Alzheimer’s disease (AD) is the most common form of dementia. The word ‘dementia’ is derived from the Latin word ‘de’ meaning “apart” and ‘men’ from the genitive mentis meaning “mind.” Dementia is the progressive deterioration in cognitive function - the ability to process thought or “Intelligence.” (MNT Knowledge Center: Medicinenet.com, 2013). It is “a general term for memory loss and other intellectual abilities serious enough to interfere with daily life. It accounts for 50 to 80 percent of dementia cases” (Alzheimer’s Association, 2014). It is not a normal part of aging. Debra Goldschmidt (2014) in her report on the news network CNN stated that, “women age 60 and older have a 1 in 6 chance of getting Alzheimer’s disease in their lifetime”. Women are the epicenter of Alzheimer disease. In this article, I describe the situation with a male patient, my husband, who was enrolled in Home Hospice Programme and was taken care of by me along with a hospice care team.

Case History

The “client”, my husband, was 79 years old at the time he passed away on 15 July 2012. He was diagnosed with Alzheimer’s disease about ten years prior to his death. He was put on Aricept 10 mg, Namenda 10 mg and Seroquel 25 mg HS; in addition to the coumadin and bronchodilators he was already on for his COPD and post-DVT conditions. An Exelon Patch was tried without any real success. During his initial 1st and 2nd stages of Alzheimer’s, he went through a host of symptoms and problems including mood swings, irritation, agitation, tantrums, aggression, repetition of the same words and instructions, loss of appetite, suspicion, hallucinations, agnosia (not recognising his wife and other loved ones), avoiding eye contact, negativity, wandering etc. Near the end, he was enrolled in a Home Hospice Programme as he was deteriorating and was at the last stage of Alzheimer’s disease. In the final stages of progressive illness that causes dementia, the nervous system fails to such an extent that the rest of the body is profoundly affected. The person will die of the dementia though the immediate cause of death is often a complication.” (Mace & Rabin, 203).

Progression of AD

According to Mace & Rabin, Dementia or AD is the medical term for a group of symptoms. It has three characteristics, (1) several areas of intellectual ability are sufficiently impaired so that daily functioning is interfered, (2) the symptoms begin in adulthood and (3) the person is awake and alert, not drowsy or unable to pay attention.” The American Psychiatric Association’s diagnostic and statistical manual DSM-IV states: “The Dementia involves a multifaceted loss of intellectual abilities, such as memory, judgement, abstract thought and other higher cortical functions and changes in personality and behaviour.” (Grey-Davidson, p26). Actually AD was first described by a German Psychiatrist, Dr Alois Alzheimer in 1906, and the condition was named after him. AD happens because of changes in the brain when there are lower levels of chemical messengers (neurotransmitters) that help brain cells work properly. “There are currently 26 million people worldwide with Alzheimer’s disease. This figure is projected to grow to more than 106 million people by 2050” (http://about-alzheimer[±infg). The cause of Alzheimer’s is not currently known. The prevailing theory is that memory loss and other symptoms of Alzheimer’s are caused by the abnormal accumulation of beta-amyloid called A-beta 42 at the point of synapse. Sue Halpern states that “it is the newly made A-beta 42 that is relentlessly attacking the synapsis and probably this is why an Alzheimer’s patient has trouble remembering what happened five minutes ago (Halpern Sue, p 117). The first symptom is memory loss. The other warning signs include: Difficulty performing familiar tasks, problems with language, disorientation to time and place, poor or decreased judgement, problems with abstract thinking, misplacing things, changes in personality, and loss of initiative. The behavioural symptoms include: sleeplessness, agitation, wandering, repetitious actions, shadowing, paranoia, suspicious mind, stubbornness, hallucinations, aggression, anxiety, and depression. These symptoms appear during the 1st and 2nd stages of the disease. Usually during the final stage, patients also lose the ability to chew and swallow. The very essence of the person is vanishing. The article “Alzheimer’s Disease Symptoms” describes how “memory is now poor and no one is recognisable. Patients lose bowel and bladder control, and eventually need constant care. They become vulnerable to pneumonia,
infection and other illnesses. Respiratory problems worsen, particularly when the patient becomes bedridden. This terminal stage eventually leads to death (http://www.nhslive.org.uk/alzdis/about/adsymp_body.htm).

**Home Alzheimer Care**

Alzheimer disease is a degenerative and terminal disease for which there is currently no known cure. The deterioration disrupts the normal working of the brain and gives rise to the manifestations of Alzheimer’s disease - the slow progressive, and so far irreversible loss of brain. Doka (2004) states “hospice care is a type of end-of-life care which offers holistic care, bringing together through interdisciplinary team the skills, experiences and abilities of the AD patient, family members, professional staff and volunteers. It ensures coordination and continuity of care which involves services available 24-hours-a-day, 7 days-a-week. The patient is admitted after assessment normally based on functional assessment (FAST, RISEBERG, 1988) and the patient has a life expectancy of six months or less.” One example of the Home Hospice Care Model is the Greenwich Hospital-affiliated Home Hospice programme that helped my husband in the final stages. “Hospice is a special way of caring for people who are nearing the end of their lives. The emphasis is on providing palliative, or comfort care, rather than aggressively treating the terminal illness. Hospice patients and their loved ones also receive information as well as emotional and spiritual support to make their time together more meaningful” (Home Hospice Programme at Greenwich Hospital, 2010). Ideally, hospice is an approach to care that is focused on the needs, values and decisions of the person and family unit from diagnosis through bereavement, as well as the concerns of all who are providing care to the ill person and/or his or her family members and the needs those providers may have for support in his work. Doka (2004) states, “it is an outlook on care that affirms life. It is a way of thinking about care that links together efforts to minimise sources of discomfort, maximizing personal quality in living, and provide opportunities for personal growth and resolution whenever possible.” The focus of the hospice philosophy is found in its upholding the value and dignity of life embodied in every human being.

The programme at Greenwich Hospital provides holistic care under the direction of the patient’s doctor and the hospice medical director. The team of doctors, nurses, pharmacists, home health aides, therapists, dieticians, counsellors, social workers and volunteers address the medical, emotional and spiritual needs in addition to providing medical equipment and medications. It also provides bereavement services.

**General nursing and bedside care at home**

There was shock, mental trauma and denial at the beginning of the diagnosis in 2002, before the final 3rd stage (in 2010) ensued. There was never a complete acceptance of the situation, because the condition of my husband kept deteriorating in spite of initial interventions for the first and second stages of the disease which included: safety, walks, music, favourite TV shows, games, assisted meals, exercise, social visits, and following six R’s of behaviour management (Restrict, Reassess, Reconsider, Re-channel, Reassure and Review as described by Mace & Rabin, 2012). The safety component was especially emphasised in the National Institute on Aging’s Alzheimer’s Disease Fact sheet that discusses topics such as general safety concerns in the home, room by room, and behaviour by behaviour. Caregivers try hard to give physical, psychological and spiritual care to the end-of-life stage client or family member in order to promote comfort, provide support, and to improve quality through the illness. During this stage, “caring for someone who is dying is emotionally and physically demanding. But primary caregivers and family members can take comfort knowing that hospice is an act of love that can improve the quality of life for everyone involved” (Patersen, 2008). The daily nursing care plan was developed and implemented with the assistance from Hospice team members. Most of the activities included: personal hygiene, mobility, vital signs, environmental safety, crushed and diluted medications, nebulisation, intake-output, frequent mouth care, psychosocial and spiritual care etc. Special attention was paid to putting on comfort clothes with Velcro, oxygenation precautions, use of soft diapers, frequent change of position to prevent decubiti, bed rails, using the commode with assistance of Hoyt Lift etc. The major problem we faced was feeding. When my husband was on Seroquel, he would sleep 10 to 12 hours at a stretch and it would be quite a struggle to keep him well-hydrated in spite of oral feedings of liquid diet. Tube feedings or other more invasive options were not in the protocol as he was placed on DO NOT RESUSCITATE (DNR). The other problem was changing position. Being a nurse, I emphasised change of position every three hours, which became quite a challenge during night hours. The final days were particularly painful with added considerations. Issues of pain management versus function needed to be addressed.

Questions and decisions about whether and when to administer palliative care drugs must be addressed with medical professionals. In the end, there were no more syringe feedings because he would start to choke. The water bottle was sprayed frequently after that to keep his mouth moist. He was on constant oxygen therapy, suctioning and frequent change of position. There was
no stool for last two days and there were only spotting of pinkish fluid on the diapers which stopped completely during last four hours of his life. My son and I took turns to get some sleep in between keeping vigilance, for we knew the final moments were at hand. He passed away peacefully in the presence of my son and me. The night hospice nurse was called. She made the final assessment and declared him dead at 3:20 am. The funeral home director was called. We got some time to sit at my husband’s bedside. We all said prayers and read religious books which were otherwise also being read frequently by other members of the family. Soon after the call to the funeral home, two gentlemen came with a stretcher and took his body away. It was, needless to say, a very painful time. Mace mentions “the death of a person who has dementia, even after a very long illness, may be painful for you, and the practical tasks surrounding death are likely to be distasteful.”

Spouse Caregiver’s Challenges

In general people do not become simpler with AD. They become more complex. Relationship is the centre of the caregiver spouse’s spiritual journey. This spiritual journey reveals to us that a person is still fully a person even when impaired in memory and mental function. The unrelenting need is for love, companionship, understanding, compassion and supervision. Grey-Davidson (1999) states, “the caregiver must let go of husband as a spouse, because it is hard and painful. If we cannot do it, we create more pain every minute of our day”.

The other challenges of the caregiver include spending an average of 12 active hours a day caring for the loved one. The caregiver also has daily needs and if those needs are not met or are being ignored, the effect is “Caregiver Stress” which is related to the caregiver’s denial, anger, social withdrawal, anxiety, depression, feelings of emptiness, uncertainty, exhaustion, sleeplessness, irritability, lack of concentration, health problems and grief. Caregivers feel resentment and frustration over being squeezed from all sides. There are changes in the personal plans, demands on personal time, emotional adjustments, patient’s non-cooperation and even physically aggressive behaviours, work-related adjustments and financial strains. Shankle, et al (2005) state, “caregivers often die before their affected loved one, because they ignore their own health needs and are under severe chronic stress”. In addition to experiencing severe stress, research indicates that “caregivers often have health problems, take more medications than non-caregivers, and experience depression” (AJN, September 2008, p 64). The physical and psychological symptoms of stress in caregivers include “muscle tightness, tiredness, inability to sleep, gritting teeth, numerous small accidents, mood swings, fear of others, feeling of despair, anxiety, chest pains, palpitations, lack of concentration etc.” (Grey-Davidson, 1999).

If you are such a caregiver, while utilising available limited resources, try to balance your needs with the needs of the person under your care. Utilise your coping mechanisms which are based upon three things: information, self-esteem and a sense of control. As the airlines reminds us “put on your own oxygen mask first before you try to put the mask on for others.” Assess your own risks and take prevention steps as early as possible. Do not feel guilty for taking care of yourself. “15% or more of caregiver spouses also have dementia which goes undetected” (Shankle & Daniel, 2005). The well-being of the person who has dementia depends directly on your well-being. It is essential that you find ways to care for yourself so that you will not exhaust your own emotional and physical resources. There are no antidotes for grief. Perhaps you will find, as others have, that it is eased somewhat when it is shared with other people who are also living with the unique tragedy of dementia” (Shankle & Daniel, 2005). Sharing feelings of sadness and grief can be comforting and can give you the strength you need to continue to care for the declining person. The Alzheimer's Disease Fact Sheet (2014) suggests that as a caregiver, “you make sure that you have quiet time, time out, and time to take part in something you enjoy. Protect your own emotional and physical health.” Other measures include: keep your doctor's appointments, give yourself a present, avoid isolation, keep in touch with your friends, organise your time, have tradeoffs, create barriers or distractions, learn new skills and get professional help to form your support system.

The modified caregiver strain index is used to establish a baseline and measure again regularly over the course of the illness. “Caregiver Strain Index was designed to appraise. Stress and burden are a caregiver’s daily physical and psychological responses to caregiving. But over time, stress and burden become strain, which is a deterioration in financial, physical, psychological and social health” (AJN, September 2008). This index contains 13 statements to assess the caregiver’s needs. The positive response to any of the statements (like sleeplessness, inconvenient, confining, emotional adjustment, upsetting, financial strain etc.) and the results of this self-administered index can be used to pinpoint the causes and degree of strain, as well as changes in strain over time. The interventions are implemented before a caregiver’s health suffers significantly. The strategies of interventions may include “preventive education, cognitive behavioural therapy and counselling; they can improve the caregiver’s quality of life and, by extension, the care recipient's as well” (AJN, 2008).
The hospice care team is also helpful in supporting the caregiver by teaching about patient’s behavior and guiding how to respond most effectively to these changes. The team also encourages the caregiver to find appropriate ways to address his or her own personal life demands and assisting in coping with the anticipatory and actual loss. According to Rando, “Anticipatory grief or anticipatory mourning is a reaction to all losses encountered in the past, present or future of a life-threatening illness. These losses and the grief reactions they evoke are part of the daily experience of those who experience Alzheimer’s disease or other dementia” (Doka, 2004) He further states, “Caregivers may experience secondary losses such as the loss of social and recreational roles, work roles and relationships.” Furthermore, the caregivers with the help of the Home Hospice Programme Team (HSPT) can work on finding ways of finding forgiveness. The usual items up for forgiveness include: “Disease and its symptoms; any wrongs that the patient did to us in the past, never to have things “right” again, forgetting a constant reminder how we fail as caregivers and to ourselves for the way we think we failed as caregivers” (Grey-Davidson, 1999). The specific steps to deal with daily problems according to Grey-Davidson are: “Limit to get definite times and commitments from the family members, neighbors, friends and other support system; do not attack each other’s future behavior and respect each other’s differences; get consensus for planning the care; and focus on daily problem-solving for behaviours, abuses, agitation, restlessness, tiredness, lack of self-esteem, hunger, boredom, loneliness, feeling useless, and unwanted emotional distress.” In addition, try to get in touch with Alzheimer’s associations which educate the caregivers about the latest research on the disease; keep a list of telephone numbers of groups of elderly care, legal advisors, hospice offices, immediate contact persons, funeral home directors etc.

**Conclusion**

No one is fully prepared to meet the challenges of a spouse’s hospice care at home in spite of the care-giver’s health education background, or strong personality. This time of crisis is also a challenge for other family members, relatives, friends and neighbours and community-at-large. Alzheimer’s associations also provide assistance in three different areas to the caregivers and patients during the 1st and 2nd stages in the areas of behaviours, communications, activities, respite care and in case of memory loss, support from local chapters, message boards, support groups, for your health and care training and in planning for future legal matters, care options, paying for cost, safety, dementia and driving etc.

In my situation, I had a home hospice programme team coming to the house for professional visits who assisted me by reminding me to address issues such as arranging for power of attorney, having a living will and advance directives signed and insurance papers handy which made it a bit easier to get through the tough times. Hospice care is palliative care because “a chronic illness or life-threatening health condition presents an array of tough questions and challenges. Patients and caregivers need to consider medical options, care options and end-of-life decisions.” (Medicinenet.com/Alzheimer’s disease: What is the prognosis: 2013). In the final stage, a dignified death is one way you can give love and care to the person who has dementia. Hospice programmes enable people to die at home within familiar surroundings without overly-aggressive interventions.

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