving careers” of elderly wives, identified outstanding patterns of wives who continued to be heavily involved in caregiving, were themselves suffering from moderate to severe depression. This study examined the caregiving career of older women following the institutionalization of their husbands. The caregiving career of wives was seen as a pattern of frequent visiting and increasing involvement in the provision of care. And wives who relinquished aspects of caregiving were more likely to be caring for husbands who were in large measure cognitively impaired (Ross et al, 1997). The significance of this study lies in the identification of changes that occur over time that signal the increasing vulnerability and potential for breakdown in elderly wives coping with the institutionalization of their husbands (Cohen, 1998; Ross et al, 1997).

Cohen (1998), Goetschius (1997), and Bonnel (1996) agree that families require support and understanding in dealing with the many prevailing losses that Alzheimer disease brings. At a time when need for social support is high, family resources may be low from physical and emotional costs of long years of caregiving and loss of the ill person as a support (Bonnel, 1996). It is important also to distinguish between informal support and family caregiving. Informal care that is given unwillingly, loses its emotional warmth and affection (Chappell, 1998).

In other words, it is critical to recognize the family’s need for formal and informal support, when the relationship within the family unit is altered due to the impact of Alzheimer disease. This impact may signal increasing vulnerability and potential for breakdown of health in spousal members.

For *Family A*, this care is offered willingly and with emotional warmth. Although Alzheimer disease has altered the relationships within the family, the family unit remains as strong as ever.

Mr. C. feels strongly that “Marriage is a sacred thing,” and once the vows are made, they shall not be broken. “I’ll always be here for Barb,” he says. “I suppose I’m lucky to have such a supportive family. The children have always been compatible, and now with this Alzheimer disease, they’re even more compatible. Mind you, that’s the way their Mother brought them up. I know, even our son who lives in Edmonton, would be here in a minute if I called. We trust one another as a family, and if something’s bothering us, we can talk about it. There are so many losses with this disease; I wouldn’t want to lose my family as well. The children remember who their Mother was, and they accept her the way she is now.”

Mr. C. feels strongly that visitation is very important for these people. He says, “it’s easy to convince yourself that it doesn’t matter if you come or not; the person won’t miss you, but it’s a tragedy to not give them the time.” Mr. C. feels that his being with Barb makes all the difference in the world. He says, “we’ll just be sitting together; I’ll be playing cards, and then we’ll hold hands. And I’m always with Barb at mealtimes. She knows I’m there.”

Mr. C. went on to say, “this is Barb’s home now. It’s almost like having a second family. I feel a need to mingle with these people in Barb’s home.” And he feels that they take awfully good care of her; “they’re sure giving people.” But Mr. C. admits that he doesn’t do much for himself; “I’m here for Barb seven days a week. I don’t have much time left at the end of the day for myself. I do try to keep up a healthy way of eating though. And with these ‘darn’ knees of mine, I can’t walk as much as I used to. It is important to stick to a routine, and that’s what I do.”

For **Family B**, the relationship issues within the family unit have been altered as well, but in a slightly different manner. Due to the impact of the disease process, Mrs. M is embracing a new reality. She feels that she “can just give Mac so much of my time.” She manages to get up to see him just about every day, but also adds “that he doesn’t know one day from the next anyway, and I’m sure he wouldn’t miss me.” Mrs. M. takes time for herself; she will have lunch with friends, have a hair–do, go shopping, and now she’s planning a trip this month to Indonesia to visit her son.

“The children do come occasionally to see their Dad, but they don’t spend the time with Mac that I do; they think he doesn’t know that they’re there,” says Mrs. M. “We always have had strong family relationships, and I think with this disease, that the relationship is even stronger.” And she adds that when the children can’t come, they do telephone.

Mrs. M. reports that Mac still likes to hug and kiss her. “Mind you, I’ve always found him to be sexy,” she says. “I think these people still feel something; I know he still has his sense of humor, and I know he still feels pain and simply can’t express it. I am fortunate that Mac can still talk. These people in the nursing home seem to acknowledge one another’s presence; they’ve all lived

together here since last March and seem to have their own way of communicating. Dr. M. smiles at them with his eyes,” she says.

But then, Mrs. M. shared with me that she really has no one to communicate with; “it sure is a lonesome life,” she said. She states that even though her husband talks to her, it’s as though he’s talking to someone else. “I have peace of mind knowing that Mac is in a good safe place; he is content. If Mac is happy, then I can be happy too.”

As identified in the literature, wives consider visiting to be the most important function they perform for their husbands. They also view the provision of love, support, and companionship as important, as well as the fulfillment of specific tasks. It is also interesting to note in the literature that a significantly greater proportion of wives who were embracing new realities had husbands who were cognitively impaired (Ross et al, 1997).

The next section will discuss how these families are preparing for the next stage.

Preparing for the Next State

Originally, the objective of the study was intended to differentiate between the individual in late-stage dementia, and the individual in late-stage dementia who is dying. As it has turned out, both families are caring for persons in moderate-to-late-stage dementia, neither individual is at the terminal stage. Consequently, the focus became rather identifying this family’s expectations of death and dying; both families were more than willing to share this part of their journey, even though they haven’t arrived there yet.

The literature recognizes that advanced dementia should be considered a terminal condition because there is no effective treatment available and the demented individuals die of consequences of dementia, most commonly infections. In addition, the effectiveness of antibiotic treatment is decreased in individuals with advanced dementia. Therefore, the primary goal of care in advanced dementia should be similar to the goal of care in other terminal conditions: patient’s comfort (Volicer, 1997; Brechling et al, 1989; Goetschius, 1997).

These authors also recognize that comfort is not the only goal of care. Dementia not only robs the individuals of the ability to care for themselves, but also decreases their ability to make rational decisions and to understand their environment (Mount, 1993). However, the individual’s dignity must be maintained. We need to recognize two components of dignity. One is related to the ability to make autonomous decisions. The second component is based on the individual’s place in society and remains after the individual cannot make any decisions (Brechling et al, 1989; Volicer, 1997; Goetschius, 1997).

For the individual with Alzheimer disease, the families become the ultimate decision-makers. Ross (1998) discusses the process of legitimization of death for older adults in the last chapter of their lives. It is recognized that these individuals want their lives to have good endings. They do not want to be a burden. They do not all think that death comes too soon. The vast majority of older people reach a point where death and their own dying make more sense than continuing to live forever. Staff can help families cope with these difficult decisions they have made and feel validated they have done their best (Ross, 1998).

Bonnel (1996) summarized the literature on helping families view tough decisions not as withholding care, but rather as substituting a high-touch care approach. Luchins & Hanrahan (1993) and Volicer et al (1986) agree that in order to improve the psychological well-being of individuals with advanced dementia, the emphasis of care must be switched from the medical to the social model, and from aggressive medical interventions to hospice care. Ross (1998) also recognizes that the acute medical model, heavily reliant on technology and an emphasis on cure, does not meet the dying needs of this individual. Rather, this individual requires optimal symptom control to ensure the best possible quality of life.

For *Family A*, they have been anticipating the impending death of their wife and mother for some time. Mr. C. feels that he just wishes Barb would ‘go to sleep’ when it’s her time. He says the children are all in agreement with this. They want their Mom to be kept comfortable, and maintain quality of life for her, but they want ‘no heroics.’ “The children are well prepared”, says Mr. C.; “they’ve done a lot of grieving already about the Mom they once knew.”

In 1993, they appointed a power of attorney, and a “‘Living Will’ was drawn up, which made it very clear for all of us exactly what Barb’s wishes were. It’s very interesting, because that’s exactly the same time when Barb started not recognizing friends and family. At that time, she was still talking though,” says Mr. C. “Now, as she slowly sinks into this abyss, she doesn’t know who we are; she doesn’t know me as a husband; her eyes only light up as I come into the room. I always thought that Barb might have wanted to go home with me, but she never did.”

Mr. C. talked then of taking care of himself, maintaining a healthy lifestyle, and the importance of keeping a routine. “My whole day’s routine revolves around getting up here to be with Barb. I don’t have time for anything else; I mean I watch TV; I like ‘Wheel of Fortune.’ But all the friends I have are right here in the nursing home. In the future, when it’s time, I might want to move closer to the children. But right now, I need to be with Barb.”

Family B has also anticipated the final passage of their husband and father for some time but has prepared in a slightly different manner. Mrs. M. states “I’ve been preparing for this stage for some time” (as mentioned earlier, Mrs. M. is very matter of fact). She states that her children are all in agreement that their Dad should be kept as comfortable as possible, and not to be suffering

in any way, but they don't want 'any heroics.' She said that many years ago Dr. M. expressed his wishes in a Living Will; he doesn't want any life support, and Dr. M. wants to be cremated, and wishes to have 'the pipes playing at the end.'

When asked about how well she felt she was coping, Mrs. M. said, "What else can I do? They take awfully good care of Mac there at the nursing home. I know he's not going to be with me forever, and I think I'm ready for that. But things are different now than they used to be," she said. When I asked Mrs. M. what things were different, she said, "it's hard to part with Mac's things when he's still living." She went on to explain that she has been giving away boxes and boxes of her husband's things (books, clothing, and personal items) to friends and family for some time. "Even selling our home; it all seems unreal to me; I feel as though I'm floating along." But then, Mrs. M. becomes focused once again, and states, "yes, but this way, I am close enough and can visit him every day." She feels that in "disposing of things already, I'm making it easier for the kids later on. I know that Mac is content there, and his face lights up when he sees me, but some days I sure am lonely."

Both families recognize Alzheimer disease as being terminal and are facing ethical dilemmas in decision-making. Formal caregivers can empower the family by offering support and education. The final section deals with some of these ethical dilemmas.

Ethical Issues

Current changes of the health care system force all health care providers to reassess their activities. The emphasis has shifted from providing any available treatment to careful evaluation of costs and benefits of different treatment strategies. Such an evaluation is especially important for an individual with Alzheimer disease, where the illness trajectory may extend for many years (Volicer, 1997; Brechling et al, 1989). Luchins and Hanrahan (1993) concur that health care professionals and family caregivers consider appropriate health care for end-stage dementia patients.

In extending hospice care to end-stage dementia patients, Brechling et al (1989) addresses some of these ethical issues:

- autonomy or self-determination is translated as the patient's right to make important decisions about his or her own life. This places the patient in the center of the decision-making process with the freedom to make choices.
- the principle of beneficence states that health care professionals should help to care for one another as best they can, or conversely, should avoid causing suffering or pain to others.

- the third ethical value, justice, pertains to the individual's access to an adequate level of health care and the equitable distribution of available health care resources.
- health care workers have stringent ethical obligations to the patient by virtue of their professional standards and code of ethics.

In other words, this concept of autonomous decision making can present problems in caring for dementia patients who are incapable of making informed choices. This is when the need for “advance directives” is imperative; the family then becomes the surrogate decision-maker.

Rabins and Mace (1986) refer to this autonomy as the right of the adult to fully determine his/her own destiny; or in the case of guardianship, when the individual with dementia clearly cannot care for themselves. Post (1994) agrees that advance directives, generally in the form of a living will, are justified as an extension of this autonomy. And the incompetent AD patient requires a designated decision-maker who can act in his or her best interest. This designated decision-maker should consider the person's previously expressed wishes and preferences (McCracken & Gerdson, 1991).

These previously expressed wishes may include the individual's preference to achieve “death with dignity.” As stated earlier by Volicer (1997), this maintenance of dignity is critical even in the late stages. And this component of dignity remains even after the individual can no longer make decisions.

Both families respect their loved one's preference for “death with dignity.” Both families agree that holistic caring should be provided for their loved one, including physical, psychological, and spiritual support. Both families insist that “high touch versus high tech” care be provided. This ethical decision making requires support and understanding from the professional caregivers.

Summary / Conclusion

This paper has compared and contrasted the lived experience of two families who are living with Alzheimer disease. Three emergent themes have been identified: structural data, relationship issues, and preparing for the next stage. These themes have then been analyzed according to the existing literature. Finally, ethical issues have been discussed in relation to autonomous decision making, health care's goal, justice for the individual, and ethical obligations of the professional caregiver.

This paper has embraced the importance of attaching significance to the family interpretation, surrounding the impact of Alzheimer disease on the family. It also has emphasized the need for formal and informal support for the family. Although support needs of family caregivers in general have been recognized, there is a dearth of literature describing the issues and needs of

families dealing with the late stage of Alzheimer disease. As caregivers of individuals in late-stage dementia, we may need to remind ourselves on a daily basis of the importance of support and education for the family members. As caregivers, we must remain constant advocates for the family's need for understanding and attaching meaning to the journey that their loved one is passing through.

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Appendix

Family A

Visit 1

I met with Mr. C. today at the nursing home. He was most gracious in welcoming me. He wanted me to meet his wife, Barbara, but she was resting, so he thought best next time. I wanted to utilize this first visit to develop a climate of rapport and trust; so rather than structure a formal interview, I explained to Mr. C. that we might begin by talking a little bit about their family life, so we did, and this is how it went:

Mr. & Mrs. C. have been married for 54 years; he is 76 years old; she is 75 years old. They have 4 children, 3 daughters and 1 son, who is the eldest. As Mr. C. talks about his wife, Barbara, he does so matter-of-factly, but at the same time, his eyes get “misty.” He remembers her as being a wonderful wife and mother, an elementary school teacher, a cub master, seamstress who sewed all the children’s clothes. She was known for having a strong will, for being stubborn, and for never giving up on anything that she had set her mind to. Barbara was a terrific cook; gardener, knitter, in fact there wasn’t anything that she couldn’t do well. Barbara was loved and respected by friends and family in the community.

Today, says Mr. C., Barb doesn’t even know who I am, she no longer speaks, cannot recognize others around her, cannot feed herself, nor transfer into the wheelchair; she is incontinent of both bowel and urine (Mr. C. used this language with no difficulty). Mr. C. has noticed the decline in his wife since 1987, when she had bypass heart surgery; he feels this was the time when her memory started to deteriorate, she began to lose interest in things around her, activities that she used to enjoy, such as gardening, she no longer seemed to enjoy. In 1993, she scored 28/30 on the Folstein MMSE; in 1994, she scored 20/30 on the Folstein MMSE. This was when a Cat scan was performed. Even though Mr. C. was still caring for Barbara at home, he was finding it increasingly difficult, due to her forgetfulness, moodiness, incontinence, and perseverance (she would sit and knit for hours on end, refusing to do anything else). Mr. C. says that friends don’t come anymore; they don’t avoid you intentionally, but rather they can’t “hack it.”

Barbara has been in the nursing home for approximately the last year and a half. In 1998, she suffered a “stroke,” and this has set her back tremendously. She no longer speaks; only makes funny little sounds. Mr. C. says that Barb “cries for happy” (when she sees him arrive), or “cries for sad” (when she’s experiencing pain or needs to have a bowel movement). He says he’ll take her straightaway to the toilet, and she will go. Also, she has had several falls here in the nursing home. Mr. C. praises the caregivers, and thinks very highly of them, but he says, “you can’t expect them to be everywhere.” There have been occasions where Barb does choke on her food,

so she now is on a pureed diet, and Mr. C. feeds her faithfully every lunch and dinner. Mr. C. expressed a feeling of unconditional love for his wife, Barbara, and said “I’ll always be right here for her.” He explained to me that the nursing unit that Barb is on is “D” unit, and this is the heaviest one. When I asked Mr. C. to explain the meaning, he said that this disease is terminal, and Barb will die here; he also said that he would care for her right to the end.

At the end of our visit, I thanked Mr. C., provided closure, and we set a meeting time for the following week. He walked me out of the locked unit to the elevator, and then offered me a glass of water, and took one for his wife as well. He closed by saying, “it’s very important for Barb to get enough fluids, you know.”

Visit 2

One of the first things Mr. C. said to me today, “Her eyes have changed, look at this picture that was taken in 1986, and, now, look at her eyes now.” Sure enough, the picture of the couple showed Barb with bright eyes, shining through. “There, that’s what I keep telling you,” says Mr. C. “She doesn’t remember a thing about her past.”

One day, they were sitting together in the lounge (Barb doesn’t like crowds); Mr. C. was playing solitaire; Barb reached over to hold his hand. “She doesn’t talk to me anymore, but I think she likes us to be together.” Mr. C. shares that it was approximately 1–2 years ago when Barb last spoke to him. She said, “Bill, you’re so good to me.” Last year, Barb’s sister visited. When they were sitting together, Barb reached over and grabbed her sister’s knee. The sister became quite excited that Barb knew who she was. “I didn’t say anything”, says Mr. C., “but I don’t think Barb knew who she was.”

“She’s oblivious to everything; she doesn’t know what’s going on,” says Mr. C. He goes on to explain that the caregivers at the facility are wonderful about decorating at Christmas time. “Barb doesn’t understand it; she doesn’t know what it’s about.” Mr. C. says that if Barb is incontinent, she’s oblivious to it; the caregivers clean her up; she doesn’t seem to mind. One of the most difficult times for the family, though, was when Barb began to have a series of falls. Mr. C. says “the girls here are wonderful, but they can’t be everywhere.” The family could really see the beginning of deterioration in Barb. Mr. C. says, “that she belongs here on this unit, because this is the last stage.”

Mr. C. assists his wife with mealtimes, every lunch and dinner. He reports that she had been having some difficulty with choking, until they gave her pureed foods, and thickened liquids (milk and juices). Now, he says, “the choking is better, but Barb drools all the time.”

On admission to the facility, Mr. C. says that he signed some papers about Barb's care. Mr. C. went on to explain that "he only wants Barb to be kept comfortable; he wants her to not have any pain, and to be as comfortable as possible." He says, "the caregivers here are maintaining quality of life for Barb, and our family will enhance her quality of life." "Oh, yes, I have no other outside interest but Barb; I'm dedicated to her; if Barb passed away tomorrow, I would feel terrible, but Barb would be relieved. I must take care of my own health, so that Barb must go first, not me, and then I will have peace of mind."

Visit 3

We had missed our meeting last week; Mr. C. shared that he had missed it, as he really enjoyed sharing these experiences. Today's discussion revolved around some of Barb's behaviors. Mr. C. says, "I wished I'd kept a diary."

When discussing any paranoid or delusional behavior, Mr. C. couldn't remember Barb ever having displayed any of this behavior, only that she would behave very strangely in front of a mirror. He denies that she had any delusions of abandonment or suspiciousness of him in any way. Barb hasn't displayed any hallucinations, although she does talk to the girls in the picture on occasion (these are her children) and asks if they will have something to eat.

When Mr. C. was caring for Barb at home, her wandering was quite disturbing, but was never sufficient to require restraint. He did find the purposeless activity annoying, such as putting on and removing clothing, and constantly pacing. Also, Barb would often remove her clothing altogether. Mr. C. does not recall Barb displaying any verbal outbursts, physical violence, or agitation.

Barb did display day/night disturbance; in fact, she would repeatedly waken. Mr. C. doesn't recall any tearfulness, only that Barb will "cry for happy", or "cry for sad." He recognizes her body language, though there aren't any real tears. Mr. C. cannot recall Barb having any anxieties or phobias, although he admits she doesn't care for large groups, and will start making sounds when they're in a group setting. He denies her fear of being left alone, fear of bathing or having different caregivers.

Mr. C. is looking pale and tired today; I commented on this and his response was, "Oh, sometimes I do get tired, but I take good care of myself; I have to take care of Barb, you know; it's unconditional love."

Visit 4

Today when we met at the nursing home, I noted that Mr. C was quieter than usual, and looked a little sad. He went on to explain that a friend had just “passed away,” a friend for many years who had actually cared for a spouse with Alzheimer disease and had led one of the support groups. This led perfectly into the topic of discussion for today’s visit: “Preparation for Dying.” Mr. C. says that he just wishes Barb would “go to sleep.” He wants her to be kept comfortable and maintain quality of life for her, but “no heroics.” “There are so many indignities attached to this disease; they may seem oblivious to it, but when it’s her time, we just want her to go.” Mr. C. says that the children are all in agreement with this. “They are well prepared,” says Mr. C.; “they’ve done a lot of grieving already about the Mom they once knew.”

In 1993, they appointed a power of attorney, and a “Living Will” was drawn up, which made very clear for all of us exactly what her wishes were. “It’s very interesting, because that’s exactly the same time when Barb started not recognizing friends and family. At that time, she was still talking though,” says Mr. C. “Now, as she slowly sinks into an abyss, she doesn’t know who we are; she doesn’t know me as a husband; her eyes only light up when I come into the room. I always thought that she might have wanted to go home with me, but she never did.”

Mr. C. talked then of taking care of himself, maintaining a healthy lifestyle, the importance of keeping a routine, “My whole life revolves around getting up here to be with Barb. I hardly have time for anything else; I mean I watch some TV; I like Wheel of Fortune. The friends I have are right here at the nursing home. In the future, when it’s time, I might want to move closer to the children. But right now, I need to be with Barb.”

Visit 5

We had our visit today at the nursing home. Mr. C. seemed very cheerful and went on to explain that he was looking forward to cooking dinner for his daughters this evening; he was planning to do a “stir-fry.” And while he was at home doing the cooking, his daughters would be giving Barb her evening bath. Mr. C is an individual who seems to like to have things in order.

He began right off by saying, “Barb’s in the final stage of this disease, you know; she’ll be in this section of the nursing home until the day she’s finished.” “Marriage is a sacred thing; I’ll be here with Barb right until the end; she knows when I’m here. And the children are all very supportive; I guess I’m pretty lucky. Even my son who lives in Edmonton would be here in a minute if I called. And the girls give Mom her weekly bath, and they do the “bubbles” and seem to have a good time. Yup I’m pretty lucky.”

“Mind you, Mr. C. went on to say, the children have always been fairly compatible, and now I think with this Alzheimer disease, they are even more compatible. We trust one another as a family, and if something is bothering us, we talk about it. Barb was a strong mother, and she brought the children up that way. The children remember who their mother was, and they accept her the way she is now. I feel very fortunate to have such a supportive family.” Mr. C. went on to tell me that he feels visits are so very important for these individuals; and that it’s easy to convince yourself that the person won’t miss you anyway, but he feels it would be a tragedy to not give them the time. “My being here makes such a difference to Barb, I know it does; I may be sitting next to her, and I’m playing cards, and then I’ll hold her hand. Or my being with her at mealtimes; I know she’s eating better than if I wasn’t here.”

This is Barb’s home now; I feel a need to mingle with the people living in Barb’s home. It’s almost like having another family. Mr. C. provided closure by saying, “this Alzheimer disease is very difficult to accept.”

Family B

Visit 1

I met Mrs. M. and her husband, Dr. M., in the dining room at the facility. She was assisting him with the “noon–time meal”, then walked with him back to his room, and then we began our visit. Just before leaving the dining room, Dr. M. took my hand and said, “Oh my, your hand is cold!” (which indeed it was, because I had just come in from outside).

Mrs. M. is a small–framed woman, she moves quickly and deliberately around the room. Following introductions, she proceeded to relate to me about the family. Dr. M. is 86 years old (they call him Mac). Mrs. M. is 82 years old; they have been married since 1942, have 4 children; 3 daughters living in Alberta, and 1 son living in Indonesia (he is a chemical engineer). Dr. M. has been a resident here since last March. Prior to admission, he had a series of psychological testing, with a tentative diagnosis of Alzheimer disease. The medication, Aricept was then prescribed for him. Mrs. M. reports that it did Dr. M. “absolutely no good; I think one has to take it earlier on”, she says. Mrs. M. herself reports good health generally; she self–medicates with one Calcium, one Vit. C., one Aspirin daily (has taken these for years; she thinks for her heart). Mrs. M. is a nurse by vocation (recently, celebrated her 50th Nurses’ Reunion at St. Joseph’s School of Nursing in Victoria).

When asked to discuss some of the caregiving issues prior to admission, Mrs. M. identifies 3 major concerns: wandering, incontinence, and being overly sexy (“he wants it all the time”, she says). Since admission, though, she sees Dr. M. regressing. “He still knows who I am, but he doesn’t recognize me like he used to.” Recently, they both attended ‘Robbie Burns’ night at the facility. Mrs. M. explained that Dr. M. is Scottish and used to love to play the bagpipes all the time (even in front of the mirror); and when the entertainment of the event included bagpipes, he seemed to really enjoy himself, although he didn’t say anything, he did applaud and seemed to have a good time. “He ate his haggis and I think he kinda enjoyed it.” Mrs. M. reports that he last played the ‘pipes’ about 3 years ago for a funeral and hasn’t played them since.

Dr. and Mrs. M. lived for many years in a home in Sooke. She describes it as a beautiful home with a pool, where they brought up the children, and for many years after, the grandchildren visited. Early last year, she put the home for sale, it sold much too quickly, and she was forced to size down, and move into an apartment in Victoria. In many ways, she considers this a positive move; it is much closer to visit her husband; the home was too much for her to keep up herself, and she constantly felt Dr. M.’s presence there. But now, she describes this as “a floating along experience.” She said she feels this is an unreal experience. Mrs. M. speaks very matter–of–factly about the situation (almost objectively, as an outsider might do), but she does express regret at having sold her property too quickly. Dr. M. always told his patients, “don’t make any

major decisions for at least a year after losing your spouse.” (I intend to explore this concept in a future visit).

A short time prior to admission at the facility, the couple was having lunch with a friend at a restaurant in Esquimalt; Dr. M. excused himself from the table to go to the bathroom. Mrs. M. says that he was gone for some time and must have been examining himself in front of the mirror. “Anyway”, she reports, when he returned to the table, he said to us, “my friend followed me to the table.”

Visit 2

The visit this day was spent in Mrs. M’s apartment. She had just returned from visiting Dr. M. for the noonday meal, she reported that he was not so co-operative this day. She says, “I like to see him every day; I think he has a nice change when he sees me.” When I arrived at the dining room today, she said, “he was sitting at the table, holding hands with one of the female residents, who has had so many strokes, she should be dead already.” He turned to me and said, “she’s my Mother.” As mentioned previously, Mrs. M. has a very matter-of-fact manner.

Mrs. M. shared with me some of the pictures of Dr. M. playing his bagpipes. At this time, he was part of a band, and this provided a great social time for both of them, as well as opportunity for travel. Mrs. M. admits to being quite lonely now; friends who they once had, don’t come anymore, the children live away and have their own lives, and sometimes she wishes that she might have moved closer to the children. Mrs. M. speaks fondly of her granddaughter, who presently is living in London, and may soon come for a visit. Mrs. M. does like to read mysteries, watches TV, and as the weather permits, goes for walks.

Mrs. M. reports that ever since Dr. M. has been admitted to the facility, he has never once asked to “go home.” Also, that he stopped driving approximately 3 years ago, and has not once asked to drive the car again. As mentioned earlier, Dr. M. stopped playing the bagpipes 3 years ago, and hasn’t seemed to miss them either. “He has a most accepting nature of what comes to him,” she says.

“I do try to visit my husband nearly every day, but if I miss a day, he doesn’t seem to mind.” Mrs. M. says that sometimes when she comes in, he will be looking like “a lost soul.” She sits with Dr. M. while he feeds himself lunch; they will take a little walk around, and sometimes, she attempts to toilet him (usually, she says, without much luck). Mrs. M. says that her husband can be quite stubborn, and this has been a frustration for her over the years. She might attempt to shave him, if he permits her to. Mrs. M. praises the caregivers highly; she says, “they look after him pretty good.” She feels that Dr. M. is more manageable for the caregivers, than for her.

As previously mentioned, Dr. M. hasn't once spoken of "going home," since admission to the facility. Mrs. M. thinks that perhaps he feels a "sense of familiar" at the nursing home. When he was admitted last March, the same other ten residents were admitted to the nursing unit; this group has not changed (though Mrs. M. thinks there may be one or two individuals who are ready to die). And, she feels that the caregivers remain fairly consistent, and this is a good thing as well. "My husband's a different person there; sometimes, when I arrive, he will be walking with another resident. When he sees me, he still knows who I am, but he doesn't recognize me."

Visit 3

Today the discussion revolved around some of the behaviors that Dr. M. displays. I had been at the nursing home earlier in the day and Dr. M. had been walking with another resident up and down the corridor. He actually greeted me, saying "Hello." Mrs. M. seemed pleased when I shared this with her. She said, "I think he's happy there."

When I asked her if she could recall Dr. M. displaying any paranoid or delusional behavior, she said no. "The only time I can think of is the time he saw himself in the mirror that day in the restaurant, and thought it was a friend he should wait for." She denies him ever having any visual or auditory hallucinations.

Dr. M. does wander, and this disturbs Mrs. M. somewhat, but not sufficient to ever restrain him. Also, he will repeatedly put on and remove his clothing, and insistently repeat the same question to her. "I would just get so frustrated," she says. "And sometimes, Dr. M. would hide things in the bathroom, or the kitchen; I could never find it. Or, he would just take all his clothes off in the middle of the day."

Mrs. M. denies that he has ever displayed any verbal or physical outbursts, or agitation. "The only thing is he gets stubborn, if he doesn't want to do something." Dr. M. has repeated wakening during the night; this can be disturbing, "because neither of us get our rest."

Mrs. M. doesn't recall her husband ever displaying any tearfulness or depressed mood. "He's always been fairly easy-going; Dr. M. just takes things as it comes to him. He doesn't have any anxieties about upcoming events. "At least I don't think he does; he seems happy to me."

Mrs. M. says, "I think Dr. M. is happy living at the nursing home; he hasn't once asked me about being away from home. He seems to get along with everyone; everyone likes him, and he likes everyone." She denies that he might have a fear of being left alone, any fear of crowds, or fear of new caregivers. In closure, Mrs. M. said, "My husband is content."

Visit 4

We met at Mrs. M's apartment today; I had seen Dr. M. earlier at the nursing home, and shared with her that he was walking about, being very cheerful and social with the other residents. This pleased her, as she had missed the visit that day, due to the weather.

Our discussion revolved around preparing for the next stage. Mrs. M. had no difficulty talking about this. "In fact, I've been preparing for some time," she said. The children are all in agreement that their Dad should be kept comfortable, and shouldn't be having any pain, "but, no heroics." She said that many years ago Dr. M. expressed his wishes in a Living Will; he doesn't want any life support, and Dr. M. wants to be cremated, and wishes to have "the pipes playing at the end," Mrs. M. commented, "these funeral homes sure take a lot of money; I'm thinking we'll just have a memorial service for Mac."

When asked about how well she felt she was coping, Mrs. M. said, "What else can I do? They take awfully good care of Mac there, I know he's not going to be with me forever, and I think I'm ready for that."

"Things are different now than they used to be," she said. When I asked Mrs. M. what things were different, she said, "it's hard to part with Mac's things when He's still living." She went on to explain that she has been giving away boxes and boxes of her husband's things (books, clothing, and personal items) to friends and family for some time. "Even selling our home; it all seems unreal to me; I feel as though I am floating along." But then, Mrs. M. becomes quite focused, and states, "yes, but this way, I am close enough and can visit him every day." She feels that in "disposing of things already, I'm making it easier for the kids later on. But imagine, if a miracle happened, and Mac got better today and came home; he'd literally "die" to see me living in this apartment."

At the end of our visit, and when Mrs. M. was escorting me to the door, she commented, "I know that Mac is content there, and his face lights up when he sees me; but some days Gwendolyn, I sure am lonely."

Visit 5

We had our visit today at Mrs. M's apartment. It was a lovely sunny day, and she had just been out for a drive to Sooke to have lunch with a friend. Consequently, this was one of those rare occasions when she didn't have a visit with her husband. "He doesn't know one day from the next anyway, and I do try to get up each day to see him, because I think he knows when I'm there sitting beside him at lunchtime."

“And the children do love their Dad, and visit occasionally, but they really don’t spend the time with him that I do. They think that Mac doesn’t know; I believe he enjoys having somebody there. Family relationships have always been important for us; I actually think though, that this disease has brought us all closer together.” She said that the children telephone her frequently as well.

Mrs. M. feels fortunate that Mac can still talk. “And he talks alot,” she said. Also, he has a need to express himself sexually. She explained, “that he’s always been kinda sexy, and he still does like to hug and kiss me. I believe that sometimes he does know me.”

Mrs. M. said that it’s interesting to observe Mac with the other residents at the nursing home. “They seem to have their own way of communicating. After all, this same group of people has lived together there since last March; I guess they are sorta like a family and feel familiar one with another. I feel happy knowing that Mac is in a good safe place; I have peace of mind, but it sure is a lonesome life.”

After–note: Upon completion of this paper, I had a telephone conversation with Mrs. M., just to see how the family was doing. She was recently home from a two–week vacation to Indonesia to visit her son. Upon her return, she visited Dr. M. and said; “he truly missed me; it almost seemed that he knew who I was and was ever so happy to see me. Yup, Mac’s still in there.”

Gwendolyn welcomes your questions/comments at gwendolyn@LivingDementia.com.

For more articles written by Gwendolyn see her website: www.LivingDementia.com