Alzheimer's Disease: Effects on Caregiving and Available Support

An Honors Thesis (HONRS 499)

by

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Abstract

Alzheimer's disease is often unknown to the general population until it becomes a personal issue. The information provided within this paper may be used as a resource for those in professional fields to share with clients in attempts to educate clients on the disease and its effects. Information on the symptoms and possible causes of the disease as well as the effects on caregivers have been provided in order to allow the reader to understand the process which occurs once the disease has been diagnosed. Areas of available support have been shared in an attempt to supply readers with knowledge on where to turn for help if needed. Interviews with caregivers and professionals have been utilized in order to add a personal dimension to the provided material.
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Informal care revolves around familial and friends interactions with the elderly. Many times the care for the elderly is continued in the home until the caregiver is no longer able to provide for the needs of the elderly individual. This inability to no longer provide care may ensue from financial, emotional, or psychological problems that result from the interactions of the elderly and the caregiver.

Familial caregiving usually includes the spouse of the elderly and if spousal help is not available adult children will often care for their aged parents. Three fourths of those caring for the elderly are women, usually adult daughters of the elderly (Beck & Kantrowitz 48). These women are often referred to as the sandwich generation or "women in the middle" (Dhooper 26). They provide care for their elderly parents while also raising their own families and working outside the home. Trying to fulfill all these roles places stress on the caregiver and may cause problems in relationships due to role overload. For instance, a female caregiver may have to miss her child's PTA meeting or ball games in order to provide care for her elderly parent. This in turn could result in feelings of guilt in the caregiver and a loss of intimacy with her child.

Regardless of whether the caregiver is a spouse, adult child of the aged, or a friend, providing care for an elderly person is often difficult both physically and emotionally for the caregiver. Meeting daily demands of quality care such as providing nutritious food, help with hygiene, and social interactions can tax a caregiver physically. Emotional strain is also placed on the caregiver because caring for elderly, unlike caring for a child, results in increased dependency (Braithwaite 15), and causes the caregiver to come to the realization of the eventual death of the aging parent. Financial strain can also be a result in caregiving both in trying to meet the elderly patient's needs and one's own. For example, a daughter who quits her job to care for an aging parent loses her salary and this may cause financial strain for her own family.

Caring for the elderly can often place a burden on the caregiver. This burden
can be looked at in two ways. This burden can be objective, and may be observable and verifiable when it results in disruptions in family life or the household of the caregiver. A subjective burden involves the caregivers perceptions and views of caregiving for the elderly person and how these views are affected by the time and commitment given to the aged individual (Platt 386). Those who care for elderly with mental handicaps or degeneration may feel this burden more heavily due to the unpredictable behavior of these individuals. A common disease dealing with mental degeneration among the elderly is Alzheimer's disease. These elderly can become particularly difficult to care for because the caregiver must watch as memory declines and unusual behaviors occur due to disillusions, and confusion.

As the number of elderly increases the number of caregivers too must increase and the percentage of caregivers working with those who have a degenerative disease such as Alzheimer's will increase as well. As these numbers increase it may be wise to look at the support for elderly caregivers and the services available to help them maintain an appropriate level of caregiving without succumbing to the stress of such a job. The rest of this paper will deal explicitly with caregivers of Alzheimer's patients. Definitions of the disease, symptoms and possible causes as well as descriptions of caregivers and affects of caregiving will be discussed. Areas of support available for caregivers as well as services available will be presented in an attempt to link the reader to available aid in this area.

Symptoms and Causes of Alzheimer's Disease

Alzheimer's disease was first discovered by Alois Alzheimer in 1906. He was a German neurologist working with a 51 year old woman who exhibited problems with disorientation and memory. He followed her case as she digressed through the disease, adding symptoms of depression and hallucinations. She later died and an autopsy revealed neurofibrillary tangles in the cerebral cortex of her brain which were believed to have caused the cognitive and emotional decline evident (Gruetzner 6).
Although Alzheimer's disease was at first thought to be rare statistics now show that approximately 5-7% of those 65+ exhibit the disease and 20% of those 85+ are diagnosed with Alzheimer's (Gruetzner 7). Alzheimer's occurs most frequently among the elderly although early onset may occur for some. Currently approximately 22 million persons are thought to have Alzheimer's and as the elderly population grows this number will increase. Alzheimer's is currently the fourth leading cause of death following cardiovascular disease, cancer, and strokes. It is a form of dementia or a loss of impairment of a person's ability to use his mind (Gruetzner 10). Alzheimer's is usually only diagnosed after all other forms of dementia have been ruled out. Currently the only sure means of diagnosis is by autopsy and since this is not a feasible method others are being looked into. A new method of taking blood/skin samples is thought to also be a good indicator of the disease.

**Symptoms and Stages**

Symptoms experienced by an Alzheimer's patient include memory loss, faulty judgment, problems with abstract thinking, behavior changes, confusion, disorientation, loss of bowel control, and wandering. As the disease progresses, these symptoms become more degenerative and the individual loses all ability to care for oneself (US Dept. of Health 3). It is an irreversible dementia with no available cure and the person may live with the disease anywhere from 2-30 years depending on progression and intensity of symptoms.

Alzheimer's disease is a progressive neurological disease and this progression can be divided into various stages. Barry Reisburg has divided this progression into five stages or phases (Gruetzner 23). These phases include early confusional, late confusional, early dementia, middle dementia, and late dementia. Each phase not only imposes certain symptoms on the patient but also entails certain responsibilities in the caregiver. One must keep in mind, however, that individual differences imply that the progression of the disease will vary according to the person.
The early confusional phase, stage one, may and usually does begin with the problem of forgetfulness. The patient’s social and occupational skills will begin to diminish noticeably as his memory problems worsen. Confusion and slowed reaction times also occur which may result in the patient becoming lost, for example, when traveling unfamiliar routes. Retainment of new information is affected and thus may cause the patient to have trouble with remembering new names or picking up data from the television or media. Personality changes occur including increased anxiety and agitation when the patient feels pressured. There is also a lessening of spontaneity. The patient may realize what is happening to him and try to deny the problems or compensate for them by avoiding new situations or blaming his forgetfulness on old age. Those closest may at this time pick up on the clues and changes in the patient but may not come to a full realization of the implications. These early symptoms appear to be just emotional problems and those loved ones who are soon-to-be caregivers may encourage a visit to a physician.

As the disease progresses and the late confusional stage is entered into, memory problems worsen. Symptoms become more evident such as noticeable lapses in the patient’s own personal history, as progression continues. Making decisions becomes a frustrating experience due to confusion and memory loss. For example, a patient who did all the financial work before may now no longer be able to balance the checkbook. Caregivers and loved ones usually step in and help the patient with these problems. Impairment in judgment and slowed reactions or over reactions may cause driving to be very risky at this point. The patient may find it difficult to remain oriented to time and place but have clear pictures and memories of past events. The patient may avoid social situations in which his symptoms appear evident and may become depressed and self-absorbed. The caregiver in this situation will have to give support and help to the patient in areas such as finances and some supervision is needed. The caregiver will often feel unappreciated and neglected by
the patient and will also have to deal with his/her own emotions as a diagnosis is reached and the realization of further deterioration in the loved one sinks in.

The caregiver's load increases as the patient enters the third stage, early dementia. Increasing dependency on the caregiver occurs as the patient needs more help in expressing his needs and initiating activities. Supervision in keeping the patient from potentially harmful situations such as leaving the stove on or forgetting to dress warmly for cold weather is also needed. The patient should no longer drive and this is sometimes a difficult issue for the caregiver to address because the patient may not understand the hazards of his driving. Gaps in memory leave the patient feeling insecure and confusion may heighten anxiety and bring on paranoia as judgment and reasoning deteriorate further. The caregiver must deal also with emotional changes and mood swings in the patient. There is a fluctuation in memory deficits makings some days better than others and caregivers must learn to make the best of each situation. The ability to reason logically and sequentially diminishes and simple decisions become overwhelming. A patient may, for example, only dress partially or place his clothes on over his pajamas. Impaired thinking capacity may cause social withdrawal in order to avoid stressful and agitating situations. As the dependency on the caregiver increases social support is needed to help the caregiver both emotionally and psychologically. It is important for the caregiver to allow the patient to do as much as possible for himself even if tasks could be done quicker by the caregiver. An example may be helping the patient pick out clothes and allowing him to dress himself even though the caregiver could help him and get the task done more efficiently.

The fourth stage, middle dementia, finds the patient encountering delusions and often fearing for his safety. Hallucinations and changes in sleeping patterns occur. It is often at this point that wandering begins as the patient walks off with a task in mind and after a few steps forgets what he was doing. The patient may have trouble with
coordination and movement thus limiting his physical capabilities. He may also act
with repetitious behavior such as continually folding clothes or undressing and
remaking his bed. Excessive environmental demands sometimes trigger violent
behavior. The patient does not understand what is expected of him and reacts when
pressure is placed on him. The patient also often develops a fear of bathing and loses
his social sense of hygiene. This fear may be linked to the inability to understand the
need for bathing or difficulties in regulating water temperature. Mental capacities are
decreased extensively and the person may lapse into a world of one’s own often
unaware of surroundings and orientation to time and place.

The caregiver at this point is needed for help with daily activities. The caregiver
becomes isolated from other roles as dependency increases. The caregiver may
become lonely and often emotionally distressed because there is no longer an
emotional relationship between themselves and the patient but only a functional
relationship remains. Caregiving can become very demanding and support is
definitely needed at this point. It is especially difficult for the caregiver to contemplate
institutionalization because of the emotional tie and the feeling of responsibility to the
patient.

The final stage, late dementia, places all the responsibility on the caregiver.
The patient's cognitive and emotional abilities continue to deteriorate and movement
and eating problems occur. In the final stages stupor occurs which leads to coma and
death. The caregiver usually gives up responsibility and institutionalization occurs.
The caregiver often must come to a reconciliation of having done all that they could.
This final stage has often been termed “a long goodbye” or “unending death” as the
caregiver watches their loved one deteriorate and slowly die (Gruetzner 29).

As the stages of this disease have been discussed, one can see the impact that
this disease has upon both the patient and caregiver. The symptoms of the disease
affect the patient biologically as deterioration occurs and loss of movement,
continence, and language abilities decrease. Psychological effects encompass the depression and anger one feels as recognition of the full consequences of the disease occur. As memory and reasoning decrease one's own environment must be monitored and changed in order for conditions to be safe for the patient. Just as one must hide medicines, sharp objects, and monitor the play of children, one must also do these things to keep the environment safe for an Alzheimer's victim. The patient himself loses his grasp with reality and a meaningful world as he loses his memory, and delusions, hallucinations, and paranoia slip in. A patient's social functioning decreases as the degeneration progresses causing problems in abilities to communicate, in functioning such as at an occupational site, in actions with others by inconsistency in following conversations, and in his inability to recognize and follow social norms in actions or relationships.

**Possible Causes**

There are various hypothesis on the cause of Alzheimer's but no sure evidence yet for a single cause. Possible explanations include theories such as the genetic theory, viral theory, and toxic substance theory (Arizona 38, Gruetzner 49). None of these theories have been proven or disproven. The genetic theory deals with how genetic factors combine with other identified factors to cause the disease. There may be a possible link with chromosome 21 and the build up of amyloid which forms the neurological plaques on the cortex of the brain. The viral theory deals with looking at some kind of extremely slow infectious virus as a causative factor. The toxic substance theory includes the belief that aluminum toxicity in the brain may be a possible cause for Alzheimer's. However, research held on this theory has been conducted in areas where the drinking water contains increased levels of aluminum so the validity of the research is questionable. There is also some belief that the autoimmune system breaks down and begins creating antibodies which destroy its own system. So far no proof has developed to show a single cause which begins the process of development
of this disease.

Roles of Caregivers

Gwyther (1982), estimated that the number of Alzheimer's victims will rise to around four million and approximately twelve million family members and friends will participate in caregiving and the suffering brought on by this disease. The family is often the preferred source of assistance followed by friends, and then formal or governmental agencies. Most Alzheimer patients remain in the community for as long as possible with aid received from family and friends. Placement in a nursing home only occurs when there are no caregivers or the caregiver's reserve of resources; financial, physical, or emotional, has run out (Pfieffer 5).

Within the family different members provide varying roles in aiding with the care of the Alzheimer patient. There is usually one primary caregiver who is either the spouse, sibling, or adult child of the patient (Schneider & Kropf 178). This primary caregiver usually enlists in daily contact with the patient and helps with daily living skills as the disease progresses. Other family members may provide help in certain task areas such as buying groceries and helping prepare meals, or giving assistance with financial matters such as balancing the checkbook and preparing taxes for the patient.

Because Alzheimer's is a neurological dementia losses will occur in the abilities and memories of the patient. Adjusting to these losses can often be difficult for family members, caregivers, and non-caregivers alike. Relationship roles with the patient must constantly be redefined as memory losses occur.

Spouses who are used to a strong competent mate find themselves taking over their mates roles as well as trying to provide for present needs. They lose the emotional companionship of their mate as the disease progresses and eventually have to prepare for widowhood. There is increasing reliance on these caregivers by their ill spouse and this may be an additional burden if the caregiver who is also
elderly has ill health. The untimely eruptions of emotional character unusual for the patient also alters the perception of the patient by the spouse as the patient's personality changes. For instance, the spouse may find that social interaction at weekly bingo games sponsored by the church is no longer possible due to her husband's erratic behavior. Thus this old role is lost and adjustments must occur in order to accommodate abilities and limitations of the patient.

Adult children of Alzheimer's patients usually provide the caring role if the patient is widowed or a widower, or if the spouse is unable to provide adequate care due to ill health. Being an adult caregiver is usually a full time job. Caregiving consumes, on the average, 25-30 hours per week and may last from two to ten years (Suncoast 6). Most adult caregivers have other responsibilities such as family and work. Finding the time and strength to balance all these roles can be challenging.

The caregiver of the Alzheimer's patient also has the responsibility of deciding when and where to place the patient when adequate care can no longer be conducted at home. Placing a loved one in a nursing home setting can be very difficult for the family caregiver. Some settings recognize the uniqueness of the Alzheimer's patient and have special units or wings dedicated for the care and treatment of these patients. Staff and care providers are often specially trained on the symptoms and conditions of the disease. These health care workers then become the primary caregivers of patients placed in their unit. Although these caregivers do not have the same emotional link as the family caregivers, they too can feel the burden and stress related to caring for patients with such a degenerative disease.

**Stresses of Caregiving**

How exactly does caring for an Alzheimer's patient affect the caregiver and the family? Caregiving for a patient with a progressive dementia can be very stressful for the caregiver. Schneider and Kropf listed three areas in which strain may be placed on the caregiver. These are financial, physical, and emotional strain (179). Financial
strain entails the money spent on items in the actual caregiving role such as groceries, gas, etc., as well as that which occurs from opportunity costs or the loss of money which would otherwise be earned if the caregiver was not providing care for the elderly patient. For example, a daughter may give up her job to care for her elderly mother and thus lose out on the income she would have otherwise received.

Physical strain encompasses the actual physical demands of caregiving such as lifting, moving, and aiding the patient with daily activities. There are proper techniques for moving a bedridden patient and a caregiver may cause herself severe physical injuries if she does not handle the patient properly. Physical strain may also result from fatigue and burnout on behalf of the caregiver. Trying to remain constantly alert and attentive to the patients needs can wear a caregiver down as easily as the actual physical labors of caregiving. Burnout may occur when the caregivers overextend themselves by trying to care for all the patients needs as well as maintain all other roles in their own lives. The person becomes physically exhausted and may lapse into depression, or have such symptoms as insomnia, weight loss, and lack of initiative and motivation (Pfieffer 9). This in turn may lead to a low morale and self-neglect in the caregiver. Pfieffer states that, “Caregivers are also vulnerable to stress induced illness such as ulcers, shingles, gastrointestinal upsets, and arthritis” (9). Those elderly spousal caregivers may be especially prone to these type of symptoms from caregiving.

Emotional strain results from caring for someone with whom a close personal relationship once existed. As the disease progresses the patient loses memories of people and the ties between oneself and others. Family members may become upset if for example “dad” can no longer remember his own sons and daughters names. Family conflict may also result when a caregiver lacks the time and energy to spend on his/her own family. A caring mother may no longer have the time to attend her child's ball games due to increased caregiving responsibilities and this can result in
relationship strain and guilt on the part of the mother/caregiver. A caregiver must also adjust his/her expectations for the Alzheimer patient because this patient's abilities will become increasingly more limited with progression of the disease. If a caregiver does not adjust his/her expectations then frustration will occur when the patient is not able to meet the demands of the caregiver. Unresolved issues from the past can also create emotional strain when they get in the way of providing time and energy to the issues of caregiving (Pfieffer 10). For example two adult children who never got along may now find themselves forced into working together to provide care for a parent with Alzheimer's disease.

Along with the above mentioned strains there is also the possibility of isolation and loss of social roles due to increased time spent in caregiving. As one increases the commitment to the caregiving role one also often decreases other social activities. This may be due to lack of time or simply to feelings of guilt when allowing oneself some free time away from the patient. Either way, isolation as a result of interaction between caregiver and patient can often lead to a sense of being burdened as a caregiver.

When a caregiver becomes overwhelmed with the demands of care there is a potential for abuse to occur. This may be either abuse of drugs and alcohol by the caregiver to "relieve stress and strain," or abuse of the patient when the caregiver can no longer control his own emotions and actions when under stress. Abuse can take many forms from physical, emotional, and psychological to medical, financial, and fraudulent behavior (Hancock 226). Any abuse by the family caregiver may result in further psychological stress on the caregiver. It is very important for caregivers to recognize when their stress levels are high to try to avoid these potentially harmful situations.

Gruetzner (111) has stated that just as dying individuals must go through various stages to come to an acceptance, these stages usually being based on
Elizabeth Kubler Ross' model, so to must a caregiver come to an acceptance and adjustment when caring for a victim of Alzheimer's disease. These stages include denial, over-involvement, anger, guilt, and acceptance. When a loved one is first diagnosed with a degenerative disease such as Alzheimer's it is difficult for family members to accept and many of them will try to deny the condition exists. This can be harmful for both the victim and caregiver as conditions worsen and no aid is given to the victim. The second stage, over-involvement, can be difficult for the caregiver as they may refuse assistance from others and isolate themselves by trying to care for all of the victim's needs alone. Once the caregiver realizes that all the attention and sacrifices made for the care of the victim cannot stop the degeneration anger may set in along with a feeling of helplessness. This anger can cause harm if it is misdirected toward the client or other family members of the caregiver. Conflict can develop and inadequate care may follow. This anger is usually followed by guilt as the caregiver realizes that the victim is not responsible for his/her difficult behaviors. They may also feel guilt about unresolved issues from the past. Wishes for more time for themselves when grappling with the oncoming death of their loved one is also a cause of guilt. Facing the idea of institutionalization can cause guilt at the idea of placing a loved one under someone else's care. When the caregiver fully understands the process of the disease and what this entails they can begin to cope with the disease and come to an acceptance of the role they are to play as progression continues and difficulties must be faced. Along with these stages may come mixed emotions. There are so many adjustments to make when caring for a dementia patient that often times inability to cope with the caring of the victim results in a feeling of burden being placed on the caregiver.

**Needs of Caregiver**

In order for a caregiver to be able to cope with the patient and provide adequate care there are certain needs which must be met. First of all the caregiver must have
knowledge of the disease and its progression. Knowing the signs, symptoms, and course of the disease will help the caregiver to have reasonable expectations in the patient's abilities as well as a basis in following the progression of the disease and knowledge of what to expect next. Knowledge of one's own limitations, emotional, financial, time commitments, etc., are important when deciding how to care for the patient and what the caregiver can reasonably provide in terms of adequate care. Knowledge of services and medical care available in the community are important as well.

Skills to handle patient care are the second need of caregivers and these go hand-in-hand with knowledge of the disease. Proper techniques for lifting, bathing, and monitoring medical signs are important for any caregiver to learn (Pfieffer 6). With elderly patients who are immobile one must watch for bed sores, dry skin, adequate nutrition and hydration. Having the skills and knowledge to handle these problems make caring for an Alzheimer patient a little easier.

Thirdly, the caregiver needs some sort of time away from the patient and emotional support from others. Caring for an Alzheimer patient can be a thankless job when the patient acts out with irrational behavior and has no recognition of the caregiver. Encouragement from others as well as time away from the patient allows the caregiver to become focused on the job at hand and allows them time to distance the behavior from the person and keep a proper perspective. Respite time away from the patient allows the caregiver time to relax or meet their own physical and emotional needs (Pfieffer 7).

Lastly, a caregiver needs legal and financial information in order to plan and manage the care of the Alzheimer victim. An attorney or social service worker may need to be contacted regarding questions with Medicare, Medicaid, or insurance coverage. Financial issues can sometimes be confusing and small stipulations in various policies may make a big difference in placement and care of an Alzheimer
Informal Support Available for Caregivers

Due to the stress and strain which often accompanies a caregiving role, it is important to look at the support areas where a caregiver may find needed help and assistance. These areas of support include family, friends, and professional workers as well as educational resources and social services. Awareness of available supports is important so that the caregiver may use them appropriately and as needed. If a caregiver does not recognize a family member or social service as a potential support then the caregiver must rely on her own resources and can miss the opportunity to involve others in care thus easing some of the strain for herself. Insights from interviews with caregivers and professionals will be used in the remaining portion of this paper to illustrate ways in which supports are important to caregivers. The names have been changed to ensure confidentiality.

Family and Friend’s Support

Often the family is a strong support for the caregiver. Caregivers report that in some instances families have grown closer as they have shared in the care of a loved one. Veronica, a caregiver for her husband for seven years as he has progressed through the disease spoke on the help she received from her daughters.

Veronica: “I’m very fortunate in having a supportive family. I have one daughter, living close by, who will drop everything to come over if I need help or have a question. Or, if I want to attend a symphony or workshop she will ‘sit’ with him while I go out. I have another daughter who’s a nurse, and I can call her anytime day or night with a question and she’ll give me her opinion. I may not always act on this opinion, and she knows that, but I really appreciate her views.”

Families such as Veronica’s can give emotional support as well as aid in caregiving duties. Brenda also found her family supportive.
Brenda: “My grandchildren are really wonderful with him and often come over to help me out. I also found that when I'm feeling down I will call a cousin up just to chat a little and then I usually feel better.”

Alzheimer's victims tend to want to spend all their time with the main caregiver, and often become agitated and upset if this caregiver is not around. Utilizing family members as 'sitters' helps relieve tension in the alzheimer's victim if the family member has been aiding in care because this person is familiar to the patient. Thus, the caregiver may go out and not worry about the Alzheimer patient. Often if caregivers try to take their alzheimer patient out with them they risk the possibility that the patient may have an emotional outburst or may refuse to comply with their wishes and thus create a scene in public. So, a caregiver may try to use a service such as an adult day care but find that they are having such a difficult time getting the alzheimer victim to the agency or meeting place that it is easier and less guilt-producing to just keep the patient at home. However, when this occurs the caregiver does not receive the needed time away from the patient which can help ease emotional tensions from daily caregiving. Therefore, if the caregiver can find some other family member or friend to sit with the patient then she can feel free to spend some time away from the patient without a major hassle, and without worry.

Although many times families will pull together to provide care for an alzheimer victim, and become very supportive of the main caregiver, there are still moments of strain and difficulty due to changes in roles created by the emergence of such a dementing illness. Sara, a caregiver for her mother who had alzheimer's disease discussed how the caregiving affected her family relationships and routines.

Sara: “My two children were grown and at college which provided me with extra time to care for my mother. However, sometimes when they would come home and I wanted to go out with them, just shopping or for lunch, I wasn't able to leave due to my
responsibilities with my mother. The children were very supportive and understanding but I feel that I lost some precious time with them due to my responsibilities in the caregiving role.”

“I also found that such little things as dinner conversations with my husband had to be monitored because my mother would get easily confused and agitated when she didn’t understand what we were talking about. We were no longer able to talk about trips we were planning because she would become upset with the thought of being alone so we had to restrict certain conversations ‘til after she was asleep.”

Sara’s story provides an example of how caregiving affects all facets of family relationships even in small subtle ways. Developing methods to cope such as her idea to restrict what was discussed in her mother’s presence helps family members to successfully adapt to new situations. Input by all members can lead to new ideas and methods for coping.

Asking questions of family members and listening to their opinions may help the caregiver make decisions objectively. Talking with family members also gives the caregiver an outlet to voice concerns and frustrations. In much the same way friends can also help the caregiver by offering a sympathetic ear and encouraging the caregiver to take time for herself every now and then. However, sometimes friends tend to shy away from the Alzheimer patient and caregiver. Brenda, who has cared for her husband with Alzheimer’s for 7 years shared a little bit of her story.

**Brenda:** The first three months were unbelievable for us. At first it was like a Jekyll/Hyde ... a quite dangerous personality and I was so afraid I took him away. I left all my support groups behind. When we came back, most of our friends were uncomfortable with him because he really wasn’t himself. I know they didn’t mean anything by it but
they were so uncomfortable they tended to stay away. This made me really appreciative of those who still help and come and visit.”

Finding friends who will continue to visit and spend time with the caregiver and patient can ease the loneliness that so many times accompanies these roles. Maintaining ties outside the family also helps to ease the transition for the caregiver once the alzheimer victim has passed away and the caregiver slowly starts to reengage in activities outside the home setting.

**Professional Aid**

Creating links to professional workers, such as doctors, social workers, or other service providers can provide a caregiver with knowledgeable informants who can be of assistance with questions and problems that arise in caregiving. For instance, Mabel utilized her doctor's aid by having him write a note which she sent with her husband on the days he attended an adult day care. He had been refusing to take his medication and was suspicious of the nurse who worked at the day care.

**Mabel:** “He wrote a note which said, ‘Dave, you need to take your medication with lunch today. The nurse will help you make sure that you take the right medicine. Please don’t forget. Dr. P.’ Whenever the note was sent he had no problems with the nurse or taking his medication. After a while he got used to it but I still send it with him and have Dr. P update it every so often in case we have trouble again.”

Brenda and Veronica also had support from their doctors.

**Brenda:** “The doctor where my husband worked was very good. The problems first occurred there and he let us talk to the company psychologist who was very helpful.”

**Veronica:** “Our doctor was very helpful. He takes his time to talk with us and is very supportive of our decisions. He always informs
Doctors and nurses may also know of new medicines or of health workshops that might interest the caregiver. They may even be able to give the caregiving information and studies done on the new medications and discuss possibilities of use with a particular patient.

Caregivers find that doctors and nurses can be of great help to them but that they too do not have all the answers. Caregivers may want to keep in mind the fact that they are the ones who spend the most time with the patient and therefore they know better than anyone else what may or may not work for their loved one. It seems hard sometimes to imagine that one can know more than a doctor on a particular client, however, if a doctor prescribes a medicine that seems to create more side effects than helpful changes it only makes sense that the caregiver would discuss this with the doctor and then do what she thinks is best in her individual case.

As Brenda mentioned psychiatrists too can often be very helpful. When the disease is first diagnosed psychiatrists can help by making assessments to distinguish the symptoms of dementia from that of depression which is a common problem among Alzheimer patients and caregivers alike. Caregivers are under a lot of stress and often in their own stages of depression. Recognizing these symptoms can help a caregiver to work through the depression so they are better able to care for their patient.

Dr. Royda Crosse Ph.D., a psychologist who has worked with Alzheimer’s patients and caregivers through her practice described some of the issues she saw in her work.

Dr. Crosse: “I have seen caregivers who are not able to deal with their own emotions. They are too busy trying to provide care for the individual with dementia and making sure that all of his needs are met that they forget about meeting their own. They refuse to give themselves permission to have needs and emotions which must also
be dealt with. I've also seen those caregivers who need outside support but due to resistance in the individual they feel guilty about asking others for help.”

Other professionals such as lawyers or financial advisors can aid a family in setting up finances for the long term care of an alzheimer patient. Information on living wills and guardianships may also be provided through these professionals. There is always a risk, in the case of elderly caregivers, that the alzheimer patient may outlive the caregiver so future provision of care in case of such a situation can be a wise investment.

**Educational Resources**

Educational resources can be an important aid in helping the caregiver to understand the disease and its progression. Coping methods and strategies may also be learned. Sara describes how such resources helped her.

*Sara:* “When I first learned that my mother had Alzheimer’s disease I tried to educate myself as much as possible. I began reading, thinking, and observing her behaviors after she came to live with us so I could find out what worked and what didn’t.”

The *36 Hour Day* by Mace and Rabins, is used by many as a guide to caring for victims of alzheimer's disease and other related dementing illnesses. This book provides practical advice emphasizing the importance of simplifying daily life and focusing on behaviors in terms of the illness and not the patient. The importance of realistic views of abilities and of needs for personal care in the caregiver are also noted. Books such as Gruetzner's, *Alzheimer’s: A Caregivers Guide and Resource Book*, give caregivers knowledge about the disease itself in simple terms and provide some insights in coping with an alzheimer patient. Suggestions on managing personal stress and the importance of the family in providing successful care are discussed. *Facing Alzheimer’s: Family Caregivers Speak*, by Coughlan relates the
stories of eight caregivers as they journey through the progression of the disease with their husbands. Discussions with two support group leaders also provide insights on the helpfulness of this service and how caregivers relate to one another. Appendixes include useful information on financial and legal matters as well as a listing of organizations and agencies complete with phone numbers that a caregiver may use to request information. These books simply serve as examples of the information and resources available for caregivers.

Caregivers may also obtain useful information by attending classes or workshops dealing with dementia or alzheimer's disease. Workshops are often offered through hospitals or health agencies and at a low cost to the general public. New ideas, research, or services may be discussed as well as new resources available on the market. Many times there will be discussion sessions following sessions to allow the participants to discuss strategies and the information they have just received. This time together can provide caregivers with new ideas on behavior management, techniques for successful meals, dealing with personal stress, and care for the patient along with other topics.

Those near universities may take advantages of guest lectures and teleconferences provided by the university. Area agencies on aging may also have resource rooms filled with pamphlets and books which can be checked out by the public. Taking advantage of such resources can only aid the caregiver in coping with changes, and in recognizing any unusual behaviors which may signal changes in their patients functioning level and thus needed changes in care.

State and national associations such as The National Alzheimer's Association will send material free of charge upon request by caregivers. Seasonal, and/or monthly newsletters describing new developments in care can also be mailed directly to caregiver's homes as well as pamphlets on the disease in general. Receiving current and up-to-date information on new developments can aid a caregiver in
decisions on care and health issues. These materials can then be shared with others to promote discussions.

There are also many videos available through gerontology centers, associations for alzheimer's disease, and area councils on aging which can provide useful information for caregivers on the disease and some useful tips on coping with behavior problems. These videos can be especially helpful for those who have trouble retaining written material or who have difficulties with reading. Libraries too may have educational films or videos on the topic of alzheimer's disease which may be helpful for caregivers.

**Personal Coping Strategies**

Caregivers often come up with their own methods to help relieve stress and aid them in coping with the behavior or emotional problems which result from progression of the disease. Some may talk with others, some write poetry such as the poem at the conclusion of this article which was written by a caregiver after her husband died. Others read or educate themselves and try to help others with the knowledge they have gained. Dan, a caregiver for his wife for five years at their home and a daily visitor for twelve years to the nursing home where she was placed, went back to school to get a degree in gerontology.

*Dan:* “The classes I took helped me with the process of caregiving. A course on death and dying was very beneficial to me and aided me through the grief process as I slowly watched my wife die.”

After his wife’s death Dan continued to work with elderly and help others by running support groups in various nursing homes in the area for Alzheimer’s patients and families. In the same way, Sara helped start an adult day care center in her town.

*Sara:* “You feel that there is nothing you can do with your alzheimer patient and this was something I could do. Starting this day care center not only helped me but others who are also in the caregiving
role. I think it was one of the best things I've ever done."

Those who are still in the role of caregiver also use certain strategies to help them manage or avoid behavior changes with their patient and to provide some relief time for themselves.

Brenda: “I try to keep everything on schedule so there is a routine to his days. I also plan ahead to try to avoid things that I know will upset him. Each morning I take 15-20 minutes for myself just to get ready for the day and each night I try to read for about an half-hour before I go to bed as a way to relax.”

Veronica: “I had real problems with my husband’s cigarette smoking. It was becoming dangerous because he would leave lighted cigarettes everywhere. Finally I limited him to one cigarette per hour and made him sit in a specified ‘smoking chair’ so I wouldn’t have to worry about the house burning down.”

Such strategies as those used by Veronica and Brenda help ease the burden of caregiving and allow the caregivers a little more control of the situation. Twelve steps for caregivers were listed in the American Journal of Alzheimer’s Care and Related Disorders and Research and these are located in Appendix A. These steps often help keep a caregiver aware of one’s perspective towards the disease and patient and are a useful resource. Beyond educational resources and coping strategies used to help the caregiver, there are also many social services which can be utilized for aid.

Formal Support Available for Caregivers

Social services for caregivers of elderly dementia patients may be accessed through church groups, area council’s on aging, nursing homes, hospitals, or referrals made by other caregivers. There are many different services available, although availability ranges within different areas. Common sources used by caregivers
include adult day care centers, respite services, home health aids or paid companions, support groups, transportation programs, and nutrition programs.

**Nutrition & Transportation**

Nutrition programs include congregate services, where meals are served in a localized area such as a senior center or community buildings, and home delivered meals. Most delivery programs provide one meal per person, per day for five days a week. These meals provide caregivers with a nutritious meal for their loved one and a little relax time because the caregiver doesn't have to worry about preparing the meal. Meals can also be provided for caregivers. Each meal meets one-third of the daily requirements for nutrients such as vitamins and minerals. This ensures that those who use the service will acquire at least one nutritious meal per day. Some adult day care centers also use this service for their clients when cooking areas are not available in the day care setting. Beth Millikin, director for DayStar, an adult day care center makes use of this service in her agency.

*Beth:* “We use the homebound meal service to have meals delivered to our center on days when we cannot go out due to bad weather. There is no charge for these meals but we also give a donation for each meal we receive. If it wasn't for this service I'm not sure how we would be able feed our clients because we would have no way of keeping our meals hot due to lack of resources in our setting.”

These meals are often provided through area agencies on aging.

Transportation services are another important service often utilized by caregivers of alzheimer patients because the patients are no longer able to drive themselves and the caregivers often lack the time to drive the patients to a particular destination. Engaging neighbors or friends to run the alzheimer indivicual or elderly caregiver to the store or doctor's office is one method of providing transportation to those who are no longer able to drive. Churches also often sponsor drivers for the
elderly parish members. Contact with the local council on aging may provide a list of specialized programs to meet this need.

Different services are set up in different areas depending on funding and need. Rural areas are often less fortunate in receiving these services due to long distances between patients and lack of funds. Some cities have transit programs with specialized buses for the elderly where the bus stops directly at the patients' homes and drives them to their destination. Muncie, Indiana has a transit program such as this where mini-buses provide transportation directly from homes to specified destinations such as adult day care centers.

**Adult Day Care & Respite**

Adult day care centers play an important role in providing caregivers with respite time to run errands and relieve themselves from daily caregiving duties. Over the last six to eight years adult day care centers specialized for elderly dementia patients such as alzheimer's victims have been established where resources permit (Pfieffer 17). Centers such as these provide the alzheimer patient with a safe environment where activities are geared toward the engagement of members. Activities include exercises, crafts, sing-alongs, discussion, reminiscence and reality orientation. Activities which are geared toward the functioning level of members often provide participants with a feeling of success and increase social interaction for the members. Centers such as these may be open from one to five days a week and they are typically used from four to eight hours a day (Pfieffer 17). Staff may include social workers, nurses, aides, and trained volunteers.

It is important to note the use of such centers for caregivers. Utilization of adult day care provides the caregivers with temporary physical and emotional relief from their daily duties of care. Many times caregivers are encouraged to attend the center with their patient a few times to help them decide if the center is right for their patient. Veronica did just this when she wanted to enroll her husband in a day care setting.
Veronica: “Before I made up my mind as to whether this is where I wanted my husband to be or not I attended the center with him for a couple of weeks. I was really pleased with what I saw and everyone was so nice to us and so competent that I felt no misgiving at leaving him there for a few hours each day. I know he is well taken care of and will enjoy himself with the others.”

Communication with staff at centers can also help caregivers identify changes or new behaviors in their patient. Brenda explained how communication with staff at the day care center her husband attends has been beneficial for her.

Brenda: “When I notice a new behavior or something unusual about my husband’s actions I will check this out with the staff at the center. This helps me to verify changes in his behavior and assures me that it is not just something that is happening at home. Sometimes the staff will point out something that I hadn’t noticed and this helps me identify changes too.”

Adult day care centers are usually most appropriately used for patients in the middle stages of dementia. Those who are ambulatory and have fairly high self-care capacities fit in best at such centers. Each center will have its own eligibility criteria and payment plan.

Although adult day care centers provide a needed rest for the caregiver there are times when the caregiver needs a longer period away from the patient. For instance, a caregiver may need to go out of town for a few days and find it impossible to take the patient with her. Respite care in institutions such as hospitals or nursing homes can cover extended time periods of caring ranging from overnight stays to a few weeks of care. Staff in these institutions are well trained to provide adequate care for the Alzheimer individual. Unfortunately respite services are often expensive and must be paid privately by the individuals. This can often be a drawback for those who
desperately need to use such a service. Also, nursing homes may offer this service if requested and if extra beds are available but may not advertise this service. In cases such as these caregivers may be unaware that the service even exists.

**Support Groups**

One form of support which is commonly utilized by caregivers is support groups. Hamdy (155) has described these groups as "open educational forums," meaning that members derive knowledge and useful techniques from others on an informal basis. Support groups range in size, structure, and sponsorship. Support groups are often sponsored through churches, adult day care centers, nursing homes, hospitals, and national or state associations. This service is usually free to caregivers and allows them to vent frustrations and concerns as well as share ideas on coping methods with others. Brenda shared some of her views on the support group she attends which is connected to the adult day care her husband attends.

*Brenda:* I felt so overwhelmed at first and totally alone. It helps to go and talk to people who are dealing with the same things. They have good suggestions and may think of something you haven't which can help you deal with a particular problem. It also makes you good to feel you can help someone else. It's also a really good place to get information and to learn about new testing, theories, and medication. I just think that the support group has really helped me.”

As Brenda mentioned, support groups often provide information on alzheimer’s disease and new medicine or research may be discussed as well as community services in the area which can be utilized by caregivers. Guest speakers may come in to speak on various aspects of care ranging from health issues to tips for managing problem behaviors.

These groups can be lead by professionals or lay persons. Support groups are based upon the philosophy of self-help and provide members with a supportive
care or to another setting because the patient refuses to comply. Having a home companion alleviates these unwanted struggles and outbursts between patient and caregiver. Sara made use of a home companion when she wanted to go out for an evening with her husband.

*Sara*: "If I tried to take my mother somewhere she would throw a fit so I found a lady who would come in and 'visit' with her for a while so we could go out. My mother would refer to her as 'this old lady' and as long as I didn't tell her ahead of time my mother would be o-kay. However, if I slipped and told her that we were going out my mother would become worried about what was going to happen to her and if anyone would stay with her or not. Things could get really hairy at times."

Besides having a companion for the alzheimer victim, the caregiving often needs help with daily chores due to added responsibilities of caregiving. At times the caregivers simply need help with daily tasks of cooking and cleaning because so much of their time is spent working with the patient. Homemakers may be used to help with such tasks as laundry, cooking, shopping, and cleaning. Use of such workers aids the caregiver by fulfilling some of the roles and tasks the caregiver no longer has time to finish. Homemakers can be accessed through area councils on aging. Some agencies also provide someone to help with chore services such as carrying wood, cleaning gutters, and making minor home repairs (Hamdy 163). These services can be especially useful to female caregivers who may not have the strength to handle such chores or who have never had to worry about such tasks before.

Another form of in-home care for alzheimer patients is home health care provided by aids or nurses. Home health aids may help the patient dress, bathe, eat, and use restroom facilities. Professionals may be sent to the home through visiting nurse and home health agencies. A physician's order is usually required for visiting
Activity directors in these units may provide more emphasis on reality orientation and reminsence than on entertainment and activities. They too have been trained to work with alzheimer victims and often develop activities which residents are able to participate in. One anonymous activity director shared her feelings on the success of an activity.

**Director:** "If one of my patients falls asleep during an activity I feel that I have been successful because that means that he/she was comfortable enough to relax and let his/her mind settle down for a while."

**Conclusion**

There are many issues to be dealt with in the decision of nursing home care and these range from financial to emotional costs to be born by the caregiver. Discovering the appropriate setting for a patient and the appropriate means of care is not always easy when one's emotions are involved. Dealing with an alzheimer patient is a difficult task and one which requires support by others. This paper has shown how the disease affects the individual and the caregiver and has given some directions on where to look for aid for caregivers. However, one must keep in mind that knowledge in this area will continue to build with research and new discoveries and thus new developments in care may develop in the future. The author hopes, however, that this paper can provide a basis of knowledge for those dealing with alzheimer's disease and caregivers. Knowledge of available support and services can provide caregivers with valuable resources and areas of help for future reference. A caregiver's life is dramatically changed by his or her caregiving role but in the end one must continue with one's own life, one must find new direction, one must survive.
Survivors

For years I've watched
an old mesquite tree -
gnarled and bent and twisted -
buffeted by winds and droughts.

It starts to grow up
toward the sun and sky.
But the soil is so poor,
the water so scarce,
the heat so fierce,
so cold at times,
it was beat to the ground.

Each Winter you'd think,
-It's dead, for sure!
It's succumbed to the odds
stacked against it.

Yet wait 'til Spring
and a miracle occurs,
New life springs up
from the gnarled old branches -
a tiny chartreuse sprout
heads straight for the sun!
It lives - overcoming
all that is hard,
telling all the world,
- I live, I will survive!

Sometimes I feel like that old mesquite tree
I feel battered by life's adversities,
I feel down - but not out!
When Spring rolls around,
I feel a fresh stirring of life.

I have things to do -
places I want to explore,
people I love!
I can hold my head high -
look the world in the eye -
and say,
- I live, I will survive!

- Maude S. Newton
Appendix A

Twelve Affirmations for Caregivers

1. Although I cannot control the disease process, I can control many aspects of how it affects me and my relative.

2. I can take care of myself so that I can continue doing the things that are most important to me and to my relative.

3. I can simplify my lifestyle so that my time and energy are available for things that are really important at this time.

4. I can cultivate the gift of allowing others to help me, because caring for my relative is too big a job to be done by one person.

5. I can take one day at a time rather than worry about what may or may not happen in the future.

6. I can structure my day in a consistent schedule to make life easier for me and for my relative.

7. I can develop a sense of humor so that laughter can help to put things in a more positive perspective.

8. I can remember that my relative is not being “difficult” on purpose, and that any behavior and emotions are distorted by the illness.

9. I can focus on and enjoy what my relative can still do rather than constantly lament over what is gone.

10. I can increasingly depend upon other relationships for love and support.

11. I can remind myself that I am doing the best that I can at this very moment.

12. I can draw upon my spirituality for wisdom and strength.

Appendix B

Considerations in Nursing Home Care

1. Can the total needs of the loved one be adequately provided for on a 24-hour basis in the home?

2. Has the health status of the individual changed so that more nursing care and medical monitoring are necessary?

3. Is the stamina of the caregiver severely taxed by the care situation in the home?

4. If the person lives alone, is there adequate supervision and assistance available to provide for his needs on an ongoing basis?

5. Is it realistic to expect the family to deliver or purchase the services the relative now needs in the home?

6. Are the financial resources of the spouse becoming severely threatened?

7. Do health concerns for the caregiver begin to rival those for the Alzheimer's patient?

8. Has the caregiver's isolation become severe?

9. Is in-home care contributing to the emotional/physical breakdown of the caregiver/spouse?

10. Is the nursing home placement as unacceptable as it first seemed?

11. Will the quality of contact with the alzheimers victim improve by placement in a nursing home?

12. Will the family be able to pull closer together around the nursing home placement?

13. Have physicians and other professionals recommended such a placement?

14. Have the caregiver's approaches to daily problems been ineffective?

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**Interviews:** On interviews with caregiver’s first names only have been given (and changed) so that the interviewer’s confidentiality will not be breached.


Mabel. Personal Interview 14 February 1994


Sara. Personal Interview 23 March 1994