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Caregiver Education Program

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CAREGIVER EDUCATION PROGRAM

by

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DEDICATION

This project is dedicated to my Grandpa Buck, Grandpa Bilyeu, Great Grandpa Efton, and Great Grandma Maude for their lives inspired me to love and respect the elderly. Their memories shall always be cherished and treasured.

INTRODUCTION

Alzheimer's Disease is a progressive, irreversible disease of the brain. It is not a normal or inevitable result of the aging process. However, as more people live to advanced age, the susceptible population will increase, as will the number of people afflicted with this disease. Alzheimer's Disease presents a challenge by taking away the patient's ability to remember, as well as the ability to learn.

Alzheimer's Disease has been characterized by many professionals as "the thief of minds" (Gewertz 23). Memories of life experiences and even one's own family members fade away leaving the person a stranger to those who love him or her. Many families try to keep their family member at home as long as possible. This can be done if necessary issues are addressed and training provided. Being the caregiver of an Alzheimer's Disease patient is not easy, because this disease does not just affect the patient. The family is affected emotionally, physically, and financially, due to the totality of Alzheimer's Disease effects on its victims. The ongoing need for family caregiving often means a complete revamping of usual family activities, because the task is increasingly complex and demanding. Family members find their normal roles are disrupted. All members need time to express their feelings and to learn how to cope with these changes. Clearly, these families need support.

With education about the disease and ways to cope, the burden of caregiving can be lifted slightly. The more caregivers know about the nature of dementing illness, the more effective they will be in devising strategies to manage behavior problems. To promote the least-restrictive living environment and to normalize living arrangements and care as much as possible, adequate support systems between home and institutional care must be developed (Briar and Kaplan 1).

This culminating project will be designed to educate caregivers of patients with Alzheimer's Disease and related disorders about the disease, ways to cope with the disease, and other issues affecting their efforts. This training manual will be an effort to reach out to the community. Those caregivers that need support, but have never had the opportunity to participate in an education program will now have a place to turn. Training models already being used will be introduced and examined. It is hoped that this project can be utilized by health professionals and non-professionals as a tool when working with caregivers. The researcher will be surveying caregivers and fellow health care workers to determine the scope of the training manual to follow.

LITERATURE REVIEW

Demographics

Alzheimer's Disease is the fourth leading cause of death among adults & the thirteenth overall (Ketelle 14). Five to six percent of all elderly are afflicted with Alzheimer's Disease or related dementias. Approximately one-half of nursing home residents have Alzheimer's Disease or a related disorder. Again, as the "baby boomers" begin to age in large numbers, these statistics will dramatically increase. Currently, the federal budget allocates $230 million to Alzheimer's Disease research, compared to $1.7 billion for cancer and $1.2 billion for AIDS research (Alzheimer's: Is There 8).

Dementia Defined

Dementia can be defined as the loss of intellectual abilities of sufficient severity to interfere with social or occupational functioning (Tebb, Poertner, and Harbert 9). It is believed to be the primary mental health problem of the elderly population. There is a thin line drawn in the diagnosis of dementias as many diseases have similar symptoms. This creates the great challenge for health professionals in the diagnosis of Alzheimer's Disease.

Diagnosis of Alzheimer's Disease

To begin the process of diagnosis, first other diseases must be ruled out, giving Alzheimer's Disease the nickname, "the disease of elimination". Diseases that mimic Alzheimer's Disease can be divided into reversible and irreversible. Examples of reversible diseases are: nutritional disorders, medication or drug toxicity, hormonal problems (thyroid, anemias), and tumors (Tebb, Poertner, and Harbert 10).

Irreversible diseases that mimic Alzheimer's Disease are: Huntington's Chorea, Pick's Disease, Creutzfeldt-Jacob, Parkinson's Disease, Kuru, and multi-infarct (strokes). It is easy to see why Alzheimer's Disease is the most overdiagnosed and misdiagnosed disorder of mental functioning in the elderly. Lab tests of blood, urine, and stool; medical, social, and nutritional histories; tests for thyroid function; and radiological studies such as CAT scan or MRI make up the bulk of testing that a prospective Alzheimer's Disease patient must undergo. CAT scans are more accurate in later stages when Alzheimer's Disease characteristic changes are revealed: atrophied or shrunken brain, widened sulci (tissue indentations), and enlarged cerebral ventricles (fluid chambers) (United States 5). When Alzheimer's Disease is erroneously diagnosed, the elderly person is "written off", and loses the possibility of recovery.

The only absolute way to diagnose Alzheimer's Disease is through autopsy (post-mortem). Brains of victims are filled with two types of abnormalities: senile or neuritic plaques and neurofibrillary tangles. Plaques appear on the outside of neurons as clumps of a special protein (amyloid), intertwined with dead and dying branches of surrounding nerves (United States 4-5). Tangles, or nerve cell malformations, are dense insoluble clots of material inside damaged neurons (Alzheimer's: Is There 3). It is not known whether plaques and tangles actually destroy brain cells or if they are simply the after effects of Alzheimer's Disease.

In 1986, a study was conducted of the experiences of families from the earliest symptoms of Alzheimer's Disease to the diagnosis (Chenoweth 267). Many families described the early years prior to diagnosis as confusing and puzzling. Several problems were noted with the diagnosis and information provided. Many noted difficulties explaining to their physician the subtle changes affecting their relative, thereby postponing diagnosis even longer. Once the diagnosis was finally made, families had difficulty learning how to care for their relative. Fifty-four percent perceived explanations of physicians as "focusing" almost entirely on the hopeless nature of dementia. The manner in which the diagnosis was presented caused additional stress. Explanations were often too brief and the caregiver felt unprepared for the behavioral changes that later occurred. Finally, no one in this study reported being given information about home health services (Chenoweth 269).

Four Stages of Alzheimer's Disease

Alzheimer's Disease patients typically go through four progressive stages. The first stage occurs when devastation occurs to the limbic system (Alzheimer's: Is There 3). Symptoms begin such as forgetting appointments, leaving appliances on, etc. The patient may become less spontaneous; move slower and with less energy; have less drive and initiative; become angry easily; and seek the familiar and shun the unfamiliar (Lindeman 4-5). In stage two, the patient's ability to understand speech, make decisions, and calculate become extremely difficult. Insensitivity to other's feelings and increased self-absorption become apparent. The patient will lose the thread of the story easily when talking (Lindeman 5).

As the sensory cortex becomes affected, the loss of speech, reading ability, and the ability to recognize places, objects, and faces, make up the markedly changed behaviors (Alzheimer's: Is There 5). The patient may become uncertain how he or she is expected to act. Short term memory becomes poor or failing. The patient will continue to cling to the long term memory recall at this point.

Finally, as the motor cortex is affected, the patient reaches the final stage. Loss of walking, talking, swallowing, and incontinency are characteristic of stage four. Patients will perseverate words, often with garbled, nonsensical phrases. Possibly the most devastating to the family members providing care, is the loss of recognition of individuals (Lindeman 5). Most deaths from Alzheimer's Disease occur in the last stage. Due to the horrific debilitation, most people at this stage are in nursing homes.

The leading causes of death in Alzheimer's Disease patients are respiratory conditions or broncho-pneumonia (Ketelle 14). The prevailing belief is that patients die of some form of complications of illness. As with any "terminal condition", the emphasis must be on making the patient as comfortable as possible. However, families should think about medical directives long before this stage is reached. At this stage the family may be approached by the patient's physician regarding artificial means of survival (ventilation, artificial nutrition, and artificial hydration). Again, as with any terminal, progressive disease, these decisions are easier to make early in the disease.

Five Causal Theories

Although, the cause of Alzheimer's Disease is not known, there have been remarkable advances in the understanding of Alzheimer's Disease in the last few years. Health care professionals have their own speculations, but to this date no theory has been proven.

There are five causal theories that will be addressed here. The Chemical Theories are made up of two parts; chemical deficiencies and toxic chemical excess. Chemical deficiencies in the brain are evidenced by diminished levels of neurotransmitters thought to influence intellectual functioning and behavior. Acetycholine is a chemical that plays a role in memory function and is found to be reduced in brains of Alzheimer's Disease patients (Morris 11). Drug therapies have been studied, the most common being THA (also known as Tacrine or Cognex (Access 5). THA's role is to enhance the activity of acetycholine. Morris found that THA produced remarkable improvement in 16 of 17 Alzheimer's Disease patients taking the medication (11). However, a 1987 multicenter national drug trial with THA found only small improvement in some memory tests (11). What appeared as improvement was an artifact of study design.

The consensus appears to be that while some changes are noted with studies of THA, the improvement is over a brief, but not sustained period of time. Most studies agree that the improvements do not sufficiently improve the everyday life of patients. In spite of these findings, THA studies continue. Recently, in May 1992 the FDA approved an "expanded access" program for the administration of THA, in which physicians can prescribe the drug to a wider number of patients (Access 5). The patients must pay for the THA and for safety monitoring tests. Sabeluzole is a new drug being investigated for the treatment of A.D. symptoms (Amyloid 5). Preliminary studies suggest that sabeluzole may improve learning and memory in animals and healthy humans, and is currently being studied at sixteen U.S. locations on

Alzheimer's disease patients. Other drugs being tested are Oxiracetam, HP-029, and DuP-996.

The second segment of chemical theories involves toxic chemical excesses, which is primarily the controversy surrounding aluminum. Dr. Daniel Peul used tiny probes to find that neurons with the characteristic tangles can contain between 10 and 50 times more aluminum that normal neurons (Alzheimer's: Is There 5). Although aluminum can be found in the water we drink, some baking powders, buffered aspirins, antiperspirants, and antacids, it has no known function in the body. The body has the capability to detoxify it, but it is thought that this capability is broken down in Alzheimer's Disease. In 1991 a drug called desferrioxamine (DFO), used to treat aluminum and iron poisoning, was given to Alzheimer's Disease patients (Part II 5). This study suggests that DFO slowed the progression of Alzheimer's Disease. Markesbery states, "Aluminum is a toxin if it gets into your brain. Since you can't stay away from it, because there's a lot of it in the environment, you should try not to take in extra aluminum when you know where it is. Whether aluminum has anything to do with Alzheimer's Disease or not, we just don't know" (Part II 5). The debate continues to be whether aluminum is the cause or consequence of Alzheimer's Disease.

The second theory is genetic. Genetic interest was stirred by the discovery of an apparent association between Alzheimer's Disease and Down's syndrome in certain families. Chromosome 21 is the chromosome affected in Down's syndrome, and houses the gene that generates beta-amyloid protein, the abnormal protein found throughout the brains of Alzheimer's Disease patients (Amyloid 5). This protein accumulates particularly in senile or neuritic plaques. Recent studies have found that beta-amyloid can cause degeneration of brain cells (Bowling 8). Beta-amyloid is a fragment of a larger protein called amyloid precursor protein (APP), whose function is not known. Morley found that injecting beta-amyloid into brains of mice caused them to forget tasks they had previously learned (Bowling 8). Yankner showed that beta-amyloid causes nerve cell death when injected into rat brains. Further, when a protein called substance P was injected, nerve cell death was reduced. Substance P could be a possible therapy (Amyloid 5).

John Fink found three changes in genetic coding in the same location of the APP gene in unrelated families with an uncommon form of Alzheimer's Disease (Alzheimer's Association 1). Dr. Fink states, "Identifying additional APP gene mutations in Alzheimer's Disease patients and analyzing the way that they change the protein will give us insight into processes that lead to the formation of plaques" (Alzheimer's Association 1).

The Autoimmune Theory speculates that certain late life changes in aging neurons might be triggering an autoimmune response evoking symptoms of Alzheimer's Disease (United States 12). It is not known what triggers the brain cell changes.

The Slow Virus Theory speculates that the brain tissue changes characteristic to Alzheimer's Disease patients may be caused by a virus (United States 13). No virus has been isolated, and no immune reaction has been found.

The Blood Vessel Theory postulates defects in the blood brain barrier, a protective membrane-like mechanism that guards the brain from foreign bodies or toxic agents (United States 13). Though none of the leading theories about the cause of Alzheimer's Disease have been proven, each has uncovered data that warrants further study.

At the present time, there are no proven treatments for Alzheimer's Disease. Some of the symptoms can be treated, such as depression. Research will continue, but in the meantime effective ways to cope are central to living with this disease, both for the patient and the caregiver. Modifying the environment by taking into account safety, as well as the least restrictive setting are essential.

CAREGIVERS - WHO ARE THEY?

Family caregivers have provided the only cradle-to-grave services in the United States (Briar and Kaplan 1). Approximately 80% of all care to frail elders comes from informal sources (Chappell 172). The patient's family provides the major caring function for most impaired and disabled individuals. The frail elderly receive five times as many hours per week of help from informal caregivers than from formal caregivers (Osterkamp 3). Frail elderly constitute an average of two to three impaired activities of daily living, and nearly 3/4 of the care recipients reside with the caregivers.

Seventy-five percent of all caregivers are women (Osterkamp 3). Regardless of the size of the family, one "primary" caregiver usually carries the weight of the burden, with little help from the remaining family members. Thirty-four percent of the primary caregivers of the elderly have children in their households (Briar and Kaplan 3). The primary caregiver is most likely the spouse, followed by adult daughters, and daughters-in-law. Daughters-in-law often step in even before the patient's own son. Daughters often provide more hands on and emotional care, while sons provide a more supervisory role, providing tangible items (paying bills, etc.) "Caregiving is a fundamental women's issue of our decade. Women are presumed to be responsible for the well-being of their family members. For women, caregiving is an expected duty; for men, it is an unexpected expression of compassion" (Sommers 2).

Informal caregiving is motivated by at least four factors: (1) love for the family member, (2) sense of gratitude and desire to reciprocate for the care that an elderly relative gave at an earlier stage in the life cycle or that is anticipated from a child, (3) allegiance to a more generalized societal norm of spousal, parental, or filial responsibility, and (4) abhorrence or fear of placing the relative in an institution or nursing home (Briar and Kaplan 4).

NEEDS OF CAREGIVER

Integrating the elderly person into the home of the caregiver may have a segregating effect on the family. Role changes, stress, and illness often reactivate old interpersonal and interfamily difficulties. The illness often affects the caregiver's relationships with others. Friends stop visiting and the caregiver has to give up leisure activities and volunteer work. All of these factors may leave the caregiver feeling isolated. Emotional strain and feeling burdened are the most cited negative effects of caregiving (Osterkamp 4). Emotional support is needed for the caregiver, often fulfilled through friends and support groups. The caregiver needs someone who is objective and caring to talk to in confidence. The caregiver also needs information. Through referrals to physicians, counselors, community agencies, and assistance with financial and/or legal matters, many questions can be answered.

Emotional support can be extended to include helping the spouse deal with grieving for the loss of the person he or she married. This loss has been termed "living bereavement" (Tebb, Poertner, and Harbert 34). For spouses, a change in roles can mean many new responsibilities and the development of new skills. A husband may have to learn how to cook. A wife may have to learn how to drive. The caregiver may have to provide personal care such as toileting and bathing. These activities challenge the traditional views of being a spouse (Montgomery 1.9). While physically the person looks the same, the personality and emotional being are not. As one man wrote, who later died of Alzheimer's Disease, "Most people expect to die someday, but who ever expected to lose their self first" (Cohen and Eisdorfer 22).

Spouses cannot mourn well, nor divorce with dignity or in good conscience, though sexual and affectional needs are frustrated (Lindeman 13). Often the spouse is told to "get on with your life", as if the husband or wife has already expired. Some stages that the caregiving spouse may need to work through are: shock, emotional release, depression, loneliness and sense of isolation, feelings of panic and confusion, feelings of guilt, hostility and anger, and finally acceptance (Tebb, Poertner, and Harbert 34).

Education and training can make the role of the caregiver less stressful. With more knowledge about Alzheimer's Disease, the behavior changes that are to come, and conditions affecting their elderly relative, the caregiver becomes better prepared for the road ahead. This could also include training about activities of daily living and tips for providing care to dementia patients.

With the burdens of caring for an elderly relative with some form of dementia, such as Alzheimer's Disease, the caregiver tends to lose sight of their own care. Sleeping habits, diet, and lack of exercise can contribute to exhaustion. While depression and discouragement are common feelings for families of people with chronic diseases, there are warning signs that indicate outside help should be considered. Lying awake at night worrying, losing weight, feeling isolated, alone, or overwhelmed, and using alcohol or medications to get through the day are some warning signs that deserve closer examination (Mace and Rabins 259). Caregivers need relief through some form of respite care to allow for attention to medical checkups and the continuation of some resemblance of their own life roles. Taking time out, away from the care of the confused person, is one of the single most important things the caregiver can do to make it possible to continue to care for the elderly person with a dementing illness (Mace and Rabins 255).

COSTS TO CAREGIVER

As previously stated, families provide the major caring function of impaired and disabled elderly. The types of care include instrumental activities of daily living - housework and meal preparation; functional activities of daily living - walking, feeding, and bathing; emotional support - 96% of community living elderly have companions, and 84% have confidant relationships; and decision making assistance (Chappell 173). Further assistance may include transportation, financial assistance, and making appointments.

For caregivers who are still employed outside the home, these increased responsibilities can mean costs such as absenteeism from work, decreased job productivity, lost opportunity costs, temporary or permanent withdrawal from the labor force, and expenditures associated with the caregiver's own increased physical and mental health problems (Scharlach, et al., 23). Denton, Love, and Slate estimate that caregivers of elders (both male and female) lost almost $5 billion in earnings annually while receiving approximately $9 million in transfer payments such as food stamps (357). Among one million caregivers who had been employed at some time during their caregiving experience, 9% reduced their work hours, 29% rearranged their work schedules, and 19% took time off without pay (Briar and Kaplan 5). Creedon found that among employees over 30, 20% were caring for an older relative or friend (16). The United States is the only industrialized nation that does not recognize the burden of caregivers through the provision of family allowances or caregiver's benefits (Briar and Kaplan 9). Many caregivers are faced with the decision of choosing between employment and caregiving.

EDUCATIONAL PROGRAMS - ARE THEY BENEFICIAL?

Many efforts are already being made to provide support and education to caregivers. Chiverton and Caine found a study which investigated the impact of an educational program on the coping ability of spouses of patients with Alzheimer's Disease (593). Three - two hour sessions were provided. The first session focused on the disease process; treatments, current research, role changes, and diagnostic evaluation. The second session dealt with general communication skills and behavioral management techniques, for example dealing with wandering. The final session provided basic strategies to assist with activities of daily living, and help in locating and utilizing resources in the community, such as respite care.

The results of this 1989 study suggest that an educational program can improve a spouse's ability to deal with the daily demands presented by a patient with Alzheimer's Disease. The greatest increase was in knowledge domain. Therapeutic competence also improved. Spouses were better equipped to carry out medical, dietary, and other treatment complications. Emotional competence increased, as spouses were able to discuss topics they had previously avoided. It is hoped that by assisting the Alzheimer's Disease patient's spouse, the patient will benefit also.

The following section highlights some of the successful programs that currently exist throughout the country.

GOOD SAMARITAN HOSPITAL

Research indicates that education, information and referral, and support and respite services can significantly improve caregiver's coping abilities. The Education and Family Support Services (E & FSS) at the Good Samaritan Hospital and Medical Center in Portland, Oregon do just that (Heagerty, Dunn, and Watson 7). The program is made up of several components. "Helping You Care", is a five week class teaching caregivers to assess their needs, communicate effectively, and provide personal care.

A general support group is held monthly, as well as 20 separate groups for individual disorders. Peer support groups have basically four functions: (1) to provide reframing and meaning to a stressful situation, (2) to help direct powerful and possibly immobilizing emotions, (3) to exchange ideas and suggestions for caring for oneself, and (4) to provide group members with role models in developing self well-being at a time of a significant loss (Tebb, Poertner, and Harbert 37). Support groups may offer families a sense of community with other families who are experiencing similar problems. Some recurrent themes and concerns of family members are feelings of guilt, fear of inheriting the disease, coping with the progression of the disease, and managing the behaviors associated with the disease.

The Caregiver's Respite Program at Good Samaritan trains respite care providers with ways to deal with patients with Alzheimer's Disease, stroke, etc. A listing service has been developed of persons who have completed the program and it is sent to families requesting these services. A Legal/Financial Planning Class was developed by a clinical social worker and an attorney. This class includes topics such as planning for long term care and guardianship.

"Strategies for Managing Alzheimer's Disease", is a two hour session that provides caregivers with tips for dealing with wandering, sleeplessness, and other behavioral problems. Lastly, the Caregiver Wellness Program teaches ways for caregivers to maintain their health. This program has gone on the road to 25 neighboring cities.

ANDRUS OLDER ADULT CENTER

The Family Training Project is a research and service program for caregivers located at the Andrus Older Adult Center in Los Angeles, California (Zarit Appendix F). Here, the approach is to design interventions that will maintain the dementia patient at home. Rather than focusing on dementia as a disease, this approach looks at the aspects of the situation which are manageable. This 3 x 3 Model of Intervention includes the following treatment techniques; (1) providing information, (2) teaching a problem solving approach, and (3) identifying sources of social and emotional support. The treatment modalities are: one-to-one counseling with the primary caregiver, family meetings, and support groups (Zarit and Orr 80).

In the first phase, accurate information is the goal. Questions are answered regarding possible causes or cures of the patient's memory loss. Questions about cures must be handled delicately. Trying a treatment sometimes gives the family the feeling they are doing something for the patient (Zarit and Orr 84). When families understand that the changes in their loved one are part of the disease, and not something done deliberately to upset them, they can cope more effectively. It is recommended that the caregiver not be bombarded with information.

In the second phase, problem-solving focuses on what the caregiver can do differently to reduce or eliminate disruptive behaviors (Zarit and Orr 93). Families are helped to understand why their relative behaves in a certain way and misconceptions are corrected. They are taught behavior modification. For example, "sundowning" is a condition in which the person sleeps the majority of the day and therefore is up wandering and pacing at night. The caregiver is provided with techniques to keep the person busy during the daytime hours, to help regain for a time their previous sleeping patterns. Problem-solving means that the caregiver must take an active role.

The final phase contains three types of support: support received from a non-judgmental service provider, support from the caregiver's informal support network, and support from community agencies (Zarit and Orr 101). Some examples of help are staying with the patient, taking the patient out, housework, or transportation. Caregivers are more likely to turn to relatives or friends for help than social service agencies.

This particular training program stresses the view that nursing home placement should be the last resort. "Nursing home placement only shifts the burden of the family's experience, rather than relieving it" (Zarit and Orr 7). Parris-Stephens, Ogrocki, and Kinney found that even after nursing home placement family members continued to assist with activities of daily living (331). Caregivers who continued to have close contact with their family member in the nursing home experienced high levels of psychological distress. In any event, nursing home placement continues to be sought when the caregiver has become overwhelmed and exhausted, and physically ill or mentally distressed due to the extraordinary demands (Tebb, Poertner, and Harbert 16).

HONOLULU GERONTOLOGY PROGRAM

The Honolulu Gerontology Program of the Honolulu Medical Group began in 1980 as a service to set up elderly people with companions/aides (Bass 40). This service continues, termed the Caregiver Respite Project. The cost is six dollars per hour and depending upon the financial situation, may be subsidized by grants. The aides typically assist the caregiver with bathing, changing linens, toileting, and light meal preparation. After six months, caregiver's are given a "stress quiz", to determine any benefits from this respite care. This program also attempts to incorporate less willing family members who may not live close by or simply choose not to assist. The program members send letters to these family members, requesting money to help with care, if no other aid can be provided. This money then goes to purchase equipment or for other services the care receiver needs.

By 1988, the gerontology program had been expanded to provide an annual eight-lecture educational series for caregivers in addition to providing support groups. The eight session topics are: Overview of the

Aging Process; Stressful Emotional Situations and How to Cope; Optimizing Your Health While Caregiving; Managing Demanding and Manipulative Behavior; Legal Issues; Long-Term Care Insurance; Acute Care, Care Homes, and Nursing Homes; and Community Resources for Caregivers (Bass 46).

The two primary diagnoses of care receivers were dementia and stroke. Originally, the program's intent and hope was to reach caregivers who were at risk for becoming abusive to the care receiver. Later, they found that in fact, the opposite was true. More caregivers were receiving abuse. The program defines abuse as anything from the care receiver demanding that only the caregiver provide care with no other assistance, to verbal and physical aggression.

After participating in the Honolulu Gerontology Program, some personal behavior changes caregivers have reported include managing feelings better, thinking ahead and planning, encouraging the independence of the caregiver, practicing assertive behavior, and asking relatives for help (Bass 48).

LONG BEACH COMMUNITY HOSPITAL

The Alzheimer's Family Care Center of Long Beach Community Hospital developed a family care guide to help families with Alzheimer's Disease in their efforts (Long Beach iv). This manual is written in layman's terminology making it quite readable and understandable. Every aspect of day to day care is individually addressed with tips and suggestions provided.

The manual begins with a brief definition of dementia and explanations of the differences between Alzheimer's Disease and multi-infarct dementias (strokes). As in previous training materials already discussed, the key is information.

Common problems are addressed with the reminder that working on one problem at a time can produce results and lessen caregiver stress. The following is a highlight of tips on interacting with Alzheimer patients (Long Beach 5-6):

(1) In interactions with the person try to:
  - Be calm and reassuring
  - Speak slowly and distinctly
  - Use simple words
(2) Before asking the person to do something, address him by name:
  - Maintain eye contact
  - Use nonverbal gestures
(3) Approach the person from the front to avoid startling him.
(4) The feelings expressed in the voice when speaking to the confused person are as important as the words you say.
(5) Try to maintain a daily routine.
(6) Always remember the importance of love and affection:
  - The Alzheimer's Disease patient responds well to hugs and touching.

Activities of daily living (nutrition and mealtimes, hygiene, dressing, grooming, incontinence, exercise, recreation, safety, wandering, sleep disturbances), and changes in behavior are explained step by step to guide the caregiver through effectively. This manual also describes common health problems and basic information about medications.

An entire section is devoted to legal issues. Common financial and legal problems that families have are: the patient gives away or loses his savings, the patient unreasonably refuses to pay his bills, or the impoverishment of the family if the patient requires nursing home care (Long Beach 37). Possible solutions discussed here are durable power of attorney, living trust, conservatorship, divorce (to protect the healthy spouse from poverty), and Medicaid. Taking action while the individual has the capacity to sign legally binding documents, will spare the care receiver and caregiver emotional stress and court hearings, i.e., conservatorship proceedings.

Lastly, this care guide deals with caregiver's feelings of guilt and grief, and caregiver stress. Many illustrations have already been discussed, however this care guide listed some additional ways to reduce stress. Planning ahead for difficult times reduces unexpected reactions to stress. Stress management through relaxation exercises such as meditation or visualization can be a way for the caregiver to deeply relax, which is essential. Writing one's feelings in a "poison pen letter" and tearing it up is a safe way to clarify feelings and relieve tension.

The Family Care Guide is used at Long Beach in conjunction with their Older Adult Health Services Program. Provided in this program are diagnostic evaluation, psychological services, support groups, a free health care program, emergency response system, and health education.

ADRDA - ST. LOUIS CHAPTER

"How to Cope With Alzheimer's Disease," is a training manual developed through the St. Louis Alzheimer's Disease and Related Disorder Association to provide education and support to health care professionals and family caregivers (Boyd i). There are two separate courses provided for professionals and families. The courses are made up of four - two hour sessions focusing on different aspects of "how to cope."

Some suggestions for an effective program are given. First, limiting participation to 15-20 caregivers permits a more intimate setting. Offering to arrange for a sitter in the home will increase the chances for a caregiver being able to attend. Providing training packets for each participant with literature about the disease and other resources is beneficial and increases understanding. This program has different speakers that cover each topic and a Program Coordinator to oversee the sessions. Pre and post tests are issued at the beginning of the first session and the end of the last to gage the impact of the program.

The "How to Cope" program is held in a variety of locations, thus allowing families equal access to sessions. Examples of areas used are the Alzheimer's Disease and Related Disorder's office, schools, churches and synagogues, community colleges, and senior centers.

While this program is quite similar to the others already discussed, there are some differences. The breakdown of topics is medical overview, communication, activities of daily living, and community resources and caregiving planning. A separate course called family dynamics is held for professionals in conjunction with the other topics.

The objectives of the Medical Overview are to distinguish between normal and non-normal aging, define dementia and identify several possible causes, explain how Alzheimer's Disease is diagnosed, and to give general descriptions of what Alzheimer's Disease is and is not (Boyd I-1).

The objectives of Session II-Communication are to provide examples of verbal and non-verbal communication, describe the type of environment most conducive for effective communication with an Alzheimer's Disease patient, describe some of the problems encountered when communicating with people who have Alzheimer's Disease, demonstrate effective ways to obtain the Alzheimer's Disease patient's attention, and name some of the emotions people with Alzheimer's Disease may experience (Boyd II-1). It is important to note that the things Alzheimer's disease patients can do are discussed, such as experiencing emotions, responding to voice tone and eye contact, performing simple tasks, enjoying previous hobbies if modified, and enjoying favorite foods and music (Boyd II-9).

Tips for dealing with common behaviors are listed. For apathy, the caregiver is told to try to stimulate the patient's interests, ask the patient to carry out simple tasks, or to ask the patient to "help" them. For restlessness and wandering, the tips are to offer comfort and reassurance, simplify and safe-proof the environment, respond calmly and gently, and to distract the patient (Boyd II-11).

Session III-Activities of daily living care provides caregivers with practical day to day management techniques. Perhaps an area worth detailing is the area of safety. Smoke detectors and fire extinguishers should be readily accessible and checked periodically. Families are encouraged to have Medic-alert bracelets for their Alzheimer's Disease patient, especially if an individual tends to wander. Falls are a common occurrence. Many falls can be avoided by removing obstacles such as throw rugs. Removing the knobs on the kitchen stove may help eliminate the possibility that the Alzheimer's Disease patient could start a fire or burn himself (Boyd III-9).

Finally, Session IV-Community Resources and Caregiver Planning is intended to provide practical information regarding legal and financial issues, and dispense information on available community resources. Upon completion of this session the participants will be able to identify at least one type of community respite and/or support service available for their needs, identify where they can find legal assistance, and distinguish between private vs. public methods of establishing legal control of the Alzheimer's Disease patient's affairs (Boyd IV/F1). Types of respite care described to the caregiver are adult day care, in-home care, and short-term residential care. The financial information is similar to previous programs mentioned.

The Alzheimer's Disease and Related Disorder's Association program has been very successful in helping caregivers, and the sessions continue to be available throughout the St. Louis area.

CONCLUSIONS

The information in the literature review makes it clear that caregivers of Alzheimer's Disease patients need support and training. Caregiving has received much attention of late due to the increased number of elderly people requiring assistance. Medical technology now keeps people alive long into their "old-old" years. Because of this growth, more and more families are going to be called upon to provide care. With this in mind, more effort and attention must be given to the growing concerns of caregivers.

Caregivers, mainly women, are facing the challenge of working outside the home, caring for their elderly relative, and raising their own family. The baby boomers are now better known as the "sandwich generation." They are trying to help their own children, live their own lives, and help their aging parents. Children may be motivated to help their aging parents by a sense of responsibility, duty, and guilt. They may also be motivated just as often by concern and love. However, when elderly parents become less independent, children may discover that love is not enough. Many feelings children have toward their parents in their later years are the same ones they always had , but they may have been able to push the feelings aside when they moved out of their parent's home. When the parent becomes debilitated, these feelings may resurface. At this time, the child is forced to deal with them.

Clearly, caregivers want and need support through education and training. The programs discussed have different approaches, but all have the same goal: to provide adequate training and preparation for a comfortable and positive caregiving relationship. This culminating project will be an incorporation of the ideas presented plus an attempt to develop a network within the educational program whereby caregivers will learn to rely more upon each other for support. The concept is similar to the sponsorship system that is so extremely successful within the Alcoholics Anonymous methodology. The hypothesis is that through the development of a "buddy system", caregivers will begin to develop a kinship for which they can draw from, in addition to the education/training that will be provided. The researcher will be surveying caregivers and fellow health care workers to finalize the scope of the training manual to follow.

RESEARCH PROJECT DEFINED

Upon completion of the literature review and an examination of the many caregiver issues, it became clear that a caregiver education program was needed. Therefore, a triangulated exploratory research method was employed. The instruments used were; interviewing, followed by a questionnaire, and participant observations of caregivers and patients by this researcher.

The caregivers have all been primary caregivers for an extended period of time. Due to the availability of these particular individuals and their relatives, this researcher chose ten people whose family members reside in the nursing home where she is employed. A further benefit of choosing these individuals was that this researcher could witness the relationships of caregiver/patient on several different occasions during visits. These particular caregivers continue to spend several days per week at the nursing home providing much of the same care they were providing at home. Parris-Stephens, Ogrocki, and Kinney indicate that caregivers who remain in close contact with their relative, even after nursing home placement, continue to have problems and concerns (331). The caregivers continue to feel an intense sense of guilt, usually because they feel they haven't done enough. Many caregivers continue to participate in the personal care of their relative, such as feeding him or her, taking the laundry home even when the nursing home provides this service, and grooming care. Many caregivers feel that even after nursing home placement, the majority of their time is spent with patient responsibilities. These may include paying bills, taking care of the patient's home or possessions, and visitations to the facility.

Expectations for this exploratory survey are that a family care program will be created with educational and support areas unique to the interests of caregivers. Within the support category will be the development of the sponsorship system, whereby caregivers will have one-on-one support from a fellow member. The sponsor will be a source of comfort even after the actual education program is completed.

Further expectations are that the caregivers surveyed would reflect similar interests and needs as those discussed in the existing programs. This guide will be an attempt to provide practical, easily accessible information on common caregiver problems and issues.

IMPLEMENTING THE RESEARCH PROJECT

Methods and Design

The first method employed was the interview. Three of the ten interviews were conducted in person and the remaining seven were completed by telephone. Prior to the actual interview, the researcher explained the purpose of this project to each caregiver. "Caregiver" was defined as one who provides care for a relative or friend through giving of their time, energy, and general assistance due to the person's illness or other limitations. The caregivers were aware that a follow-up questionnaire would be sent to them through the mail. All caregivers appeared eager to participate.

The interview schedule was intended to gather broad information about the caregiver. Information was collected on demographics, the caregiver's lifestyle, the relationship between caregiver and patient, their feelings about being a caregiver, caregiver self-care, and lastly, specific questions about the caregiver education program. Each caregiver was asked the questions in the same format. The researcher wrote the responses as the caregivers spoke. The caregiver did not see the interview schedule prior to the questioning, and there were no time limits given. The average interview time was 41.5 minutes.

The second method used was the questionnaire. Approximately two weeks after the interviews were conducted, questionnaires with cover letters were sent to the residences of the ten caregivers. The cover letters again explained the purpose of the research project and ensured the caregivers of their complete confidentiality. Return envelopes were provided in hopes of prompt return of completed questionnaires.

The questionnaire consisted of eighteen open ended questions, similar in content to the interview schedule. Areas of concentration were the caregiver's view of the relationship between him or herself and the patient, their feelings about being a caregiver, caregiver self-care, and again, specific questions about the caregiver education program. In both the interview and the questionnaire, the researcher encouraged caregivers to provide suggestions of topics for the educational program, beyond those provided.

The questionnaire had two purposes. First, this researcher was interested in studying consistency of responses, in comparison to the interview responses. Second, the speculation was made that caregivers would reveal more information in the questionnaire, given the lack of confrontation and luxury of time.

The final research method utilized was observation of caregivers and patients by this researcher. Due to limitations of time for this project and the fact that interactions between caregivers and patients are sporadic, the observations were somewhat limited. Consultations with other facility personnel, i.e., nursing, administration, were done to improve the scope of information. The major areas observed were frequency of visits, verbal and non-verbal communication, caregiver's interest in the patient's care, caregiver's involvement with the patient, and behaviors apparent during the exit from the nursing home upon each visit.

Results

This triangulated exploratory research methodology yielded ten caregiver interviews and ten observational studies. Six of the caregiver questionnaires were returned, or sixty percent. The results of each schedule have been combined to provide an overall picture of the responses.

The demographics studied indicate the average patient age is 83.3 years. The following Table 1 shows the scope of patient diagnosis in this study.

Table 1.

Scope of Patient Diagnosis

Diagnosis	Patient #'s
Alzheimer's Disease	4
Dementia (no known organic cause)	2
Stroke/Dementia	2
Heart Attack/Dementia	1
Alcohol Abuse/Dementia	1

The average length of time that these patient's have resided in a nursing home is 17.8 months. Prior to nursing home placement, one of the ten caregivers had moved the patient into her own home to live for a period of three years. The remainder had kept the patient in their own home. The majority (40%) had hired daytime home health aides through area agencies. Seven of the ten had used some form of outside assistance (Table 2).

Table 2.

Types of Outside Assistance Used Prior to Nursing Home

Outside Assistance	Utilization
Home health aide (4-8 hours per day)	4
None	3
Adult day care+home health aide	2
Full time live in assistance	1

Item 18 of the interview schedule and Item 5 of the questionnaire asked what the deciding factor was for nursing home assistance. Sixty percent indicated that physical decline and decreased ability to provide self-care were the key factors. Thirty percent stated that increased confusion and concerns for the patient's safety were deciding factors. The responses during the interview coincided with the questionnaire responses, however a new factor was mentioned. One person noted that outside sources, primarily the family physician, helped to finalize the decision.

The average age of caregivers studied was 61.8 years. Eight of the ten are married and fifty percent are still employed. Only two of the ten still have their own children at home. Eighty percent were born in the St. Louis area and all reside here now. In the area of self-care and support, seven of the ten caregivers have hobbies or outside interests that they enjoy. Eighty percent indicated a strong spiritual involvement. All of the caregivers stated that they have a close friend/confidant to discuss problems and successes.

Item 20 of the interview schedule and Items 7 and 8 of the questionnaire dealt with stress levels experienced by caregivers. The responses were conflicting. During the interview one-hundred percent stated that their stress levels had decreased since nursing home admission, but on the written questionnaire two of the six indicated otherwise. The researcher postulates the conflict in responses is from lack of confrontation during the written questionnaire. The respondents may have felt more at ease answering this question in private. When asked on Item 8 if there were areas that had increased, the following responses were given. Forty percent said there was no increase. Of the six that voiced concerns, one stated he still had no time for himself because he visits six days per week. One caregiver pointed out that some of the patient's clothing was missing from the nursing home which caused her added stress. Two people felt guilty that they weren't visiting enough, and the final two found stress was created when they discovered damage the patient had done before being admitted to the nursing home through mishandling of the finances. The patients had not relinquished control of these lifelong responsibilities until directly before nursing home admission. One of the caregivers even had to hire accountants to sort out their affairs.

Through the three research methods used, the relationships between caregivers and patients were thoroughly explored. Item 21 of the interview schedule and Item 4 of the questionnaire asked the caregiver how he or she felt about providing care for their relative (Table 3).

Table 3.

Caregiver Feelings About Providing Care

Responses	Caregiver #'s
I have no choice/There is no one else	6
I feel sorry/sad	2
I feel strained and resentful	1
I feel totally unsuitable for this role	1

These numbers indicate an overwhelming feeling of obligation that leads these people to their role as caregiver. Further, all ten caregivers in the interview phase stated that no one else in the family would takeover this role of caregiver. Item 9 of the interview schedule investigated the actual numbers of other significant family members (Table 4).

Table 4.

Significant Family Members Available to Assist

Other Family Members	Caregiver #'s
No family members	4
One family member	4
Two family members	0
Three family members	2

Caregivers were asked during the interview what they would like to change in their relationship with their relative. There were a variety of different feelings (Table 5).

Table 5.

Caregiver's Desired Changes in the Patient

Desired Changes	Respondents
For confusion to stop increasing	1
For patient to recognize caregiver	1
For patient to be more independent	2
"There has been a change. I can love her again without being resentful."	1
That caregiver lived closer to patient	2
"It's hopeless. We never had a good relationship."	1
To know how much patient comprehends	1
For the patient to be less unsettled and more content	1

During the observation phase, the relationships were further investigated. Fifty percent of the caregivers visit more than once weekly. During the visits, verbal and non-verbal communication were observed. Seven of the ten caregivers were openly conversing and fifty percent were touching during the interactions.

Regarding the patient's care, nine of the ten asked questions to staff about the care and the patient's condition. Fifty percent attend the care plan meetings offered by staff. Eight of the ten caregivers have attended the monthly support group already in place at this facility. Three of the ten take the patient out of the facility for short day trips. Four of the caregivers appeared visibly stressed when leaving the facility after majority of visits, while sixty percent appeared content.

The final area was an investigation of interests surrounding the caregiver educational program. The majority of caregiver's expressed an interest in such a program (70%). The majority of respondents agreed that they would enjoy guest speakers. Caregivers were given a total of fifteen topic choices, and were encouraged to include their own ideas for topics. In comparing the responses during the interview to those given on the returned questionnaires, inconsistencies occurred in two areas. These topics were "Information About Dementia", and "Legal Issues". Three of the caregivers indicated that these topics would or would not be interesting during one mode of questioning, then indicated differently later. There are many conclusions that could be drawn here; the respondents could ask detailed questions during the interview, which could affect their responses; the questionnaire was worded differently; or possibly the respondent felt differently about the topic after further consideration.

The final choices of topics for the educational program are to be drawn from the accumulation of caregiver responses during interviewing, the caregiver completed questionnaires, and from the observations completed by the researcher. The interests and apparent needs of the caregivers are many.

CAREGIVER EDUCATION PROGRAM DEFINED

Program Procedures

The caregiver education program is designed to provide knowledge and insight on topics common to caregivers of people with Alzheimer's Disease or related disorders. Through the triangulated exploratory research conducted, the program topics have been developed.

The program meetings will be held at an extended care facility. The program will be scheduled at one month intervals to be repeated quarterly. The Caregiver Education Program will follow the format below:

- Session I. Dealing with Behavior Problems
  - A. Effective Communication Skills
- Session II. Factual Data About Dementia
  - A. Definition of Dementia
  - B. Reversible Causes
  - C. Irreversible Causes
    - a. Alzheimer's Disease
    - b. Stages of Alzheimer's Disease
- Session III. Emotional Support for the Caregiver
  - A. Dealing with Guilt
    - a. Getting Rid of Guilt
  - B. Informal Support Group
- Session IV. Legal and Financial Issues
  - A. Durable Power of Attorney
  - B. Living Trust
  - C. Legal Guardianship

D. Advance Directives
  a. Living Will
  b. Durable Power Of Attorney/Health Care
E. Medicare/Medicaid

With the vast number of educational programs available that deserve merit, and the wide array of interests indicated by the caregivers, Session IV will alternate each quarter. The alternates are suggestions from caregivers during the research project, as well as areas that were included in the interview schedule that were not unanimous choices:

Assistance with Activities of Daily Living
Tips for Choosing a Nursing Home
Dealing with the Medical System/Medical Ethics
Death and Dying

Four sessions will be held, meeting on Wednesday nights from 7:00 p.m. to 9:00 p.m. The meeting place will be the education center at the nursing home for which this researcher is employed, as there are facilities available for video presentations. The social worker at the facility will be the program coordinator. She will oversee the program; schedule guest speakers; facilitate the support group; and arrange for sitters allowing homebound caregivers in the community to participate. While the education series will only be held quarterly, the informal support group will continue to be held once monthly throughout the year.

This education series will be available to the community, not just the facility's family members. Due to the affiliation with a nearby hospital, and it's subsidiaries, publicity will be widespread throughout west county. To allow for more intimate discussion, group membership will be limited to 15 people. Within the publicity information will be the phone number to the facility operator for making reservations.

Guest speakers will be obtained through, again the hospital affiliation, health care workers at the facility, the state ombudsman program, home health agencies, and the Alzheimer's Association. The program coordinator will be familiar with each program series to fill in if a speaker is unavailable.

The sessions will begin with an introduction of the program coordinator and guest speakers. The goal of the program will be announced: to allow family members and/or caregivers an opportunity to share their experiences and feelings while providing them an opportunity to be educated on a variety of topics pertinent to Alzheimer's Disease and related dementias. During each session, a question and answer period will be provided prior to closing. Each session will end with an announcement of the upcoming sessions. The program coordinator will solicit topics for session IV from the alternate list.

The following descriptions of the sessions are basic topics that will be covered. Dependent upon the particular guest speaker, the emphasis may be different or approached from another perspective.

Session I: Dealing with Behavior Problems

Patients with dementia, regardless of the cause, require special care and have unique behavior problems. In the early stages of memory loss, there are definite tasks family members can do to assist the patient, such as keeping items in the home in familiar places. Maintaining routines is helpful and can eliminate some feelings of frustration for the patient. Oftentimes in the early stages, family members may notice that the patient is trying to compensate for memory loss. Family members may see notes attached to the refrigerator, mirrors, or other areas throughout the home reminding the patient to do everyday tasks, keep appointments, or make phone calls. These notes are beneficial, because they may help the patient to hold on to their memories and mental capacities a little longer. Family members should encourage this as it is an aid for prolonged independence.

As the dementia progresses, other problems may start to arise such as wandering. It may be at this point that nursing home placement is considered. While the patient is still at home, and even after nursing placement, a major concern is safety. Within the home, pathways should be kept uncluttered. Throw rugs and foot stools should be removed to try to eliminate falls. Patients may wander to the point of exhaustion and need to be forced to sit for a time out to rest. When the patient is in a nursing home, this is easier to do with more supervision available and special chairs with trays to eliminate the patient from getting up immediately after being seated. While the person is still at home, the caregiver may purchase a geri-chair, a reclining chair with a tray that covers the lap. A less expensive item is a posey vest, which is a form of restraint. While this should not be used for extended periods of time, it may be helpful for short time outs when the patient has walked to the point of exhaustion. The patient's physician should be consulted for further advice regarding restraints.

Another consideration of safety with patients that wander is the possibility that they will get lost outside. Most nursing home have alarmed doors that are designed to prohibit this from happening, but in the patient's home other precautions must be taken. First, the patient can wear a special Med-Alert bracelet containing a pertinent contact name, address, and phone number. These can be purchased at the local drug store. Special bolt locks can be purchased that require a key to open. When someone has reached this point in their dementia, it is not recommended that they be left alone in the home for long periods of time.

Sleep disturbances are a common problem with the dementia patient. Sundowner's Syndrome is common to dementia patients, especially those suffering from Alzheimer's Disease. The patient seems to switch their days and nights. No cause or cure is currently known. When sleep does become unstable, wandering behaviors may occur at night. Caregivers can take precautions to help alleviate sleepless nights. The dementia patient should be kept as active as possible during the day and naps should not be encouraged unless the patient has exhausted him or herself from wandering. Some patients may be taking medications during the day that make them sleepy. In this case, the patient's physician should be consulted for a possible change in medication or scheduling.

Effective Communication Skills

Dementia patients begin to have problems with communication as their memory becomes increasingly impaired. The communication problems are twofold. The patient has problems understanding what others are saying, and the ability to express him or herself becomes difficult. With proper skills, the family member can decrease frustration for both parties. The primary tip is to remain calm and reassuring when approaching the patient. The following information regarding communication skills is adapted from the Alzheimer's Association "How to Cope" program:

TIPS FOR COMMUNICATING WITH THE ALZHEIMER'S PATIENT

Approach the patient from the front.

Move slowly and gently and try to avoid startling the person.

Establish and maintain eye contact.

Identify yourself by name.

Call the patient by name.

Keep tasks simple and manageable.

Praise successes and emphasize the positive.

If the patient becomes agitated, remain calm and reassuring.

Take a break and try again in a few minutes.

Talk to the patient as an adult, not as a child.

Keep your stress to a minimum, for feelings such as anger and frustration can be sensed (Boyd II-7).

Session II: Factual Data About Dementia

The key to understanding the dementia patient's behavior, begins with learning about the diagnosis. The term dementia describes a group of symptoms. It is not a normal part of the aging process. The information in this session will include the definition of dementia; causes, both reversible and irreversible; a description of Alzheimer's Disease; and the stages of Alzheimer's Disease. All of this information was provided in the literature review, pages 4 - 11, therefore it will not be repeated here.

Session III: Emotional Support for the Caregiver

Caregivers have a 24-hour job that is often thankless. They may lose sight of their own needs and as a result become resentful toward the patient. Caregivers therefore, are a high-risk group starving for emotional support. From the research gathered, it became clear that this session is needed, both from the verbalizations of caregivers and from their actions during interactions with the patients. As the patient becomes more confused, the caregiver feels more and more isolated. With dementia, the patient eventually requires continuous supervision unlike other illnesses that may afflict the family.

Dealing With Guilt

When caregivers decide that a nursing home is the only alternative for their family member, a whole new group of feelings come to life. Guilt is an emotion people feel when they think they have done something wrong. Caregivers often feel guilt because they believe they haven't done enough for the patient. When the person's disease nears the final stages, the caregiver may feel that nothing they do yields a positive outcome.

Upon the patient's admission to the nursing home, the caregiver's feelings of guilt, as well as hopelessness and anger, heighten. He or she is usually exhausted after several months of providing continual care with limited sleep. At this time the caregiver is most vulnerable to self-doubt. "How can I do this to my spouse, parent, sister." "I always said that I would never send her to a nursing home." These are common cries for help that need to be addressed.

Getting Rid of Guilt

Guilt is a common emotion for caregivers. While it is a very painful emotion to have to deal with, their is a positive side to it. Without guilt, the caregiver may never make the educated decision to place their family member in a nursing home. When the caregiver is overcome with the reality that they can no longer do enough, they are more easily led to the decision for long term care. In my experience as a geriatric social worker, over and over again families come to the nursing home with these overwhelming feelings and can see no end in sight. Invariably, time helps to ease these feelings. After three to six months, the caregiver's own life begins to become "normal" again, and the fog that has been guiding them all of those months prior to nursing home placement, is lifted. Granted there will always be incidents that bring the feelings back, and some people are exceptions to this, but as a whole time heals most of these wounds. Most of the exceptions to this are those people who don't get involved in outside interests and come to the nursing home nearly every day.

Some ideas for dealing with guilt are:

Grieve for and let go of the person who used to be and learn to relate to their current state of being.

Get involved in outside activities, through the church or synagogue, or a neighborhood organization.

Revive old friendships that have gone to the wayside during the intense days of caregiving.

Get to know the routines at the nursing home.

Establish a schedule for visiting that is convenient for you. (This doesn't mean you have to visit everyday).

Take advantage of the nursing home social worker, as he or she can link you to community resources.

Remember that with the bad comes the good. There will still be special moments to share with your loved one.

Participate in an informal support group.

Informal Support Group

The caregiver support group is a major part of the education program. This group will meet monthly at the same location. Due to the variety of educational opportunities available within the program itself, the support group will emphasize member involvement and an opportunity to ventilate feelings. The major objective is to provide an opportunity to express feelings, needs, and concerns in a supportive and non-judgmental environment.

The sponsorship concept shall take place within this group. The goal is to create a support network for caregivers struggling to cope with similar experiences. This buddy system will be voluntary, however the concept will be encouraged from the facilitator of the group as members join the group. To further support newcomers, information packets will be made available. Included in the packets will be a schedule of support group meetings, a fact sheet about Alzheimer's Disease and related disorders, a brochure from the long term care facility, a listing of reading materials available on pertinent topics, the facilitator's name and phone number, and the names and phone numbers of support group members who have voluntarily become involved in the sponsorship system and agree to provide said information.

The role of the facilitator is to oversee the meeting. The facilitator should encourage and allow all group members to participate in discussions. Once the discussion becomes active, the facilitator should allow members to share experiences and only step in if the discussion becomes one-sided or lacks group participation. The caregiver support group, being a part of the education program, should be facilitated by a professional. Professional facilitators, as opposed to caregiver facilitators, are better able to achieve objectivity, possess counseling skills, and have access to community resources.

Session IV: Legal and Financial Issues

The best advice for caregivers is to plan ahead with regard to legal and financial issues. If addressed in the very early stages of the dementing illness, unnecessary legal proceedings can be avoided. If these issues are faced while the patient still grasps the ability to understand, their true wishes can be declared and therefore followed through with later. Taking action while the person has the capacity to sign legally binding documents, could spare the family emotional stress during a crisis situation.

Many options for legal action are available. For this session to be effective, area attorneys will be sought to speak and offer insight. A broad, descriptive presentation should be given to this sensitive subject so as not to make caregivers feel they are obligated to one legal option or another.

When legal assistance is needed caregivers should first be advised to consult their family attorneys if they have one. If they do not have an family attorney, friends and other family members should be consulted for recommendations, as it is better to get personal references. A further option is to contact the Alzheimer's Association for they may have the names of attorneys who are particularly informed about issues relating to families suffering from dementing illness.

Brief Examination of Legal Options

A patient who is still considered competent may sign a general durable power of attorney, authorizing someone else who is of legal age, to manage their affairs and purchase or sell property. In order for this document to be legal the patient must sign it while still possessing a great deal of mental capacity. The power of attorney can be as broad or as limited as the patient desires. Ideally, the attorney-in-fact does not become decision maker until the patient is no longer competent.

A living trust is designed to transfer specific property from the patient to a trustee. The patient again must be competent to sign the complex trust instrument. The patient instructs precisely how the assets should be used and if the trustee doesn't follow these instructions, he or she is at risk for legal repercussions. As with the general durable power of attorney, the trustee does not have control over the patient's person.

When the patient has lost the mental capacity to make their own decisions, legal guardianship may be sought. At this point, an attorney must file a petition in court and a judge decides whether the patient is mentally capable of managing their own affairs. A guardian is assigned to look after the personal welfare of the patient and the courts supervise this management.

Advance Directives

Advance Directives are designed to allow the patient to have a pro-active role in their medical decisions. The patient must be competent to complete advance directives.

A durable power of attorney for health care or health care surrogate is similar to the general power of attorney, except this document strictly covers health care. The patient assigns someone to follow their wishes in regard to medical decisions. For this document to be legal, it must be notarized. It is possible for the two documents to be written as one if the same person is being assigned.

A living will is a document which can be written by anyone and should be as detailed as possible to be assured that the patient's wishes are truly understood. To be legal, the living will simply needs two witnesses. It is recommended that copies be submitted to the patient's family, physician, clergy, and if applicable, nursing home, to ensure that his or her wishes are known and therefore properly followed through.

Medicare/Medicaid

Medicare is a program of health insurance available to older Americans that is administered by the Social Security Administration. Medicare consists of two parts: hospital insurance and supplementary medical insurance. The supplementary medical insurance is optional and requires a premium. Under hospital insurance falls nursing home coverage, which is quite limited. To qualify for a Medicare certified bed in a long term care facility, one must meet certain criteria. First, the patient must have spent 3 consecutive days in a hospital within the previous 30 days. Next, the patient must be receiving skilled nursing care or skilled rehabilitation therapy while at the nursing home. Beyond these qualifications, the patient must continue to qualify, or a Medicare denial will be submitted to them. To continue to qualify, the patient must continue to require skilled nursing care on a daily basis, and/or skilled rehabilitation therapy five days per week.

Each Medicare recipient receives 100 days of coverage per "spell of illness". To break the spell of illness, the patient must be without skilled care of any kind for a consecutive 60 day span. This virtually means that the patient is receiving only custodial care; bathing, dressing, help with feeding, etc., during the 60 day span. If someone breaks their spell of illness, they receive a new 100 days of coverage.

While a patient is qualifying for a Medicare bed in a nursing home, they are only responsible for their personal needs; beauty shop, newspapers, etc. Of course, personal costs vary from nursing home to nursing home. When not in a Medicare certified bed, the cost could either be covered privately, or if the patient qualifies, through Medicaid.

Medicaid is also a government sponsored program, but the criteria is primarily based on finances. For a patient to qualify for a Medicaid certified bed, they must have only $999.99 in total assets. If the patient is married, the assets may be divided, to protect the spouse. The patient's house is exempt from the determination of total assets, as long as the patient came directly from the hospital, or directly from their home to the nursing home. The philosophy behind the home exemption is that the patient must have a place to go if he or she is to be hopeful of recuperating.

The patient and/or their responsible family member must make application for Medicaid at the local Division of Family Services office. Many nursing homes do not have Medicaid beds in their facilities, due to the low profit margin, therefore the search for a desirable facility becomes quite stressful.

Conclusions

There remains no question that caregivers of patients with Alzheimer's Disease and related dementing illnesses are affected emotionally, physically, and financially. Whether the patient is living at home or nursing home placement has been sought, many stresses are present. Education and training can help make the role of the caregiver less stressful.

The purpose of this triangulated survey was to learn more about caregivers of patients with dementing illnesses and to get their input for the caregiver education program. From the data collected, the caregivers feel a sense of obligation leading to their caregiving roles. The majority feel they have been thrust into this role, because their is no one else to do it.

The majority of the ten caregivers studied have outside interests, continue to work, or have a close friend/confidant to share their feelings. While nursing home placement has decreased some stressors, the caregivers continue to agonize over the patient's state of well being even after nursing home placement.

The goal of this program is to allow family members and/or caregivers an opportunity to share their experiences and feelings while providing them an opportunity to be educated on a variety or topics pertinent to Alzheimer's Disease and related dementias. The Caregiver Education Program will be a tool to help caregivers deal with the issues they face daily.

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