

Dealing with Alzheimer's Dementia: One Step at a Time

by

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It is tough being told you have Alzheimer's; at least, it was for me. There is no family history of the disease so I was not expecting it. I knew something was wrong for some time before receiving the diagnosis, but to hear the words "Alzheimer's Dementia" was difficult.

Dementia itself is not a disease, for dementia can take many forms, related to a number of different diseases. The common thread for those with dementia is the impairment of cognitive ability that increasingly interferes with everyday activities. With the addition of the word *Alzheimer's*, there is the promised decline in mental and physical functioning that will inevitably lead to the mind's window closing so that the person as he or she has been, will be no longer.

What is it like to, little by little, "lose" one's *self*? Our brains define who we are. Our psyche, our sense of self in relation to others and about ourselves are all functions of the brain. But those of us with Alzheimer's will experience ourselves dying bit by bit, as the disease eats away at the brain, until our ability to think and reason is gone and our personalities have disintegrated. Of course, it is not just loss of self, but also loss of a sense of place. Familiar will become strange. For some, strange will become feared. When this happens, the world may be a frightening place, with people and places we will not recognize. For some, a calming may occur when quiet reassurance is given, but for others such a release may not happen. The world will become less and less complex, as our minds are destroyed. For most, in due course there will be the still – but ever more limited – functioning body but not a still functioning mind as we know it now. This is an awesome prospect for any person diagnosed with Alzheimer's to come to grips with. Caregivers too will surely experience immense pain and suffering as they also grapple with the promised future and then witnesses the gradual loss of the partner's personhood, until there seems to be nothing.

In this paper I address some aspects of how one deals with the diagnosis. I also identify some aspects of the challenges faced by caregivers, though I readily admit I see those challenges from the perspective of a person with the disease, not as a caregiver. For both – the person with Alzheimer's and the caregiver – I (perhaps simplistically) suggest ways to deal with the disease and how to get on with what remains of life, by taking it one step at a time.

What I discuss here is with Alzheimer's Dementia in mind, but parts surely will resonate with those who face challenges from, for example, Frontal Lobe Dementia, Vascular Dementia, Parkinson's Disease Dementia, or dementia from Lewy Bodies or from Normal Pressure Hydrocephalus.

Diagnosis and Early Reactions

First, some personal observations. I knew I was in trouble because I found myself getting lost in the middle of sentences, making up words – by combining part of one and part of another – and forgetting the names of people I saw every day. I sought professional help and was given neuropsychometric tests which identified that something was indeed not right. I was then referred to a neurologist in Toronto, a specialist in Alzheimer's, who had me undergo further tests. Thereafter he concluded that I likely had early stage Alzheimer's.

There were several stages to my reactions which, I believe, are similar to those experienced by many others. When the doctor told me his diagnosis, I at first denied it, choosing to not really hear what he had said. My denial of the diagnosis was helped, in a way, by some friends who said categorically, “*You don’t have Alzheimer’s!*” Their comments helped feed feelings of doubt. I would say to myself, “Well, maybe I do have Alzheimer’s,” followed by, “But maybe I don’t!” Depression followed, and had to be addressed with professional help. I began to have troubling dreams, some with violent endings. I felt that life, for me, had ended. I dropped out of some organizations, stopped reading and writing, avoided seeing friends (though, thankfully, one insisted on keeping in touch with me), and I had difficulty in groups, even family gatherings. My wife, Janet, must have despaired, for I became a lump! I felt truly hopeless, as I wallowed in solitude, mulling over my diagnosis.

A major issue for me was that I lost my job two weeks after getting the diagnosis of Alzheimer’s. Because of the diagnosis, I was told to go home right then and there, and to not go back to the office! There was no transition. Apart from some senior colleagues, most of my colleagues knew just that I was “ill” and that I was gone. With no follow-up, I felt like having been dispassionately discarded on a junk pile. The loss of my job thus was brutal for me. My experience differed from several people I know whose employers helped them by changing their responsibilities, and giving them a lengthy period of transition toward the time they were to leave their jobs. For example, a friend admitted to her colleagues that she was having trouble with keeping the books, so others in the office helped her and she was given other assignments, which she was well able to handle for many months thereafter. Significantly, her colleagues did not strip her of her dignity. But from my own experience and from talking with others I know that not all employers are understanding and compassionate. What some employers do not appreciate is that a person with early stage Alzheimer’s is still a functioning person (with some memory problems and perhaps, on occasion, some confusion) and that he or she is still able to make decisions and perform many types of work.

While trying to deal with the double whammy of the diagnosis and job loss, I happened one night to see on TV the Scandinavian movie *A Song for Martin*. It is about a composer and his orchestral-musician wife. It opens with Martin experiencing some early signs of Alzheimer’s, and then, interwoven with family life and various day-to-day activities, the dementia progresses relentlessly until Martin is but a “vegetable” in a hospital bed. We witness Martin’s frustrations and fears, his joys and anger, his earnest but fruitless struggle to continue to compose music, and his gradual loss of self. Ultimately, we witness his tragic total loss in the battle of “still to be.” We also witness his wife’s suffering as she shares in what is happening to her husband who gradually disappears as the person she has loved until, in the end, only his physical frame remains, needing full care. He has become like a helpless infant, with no outward sign of selfhood left. In a concluding emotionally charged, truly poignant scene, she says goodbye to the Martin she has known for so long, but he has no comprehension of what she is saying. By then he is beyond the ability to comprehend the world around him. All he can do is feebly open his mouth when offered a small spoonful of food. The image of a helpless baby bird being fed by its parent came to my mind at that moment. We begin the movie knowing *him*, Martin. As the story unfolds, we see his troubled self trying but eventually failing to understand what is happening. It is painful to watch.

Of course, “*A Song for Martin*” is a movie, but it is a powerful one, one that deals front and centre with Alzheimer’s, no holds barred. Because of that, I recommend the movie to

caregivers. However, I highly recommend that they should be with others so they can talk about it as they relate what they see and hear to their own experiences and as they talk out what lies ahead. Equally, the movie can also be seen by those with Alzheimer's, though I strongly recommend they too see it with others, preferably led by a knowledgeable leader, so they also can share reflections and perhaps talk about their own fears of what lies ahead. I say this because I watched the movie alone that night, after Janet had gone to bed, and I was jolted by the frankness of the trauma, as experienced by both partners, Martin and his wife. The movie proved to be highly provocative and deeply troubling, and yet revealing of so many questions I had. I was able thereafter to tell Janet some of my own fears and concerns, things that I had held within me to that point.

Seeking Help and New Understanding

Thankfully, for me, Janet did not give up hope, and, wisely, she sought help. She reached out to the Alzheimer's Society of Guelph-Wellington and so learned of a support group for persons with Alzheimer's and of a separate group for caregivers. She then tenderly suggested that I attend the support group. I did so reluctantly, for I feared facing anyone with what I had. What could I learn from them? They didn't know how much I hurt! But I was wrong for, of course, they knew! Helped by two superb leaders, we learned about Alzheimer's. We shared how we felt. We talked about our experiences with the disease. We had candid discussions about our prospects. We learned from each other that dreams, fears, and ignorance – our own and that of others – were shared. We talked about what it would be like when we could no longer make decisions, or when we would no longer appreciate the beauty of the people and places around us. Importantly, we learned that we were not alone. We helped each other come to terms with the diagnosis by discussing how each of us was experiencing and dealing with the basic issues of short-term forgetfulness, difficulty with word finding, confusion, lethargy, tiredness, emotional flatness, anxiety, fear, irritability, frustration and flashes of anger, discomfort when surrounded by many people, and so on. None of us was happy with the diagnosis but we began to see that it was good to talk with others who were in the same boat, so to speak. I came to realize that each of us was on a separate but linked journey. In time, with the help of the group leaders, Theresa and Susie, and the others in the group, I was able to say "I have Alzheimer's" and so began the journey on how best to deal with the new limitations.

Learning to deal with new limitations can open us to interesting accommodations. One I'd like to share was told to our group by "Mary." Because of the advancing disease, she felt it was important to travel to the UK to see relatives. At Toronto's airport she asked the British Air ticket agent to write down the directions to the departure gate. The agent said, "Oh, I'll get you a wheelchair," to which "Mary" responded, "No thanks. My problem is not down there," pointing to her legs, "but up here," pointing to her head. "You see, I have Alzheimer's!" The agent smiled and called for a person to come and take "Mary" to the gate, and she arranged for an attendant to meet her in London to walk her to the appropriate exit door. "Mary's" frank admission of the disease, said pleasantly and with a touch of humour, was readily accepted, and she was given assistance.

A topic of importance within our group was how and when to tell others we have the disease. "Mary's" admission to the BA ticket agent gave the rest of us courage. However, not all admissions to others are rewarded with positive responses. When I tell people about my diagnosis, reactions are generally either acceptance – often with genuine expressions of caring,

which can lead to interesting conversations – or varyingly negative – cold, distant, in one case hostile. Some people simply deny that I have memory problems. They say such things as: “There is nothing the matter with you. You are fine.” Or “Don’t worry. It is just a senior’s moment. *I* have them all the time too.” Or, most precious of all, “If you think you have Alzheimer’s then so do *I* – and *I* don’t have it!” This negation of something that is now part of who I am is tough to take for *they* are not open to hearing *me*. Even when I mention the issues (the things listed above) they rule them out, as if to say that if *they* reject them firmly enough then *my* problems will go away! When they reject my disease they are in effect rejecting *me*.

Some people try uncomfortably to change the topic or quickly end the contact. One person I know suffered when he overheard a mother say to her child: “Don’t go near him. He’s sick.” Clearly, some people do not want to know about the diagnosis or are ignorant about it. Perhaps, like that mother, they fear that it is catching, for they seem to want so quickly to distance themselves from me. One person I have in mind should have been in the Olympics, so fast was his departure from me when I told him of the diagnosis. At least, these people must think the worst, with strong negative images of someone with Alzheimer’s. Some clearly assume that a person goes directly from diagnosis to total care, with nothing in between. In fact, I think some of them wonder why I am not in a nursing home! They are ignorant about the speed of decline, which varies from one person to the next, and they falsely assume that *immediate* global decline occurs.

Others, in contrast, are accepting, without judgement, or they may make a comment like, “Oh, my mother had Alzheimer’s,” and leave it at that. They have an understanding of what I face. Former work colleagues generally have been difficult to talk with. Perhaps they are embarrassed to raise the topic. In contrast, one former colleague at work recently was refreshing in his approach when I told him of the diagnosis. He simply focussed on me, not the disease. His comment was direct: “You must be facing great challenges.” This comment led to a meaningful conversation with that man, for whom my respect, already high, became greater still.

A topic often raised in the support group is the loss of a driver’s licence. Several members of the group I am in have lost their licenses (though one, happily, can still drive his motor boat). For most, this has been a significant loss, for it represents more than just the loss of the right to drive. It is a major loss of independence and, thus, it is a foretaste of what is to come.

Activities and Memory Joggers

Probably the most important lesson I learned from my friends in the support group was that it is essential to remain active. This was important, for I had given up. Members of the Alzheimer’s support group I am in have impressed me by their continuing involvement in cycling, walking regularly, playing card games, doing their best with computer and other games, going on trips with their spouses, playing golf, and so much more. The golfer, incidentally, has been able to continue to play because his friends now keep his scores. To me it is significant that they have not written him off, but are willing to help him so that they can all continue to enjoy golf and their fellowship. In my case, with the help of an occupational therapist, I returned to writing and since the diagnosis I have written three books and some journal articles, have worked as a consultant to two agencies in Ottawa, have given five talks on the experience of having Alzheimer’s, and have returned to performing music, currently in three orchestras. So much for having been written off by my employer!

Keeping one’s mind active is important. For those with early stage Alzheimer’s there are

a number of things that may serve as mind stimulators and others things that may usefully help jog the memory. First, a number of therapeutic mental exercises have been identified by Brenda Hounam and colleagues in *Memory Work Out*. They suggest that we “take [our] mind to the spa” by playing word and number games (such as crosswords, word searches, and Sudoku), matching games, solitaire, and such brain teasers as the Rubik’s Cube and peg games. They also suggest doing jigsaw puzzles, trying video and computer games, playing musical instruments, playing darts and billiards, doing basic math, and memorizing. Practising these various exercises can be therapeutic. “It’s like stretching your brain,” Brenda reveals. Dr. Devi Gayatri of The New York Memory Services has identified many other “brain booster” exercises, including some for persons with diminished capacity (see Devi and Mitchell).

Similarly, some researchers at Toronto’s Baycrest Hospital are testing a variety of things to help some people with their memory and cognitive functioning. In a recent issue of the *Baycrest Bulletin*, Dr. Kelly Murphy identifies both internal and external strategies, some of which persons with early stage Alzheimer’s may be able to practice. I believe Dr. Murphy and colleagues have been testing their strategies with persons with Mild Cognitive Impairment but not yet with persons with early stage Alzheimer’s. No matter, their *internal strategies* may help those of us with early stage Alzheimer’s. Dr. Murphy identifies spaced repetition, associations, and visual imagery. Spaced repetition can be used to learn a new phone number, for example. Rather than simply repeating the number over and over in the hope that it will stick, she suggests that we should gradually space out the intervals when recalling the number, from one minute to five, 10, 15, and then 30 minutes. I admit to having difficulty with this strategy. By associations, Dr. Murphy suggests we can recall a name by making an association and tying it to a visual image. For instance, if you met “Fred McIntosh, you might think of Fred Astaire eating an apple!” I happen to have trouble with this strategy which makes me think that some of the internal strategies may be difficult for someone who has Alzheimer’s, especially as the disease progresses.

Dr. Murphy’s *external strategies*, in contrast, are of use by someone with early stage Alzheimer’s. If learned early enough, whereby there is a patterning of the brain, the use of various aids may prove to be beneficial as the disease advances. For example, a timer can be useful when remembering to do something, such as when to take a pill. Using a labelled container (or in my case, three containers) for one’s pills is great as an aid to hopefully avoiding confusion as to which pill to take at which time and on which day. Use of calendars, date books, diaries, and Post-it notes to keep track of what you have to do, and when, can be helpful. For example, I have my own large calendar on the refrigerator door, onto which all of my appointments and other activities go. Dr. Murphy also identifies what I call locational habits, i.e., such things as keeping one’s keys in the same place, laying out the next day’s clothes on a specific chair before going to bed, keeping medications in a specific place, and so on. Janet and I also use notes as reminders. Rather than hounding me to do something, such as “please take out the garbage” or “please empty the dishwasher,” she writes me notes, which are placed on the hallway floor so I see them whenever I walk from one room to another. This method of communication reduces her frustration at having to repeat things, and it reduces any emotional stress we each may feel. Another useful external aid is the Call ID screen on our phone. Janet now knows if someone has called while she was out, even if I have forgotten about it – after having taken the call!

At Dr. Murphy’s suggestion, I now carry a pocket diary into which key information goes,

e.g., doctor's appointments, orchestral rehearsal times and locations, things I must do (such as phone a friend or write some program notes), and, at the back, people's addresses and telephone numbers. This book is always with me and has proved to be invaluable. And when I recently went to Ottawa to give a lecture on the city's selection as capital in 1857, I carried with me a looseleaf folder filled with my typed notes of key dates, names, parliamentary votes, etc., with reference tabs directing me to the various sections of the material. Only once did I have refer to my "memory book," but it was comforting to have it on hand.

Discussing memories with family can be important. Retelling stories can be fun, and do help to stimulate the mind. Sharing memories with others can be therapeutic, as I know from the Alzheimer's support group I am in. Indeed, this aspect of our gatherings became so important that we named ourselves "The Reminders."

Writing down memories or recording them on tape can be good too, for the time will come when I, for instance, will not be able to express or even recall memories that are in my mind now. Two summers ago I wrote an autobiography covering my first nineteen years. My kids may someday find it interesting. I really must complete the task of writing down my memories of the years since I was nineteen!

For those of us with advancing Alzheimer's an important external strategy can be the use of the "Safely Home" program that was developed by the Alzheimer's Society of Canada in partnership with the Royal Canadian Mounted Police. Also known as the "Alzheimer Wandering Registry," local Alzheimer societies register a person and provide an identification bracelet and identification cards that are to be kept in a coat pocket. If the person wanders, gets confused and then lost, the caregiver can call the local police (who have access to the national file of registrants) who will find pertinent information which may assist them in finding and identifying the person.

Support Groups

I have mentioned the Alzheimer's support group I'm in, i.e., "The Reminders." The group has been important for each of us for several reasons: companionship with others who have the disease; a safe place to talk, since the others in the group all know what we are living with; a place where our ignorance about the disease is dealt with in an informed manner; a place where we can share memories and discuss our frustrations, hurts, triumphs, hopes, and concerns; a place where we can reveal exactly how we are feeling, without fear of emotional fallout.

Lest the significance of such groups is downplayed, let me remind you of what we are grappling with. We are living with a disease that is robbing us of our thinking capacities and which is eating away at our brain in insidious ways. Ultimately, it will destroy us as thinking persons, even though our bodies may continue to function for quite some time, albeit in ever decreasing capacities. As we grapple with this frightening future, I know that we, in the group I am in, are all helped by each other and so the future, while bleak, is not quite as frightening. As I noted earlier, we all now know that we are not alone.

Losses, and Shame

There will be inevitable losses. One member of "The Reminders" lost the ability to carve duck decoys, something that he had enjoyed doing for many years. It became dangerous for him to use the sharp tools for he had reached the stage when he no longer understood what to do with the tools. His wife had to remove the now lethal implements. Partly to replace his beloved

carving, he went to the St. Joseph's day program for persons with dementia and so he was exposed to a variety of other activities that helped to keep him engaged. I have a second friend who now attends that program and while he finds some of the activities a bit silly he does enjoy the baking lessons. One friend is now in a rapid decline, and may soon have to be hospitalized. Another friend is in a total care situation, no longer able to identify his wife and children. And two friends in our group died during the past year.

A wonderful man in "The Reminders" support group said a powerful thing to us one day last year. Alzheimer's Dementia was clearly taking its toll when "John" said, "it might be nice to go before this damned disease totally gets me for then people will still see the real me when I die." Sadly, he got his wish, for he succumbed to a cancer some months later, before Alzheimer's could take its full course. This is an issue for all of us diagnosed with the disease, for it is not only that we want others to continue to see and know us, but for us to see and know them. But, tragically, for many with the disease, the day will come when such is no longer possible.

The title of a marvellous book says it all: *Who Shall I Be When I Die?* Written by Australian Christine Boden, who was diagnosed with Alzheimer's when she was still a young woman, the book spoke directly to me when I read it this past summer. Among other things, she addresses spiritual issues, something I admit that my friends and I have generally skirted. She also says many other things that deserve wide circulation.

We need to remember that Alzheimer's is a disease, not a state of mind. But it is a disease that causes discomfort, and for some, shame. Shame can be a terrible *dis*-abler. I know, for after getting the diagnosis I felt shame, which led to me not wanting to see people. Boden asks, "Why be ashamed of the physical breakdown of brain cells any more than the physical breakdown of any other parts of our bodies?" It is not just persons with the disease who may feel shame for family members may too. To them, Boden nicely says: "We are not mad, but sick, so please treat us with dignity, do not make fun of us, and do not be ashamed."

"I'm still Here"

Boden could also have stated, "Do not ignore us. Do not shut us out." Some of the people I know who have Alzheimer's have found that their caregivers and families have begun to exclude them from decision making, or carry on conversations as if they are not present. This hurts. One friend with early stage Alzheimer's got terribly frustrated because her spouse constantly barged ahead without consultation and made decisions about all sorts of things, things about which "Marge" still had the capacity to be consulted. "Marge" felt negated. Why? Because a person with dementia still wants to feel wanted and valued, and to be treated with dignity and respect. While she clearly was having difficulties with her memory and was sometimes confused, "Marge" still had feelings, desires, a sense of morality, and imagination, yet she was being ignored.

Another person I know recently said to the family: "Don't write me off or ignore me – I'm still here." So, while it may at times be frustrating for the caregiver or for family members (because of the need to be repetitive and because of a sometimes confused mind), it is important to keep the person with Alzheimer's engaged in family activities and decision making for as long as possible. Just because the person has the diagnosis of early stage Alzheimer's does not mean that for some time he or she can no longer be part of family activities or participate in decision making. One person I know appreciates that his wife continues to involve him in decision making, even though he knows that in the end her decisions will be enacted.

Communication, Engagement, and Care

Interacting with one's partner and family remains vitally important, throughout the course of the disease. There is an interesting ongoing study being done at the University of Guelph on the importance of mealtime for couples impacted by Alzheimer's. Initial findings have shown that preparing meals together (even if the person with Alzheimer's is limited in his or her ability to assist) can be enjoyable, just as can be the time spent eating together. Clearly, communication is key, as is simply being together. Communication can become increasingly difficult as the disease advances, due to the shutdown of the person with Alzheimer's and to the caregiver's need to be repetitive and to working out how best to deal with the Alzheimer's person's growing confusion and changing physical needs. This surely must be emotionally draining for the caregiver.

Engagement continues to be important to the end. Some persons with advancing dementia can get frustrated and angry if a request or instruction is given in a way they cannot comprehend. I saw this with my father-in-law, who had to be placed in Friendship Village, a care facility. He generally was a delight to interact with but on occasion a staff member who asked him to do something was angrily rebuffed, for Dad could not understand the basis for the request. Most of the staff members were sensitive and caring and they had gentle ways to get him to do something without getting his dander up. The staff would engage patients (who were not so badly affected) in interesting conversations, sometimes about things that seemed to make little sense to a casual listener but which appeared to satisfy the person with dementia. Their technique was similar to that identified in a recent article in the *New York Times* in which Denise Grady tells us: "Learn the art of fragmented, irrational conversation and follow the patient's lead instead of trying to control the dialogue." Without being told any of the details, I understand from my wife that this is a topic much discussed in the local society's caregivers' support groups. The staff at Friendship Village also engaged those for whom the disease had already taken a terrible toll, by using words, songs, and assisted physical movements. In sum, they respected each individual and lovingly cared for them, even though some of those persons were truly lost to the ravages of Alzheimer's. Sadly, I am aware that not all care facilities apply a similar philosophy, nor may they have such caring staff.

Caregiver's Challenges and Needs

Loss of familiarity with oneself clearly is painful, for the person with the disease and, of course, for the caregiver. The well-known actor David Hyde Pierce states that the caregiver is the recipient of "collateral damage" from the far-reaching effects of the disease (quoted in Shimer, p. xviii). Thomas DeBaggio adds a punch to this observation when, with reference to his wife, he states that "Alzheimer's deprives us *both* of life. It is the most unfair thing about *my* predicament." A caregiver surely experiences sadness, frustration, and a profound sense of loss as the months go by, as he or she witnesses the harsh reality of the loss of the person she or he has known. There is the loss of a future together. And there is loss of freedom, for one becomes tied down due to the increasing limitations being experienced by the person with Alzheimer's. Demands on the caregiver can be great. Joanne Parrent says it takes "courage to care."

It is vitally important that the caregiver's emotional and physical needs are met. A specialist warns: "Don't go it alone!" (Martin, p. 27). The "martyr syndrome" needs to be resisted, for it is unhealthy, even dangerous, to try to do it all. Self-preservation is essential if the

caregiver is to continue to care for the person with Alzheimer's. Many experts on the topic recommend that help should be sought. This can be from family or, if necessary, local agencies. The local Alzheimer's Society can help identify pertinent agencies. Keeping a physically active life (such as taking walks or working on a hobby) may help keep stress levels lowered. And it is important for the caregiver to not be isolated since it is best if there is someone to talk to, with whom to share one's observations of and personal feelings about what is happening as he or she contends with the daily frustrations and pressures and with the profound sense of loss, that can only get worse before there is the final release. Crying and laughing with others who are also living through the experience can be cathartic, and can make the pain easier to bare. Many Alzheimer's Societies have caregiver support groups.

Sometimes it is important for the caregiver to get some respite. Within the home, it may be possible to have a sanctuary, a room of one's own, to which to go for some quiet moments, perhaps while the partner is asleep. Day programs exist to provide interesting stimulation for the person with Alzheimer's. They thus also provide a gift of time the caregiver, for use, e.g., for shopping, meeting friends, or simply resting quietly. Longer respite may be useful. Without knowing the details, I'm aware of a couple who recently took advantage of a program that permitted the person with Alzheimer's to be housed on a temporary basis while the spouse took a several day break. It is important for caregivers to not feel a sense of guilt by taking a break, even if for a few hours, for surely they can only better help their loved one if they first take care of themselves. "Respite breaks" may in fact be useful for both partners!

The need to come to terms with the gradual loss of their loved one surely becomes increasingly intense for the caregiver as the person moves into the more advanced stages of the disease, when she or he becomes highly and then totally dependent on others. Carol Sifton suggests that if possible the caregiver should let go of past constraints and future fears, for "letting go creates the possibility of some really amazing rewards, to balance the endless, difficult job requirements of caregiving" (Sifton, p. 85). This may harder to achieve than these few words imply.

Earlier or later, depending on the circumstances, the person with Alzheimer's may have to be institutionalized. If possible, this should be discussed by the partners prior to the time the disease's advance makes decision making no longer possible for the person with Alzheimer's. At this time too it is important to get legal papers signed, such as a will, a living will, and powers of attorney for financial and medical matters. I imagine all sorts of emotions are experienced by the caregiver at this time, and later. All I hope is that every caregiver has a good, strong support base, so that he or she is not alone. One thing that struck me powerfully as I watched *A Song for Martin* was the wife's immense pain as she said her final goodbye to her once knowing but now vacuous husband. By finally "letting go" she was able to open herself to new possibilities.

Humour

Clearly, living with a person with Alzheimer's must be exceedingly difficult, until the day the window closes and the person has "gone." Janet and I laugh a lot, finding humour in many everyday activities. And my "Reminders" friends and I also laugh a lot, sometimes over quite silly things, but also over some provocative observations, as we reflect on our shared situation. And something we have all learned is that not every one of our problems is due to Alzheimer's. I shared with them an observation by my doctor: we are still entitled to have a senior's moment now and then! And we laugh about them.

Drugs and Hope

All of the members of “The Reminders” are taking one or more of the drugs now available for use by persons with Alzheimer’s. I have taken Aricept since late 2002 and Ebixa (also known as Memantine) for the past two years. There are also other drugs on the market. I should note that members of “The Reminders” have not all responded in the same way to being on the currently available drugs. For example, a couple of us have reacted positively, in my case most positively, perhaps atypically. Others seem to be in a holding pattern, which is good. But some have experienced marked advances in their disease, despite being on medications. And one person could not tolerate one of the drugs and had to stop taking it. In other words, we are each different, and we react differently. We have together concluded that the drugs we take are not a cure-all. However, whether or not the drugs are actually working for each of us, they give us a sense of hope.

An anonymous author reminds us that “Hope is not pretending that troubles do not exist.” Continuing, hope “is faith that a source of strength and renewal lies within us to lead us through the dark to the sunshine” (quoted in Bell and Troxel, p. 210). Another author notes that some people are able to “transcend suffering and find meaning in their lives” (Cohen and Eisdorfer, p. 24). For some this refers to one’s religious faith, as Boden so strongly identifies for herself. For others, hope is derived from the companionship with friends who also have the disease, or from continuing to have sound and meaningful relationships with their primary caregivers and families. For still others, it is the hope that our drugs will keep us in a holding pattern until new drug treatments are available that will halt or even reverse the disease’s course. Whether or not such hopes are realistic, they nevertheless give some persons with Alzheimer’s – and perhaps their caregivers – strength to continue to face the daily challenges.

Conclusion

As I finish, I wish to repeat that I greatly enjoy the support group I am in because of the general lack of gloom. We have learned – as hopefully our caregivers also have – that it is important to take one day at a time, enjoying what we have at this moment, and not spending too much time contemplating what is to come. We share and laugh, and enjoy each other’s company. As an example of our humour, I’ll let you know that we had a grand laugh at a recent meeting when a member walked in wearing a T-shirt his sister had given him. On the front were the words:

At my age
I’ve seen it all
Done it all
Heard it all
I just can’t remember it all

NOTE

My friends in the Alzheimer’s support group kindly gave me permission to use some of their observations and tell some of their stories, but I have not used their real names.

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