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Services Available to Alzheimer's Diseased Patients and Their Families

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ABSTRACT

SERVICES AVAILABLE TO ALZHEIMER'S DISEASED PATIENTS AND THEIR FAMILIES

One wants to be capable of handling every aspect of the disease we see today. One must also protect the client and health care professionals. The client must be allowed to live a productive and happy life. Unfortunately, because of the disease process, I feel it takes the client of the happiness they are entitled to. There will be insight as to how a family may cope with an Alzheimer's diseased loved one - how the disease will affect the family members - how the husband, wife, or children may cope with the unpredictability of an Alzheimer's patient - the changes that the patients/clients will experience.

In the field of health care, I have found varying correlation in the study of Alzheimer's Disease. What I have set out to accomplish is some understanding of the intricacies of the studies. However, I find it necessary to concentrate on the services available to Alzheimer's patients. I have found that the number of patients in nursing facilities are increasing. Also, yearly, large numbers of patients are diagnosed with signs or symptoms of Alzheimer's Disease. It's believed that the disease has relationship to previously termed Dementia. Dementia is not a disease in itself, but a group of symptoms that have characteristics of various diseases and conditions.

Ricky A. Fielder, B.A.

An Abstract Presented to the Faculty of the Graduate School
of Lindenwood College in Partial Fulfillment of the
Requirements for the Degree of Master of Science

1990

ABSTRACT

The focus of this project is an overview of services that are available to Alzheimer's Disease clients. Since our society has seen an increase in the number of patients diagnosed with the disease, it's necessary to plan into the future and direct our goals in providing good health care.

One wants to be capable of handling every aspect of the disease we see today. One must also protect the client and health care professionals. The client must be allowed to live a productive and happy life. Unfortunately, because of the disease process, I feel it robs the client of the happiness they are entitled to. There will be insight as to how a family may cope with an Alzheimer's diseased loved one -- how the disease will effect the family members -- how the husband, wife, or children may cope with the unpredictability of an Alzheimer's patient -- the changes that the patients/clients will experience.

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COMMITTEE IN CHARGE OF CANDIDACY

Advisor: Professor James A. Myers, Ph.D.
Chairman: Advisor

**SERVICES AVAILABLE TO ALZHEIMER'S
DISEASED PATIENTS AND THEIR FAMILIES**

Advisor: Professor George F. Gorman, M.A.

Ricky A. Fielder, B.A.



A Culminating Project Presented to the Faculty of the Graduate School
of Lindenwood College in Partial Fulfillment of the
Requirements for the Degree of Master of Science

1990

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Adjunct Professor Cristle Coleman, M.A.

DEDICATION

This work is dedicated to my loving wife, Margaret, who has dedicated herself to me, our children and my educational goals. For listening when I needed her, and keeping me moving on the right track. To my children, Elizabeth, Robert, Kimberly and Rebecca who have tried to understand why Dad went to school. My Mother, who has been there when she had hard times herself. I love all of you.

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*The above Tables list various health care facilities that provide services to Alzheimer's Disease patients. Within the tables are listed the names of the facilities, their fees, required level of care, day/hours of operation, etc. If further information is desired, one may call or seek information by writing the individual health care facilities. The recommendation for informational services by A.D.R.D.A. is subject to change.

CHAPTER I

INTRODUCTION

Alzheimer's Disease has had an increasingly profound impact on our society. The continued increase in patients presumed to have Alzheimer's has steadily increased each year. Scientists have made significant advances in their understanding of Alzheimer's Disease. It affects on more than 2.5 million American adults. Researchers have focused their work on the cause of Alzheimer's Disease and its cure. The ultimate goal will be to define an adequate cure for stricken patients. We will continue our efforts of providing good care and improving the lives of these patients. We will need to show support and care for these patients until a cure is discovered. Furthermore, one needs to be concerned with the life expectancy of Americans and the number of patients we will see with Alzheimer's Disease. Due to the increase in the life expectancy of Americans, the medical professionals must broaden their services. Since Alzheimer's Disease is rapidly being pre-diagnosed in Americans, there needs to be more emphasis on Alzheimer's care units. These care units should direct their care toward the patient and their immediate families. The families of Alzheimer's patients need to understand the disease also. Their total understanding of the disease will possibly decrease some of the discomfort one experiences when a loved one has signs or symptoms of Alzheimer's Disease.

Missouri has some regulations that govern the health care facilities that these patients live in. There are rules that outline safety, health care procedures and operations of facilities that have Alzheimer's Disease patient units. Some health care groups may shy away from this type of service

because of the requirements for caring for these patients. The various types of health services required for effectiveness make it necessary for providers to remain competitive. This requires quality care at minimal cost to all parties. To operate a facility in this manner becomes more difficult when you consider all the factors involved.

It was first described by German physician Alois Alzheimer in 1907. Then, Alzheimer's Disease was considered a rare disorder. Today it is recognized as the most common cause of dementia. The disease, first defined as "senility," had effects on the non-aged and elderly population. The disease was generally identified as senile under the age of 65.

Dementia is not a disease itself but a group of symptoms that characterize decline and problems. In Alzheimer's Disease, there is a decline in intellectual functioning that is severe enough to interfere with one's ability to perform their routine activities.

Alzheimer's Disease can be distinguished from other forms of dementia by the characteristic changes in the brain that are usually visible upon microscopic examination after death.

Due to more recent studies by scientists in the 1980's, there have been other important discoveries. For example, there was evidence that there existed a defect in a gene on the chromosome 21. However, until recently, it was not of this size. There are probably many patients suffering from this disease that have yet to be truly diagnosed. "Approximately 60 percent of all nursing home residents have some degree of mental impairment, with Alzheimer's Disease probably being a major reason for admissions" (Heisberg, p. 11). Of these admissions, it is assumed at about 25 percent of those 60

CHAPTER II

ALZHEIMER'S DISEASE

Alzheimer's Disease (pronounced Altz'-Hi-Merz) is a progressive, degenerative disease that attacks the brain and results in impaired memory, thinking and behavior. It affects an estimated 4.0 million American adults. It was first described by German physician Alois Alzheimer in 1907. Then, Alzheimer's Disease was considered a rare disorder. Today it is recognized as the most common cause of dementia. The disease, first defined as "dementia," had affects on the middle-aged and elderly population. The disease was generally classified to those under the age of 65.

Dementia is not a disease itself but a group of symptoms that characterize disease and conditions. In Alzheimer's Disease, there is a decline in intellectual functioning that is severe enough to interfere with one's ability to perform their routine activities.

Alzheimer's Disease can be distinguished from other forms of dementia by the characteristic changes in the brain that are usually visible upon microscopic examination after death.

Due to more recent studies by physicians in the 1980's, there have been other important discoveries. For example, there was evidence that there existed a defect in a gene on the chromosome #21. However, exact research is unclear at this time. There are probably many patients suffering from this illness that have yet to be truly diagnosed. "Approximately 50 percent of all nursing home residents have some degree of mental impairment, with Alzheimer's Disease probably being a major reason for admissions" (Reisberg, p. 11). Of these admissions, it is present in about 25 percent of those 85

years old or older. The disease can occur in the middle ages also. There has been a case where a 28-year-old patient had Alzheimer's Disease.

The signs and symptoms have been associated with past illnesses. For example, earlier scientists in the 1800's have associated these "symptoms" as those like dementia illnesses. These symptoms (conditions) are found in patients with depression, drug reaction, thyroid disorders, brain tumors, alcoholism and others. Alzheimer's is a long and devastating disease. This disease has been known to survive for as long as 25 years in some patients. It not only affects the patient, it also affects the entire family in some way. The family members have/show difficulties in dealing with loved ones stricken with this disease. Their inability to cope with the patient is devastating to most. The patient can't remember who family members are, they become combative, and ignore the family members who visit them. The patient will wander aimlessly about. These activities are a few found within Alzheimer's patients.

The Disease Process

Alzheimer's Disease is a progressive, irreversible brain disease for which there is currently no known cause or cure. The patients will generally proceed through three stages. They may overlap from one stage to the next. The first stage consists of signs or symptoms as follows:

- A. Memory loss/forgetfulness
- B. Impaired judgment
- C. Depression
- D. Can't perform activities of daily living (i.e., comb hair, bathe, cook, brush teeth, etc.)

The biggest concern is the memory loss -- the patient can forget important details that get them through the day. Next will be the inability of a patient to bathe and care for themselves as they did previously. The family starts to show concern now, because of their mother/father having offensive odors and looks when up and about. It's not that the patient won't bathe -- it's just that they forget or think they may have just had a bath.

In the second stage, the signs or symptoms from stage one become more severe. With this severity comes other related problems. For example:

- A. Restlessness
- B. Wanders about aimlessly
- C. Muscle dysfunction
- D. States of confusion
- E. Seizures

In this second stage, the patient will wander about continuously. He/she may sit or rest for very short periods. The Alzheimer's patient may wander outside of the home or facility and become lost. When questioned, they may present signs of other diseases. For example, the patient may appear to be intoxicated or may have seizures if they become unconscious. Muscle dysfunction can be periods of weakness, to loss of bowel control, not to mention others. What is necessary to remember is an Alzheimer's patient may exhibit signs of other illness also. It's necessary to seek appropriate medical attention at all times. If you fear a loved one has signs or symptoms "like" these, it must be confirmed by a physician.

In the third stage of the process, the patient:

- A. Is completely dependent on others for safety, welfare, care, etc.
- B. Becomes emaciated.
- C. Can't recognize themselves or loved ones.
- D. Suffers loss of body functions.
- E. Is completely disoriented to person, place and time.

These patients forget to eat, drink and sleep at times. They become difficult for family to care for. These patients lose weight, become combative to others, and fear their loved ones are enemies. I have seen patients in this stage that would stand and talk to themselves in front of a mirror. They sometimes don't recognize themselves when they see their own picture.

This third stage is of greatest concern for the health care professionals. One tries to provide services for problems which they cannot readily define. One constantly tries to reassure those patients and their families on their debilitating disease. These patients in earlier stages need constant interaction with people, but in the advanced stage the Alzheimer's diseased patient can't tolerate the interaction very well.

The Alzheimer's process affects all social and economic boundaries. It affects men and women almost equally. Most victims are over the age of 65; however, Alzheimer's Disease can also strike those in the 40's to 50's. Most of these patients are cared for at home. Approximately 70 percent of the care for these patients are given by the victims' families at home. The other 30 percent of the patients are cared for in a skilled nursing facility.

Alzheimer's Disease affects all walks of life. The signs start with forgetfulness and depression. In my project, I have found senility to rank high among all nursing home residents. This is followed by arthritis which plaques 38.5 percent of all patients and heart ailments ranked third, affecting 33.5 percent of all patients. Many researchers felt that Alzheimer's Disease ranks among the top in many age-category illnesses. Senility was used in terms as "an infirmity of the mind which is frequently associated with aging." Reisberg stated, "If the term were used in this sense, then senility would affect 58 percent of the more than one million Americans in nursing homes, making it, according to government health survey, the most common chronic illness to strike them" (p. 3).

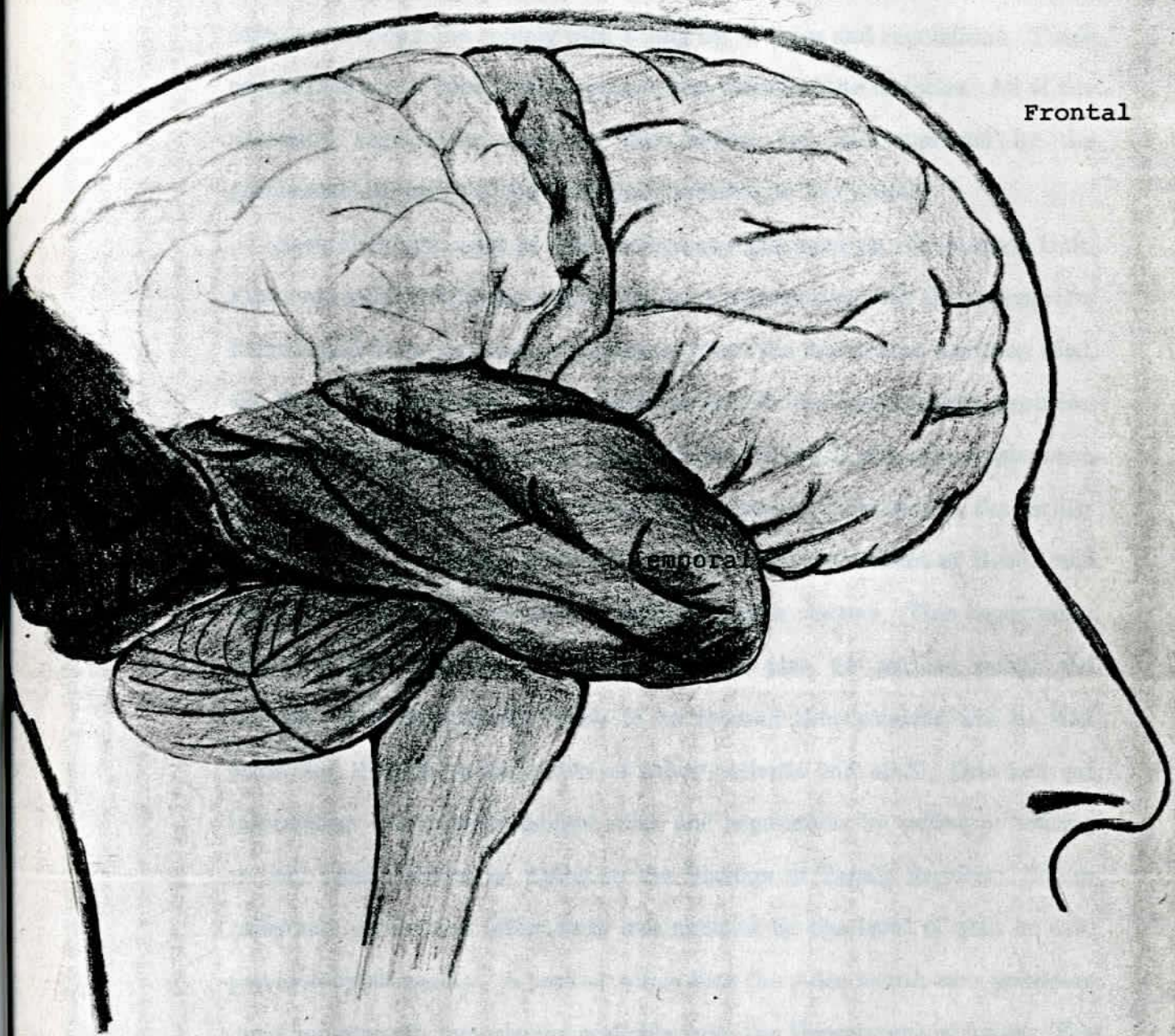
Senility was once thought to be a precursor of Alzheimer's Disease. However, that fact was laid to rest years ago.

Study has shown researchers that the most severe area of the brain affected was the forehead -- the region of the frontal lobe and at the temporal regions. Then eventually the entire brain was affected. Clinically speaking,

"Alzheimer's Disease remains a diagnosis of exclusion during an individual's lifetime. A physician is obligated to consider a diagnosis of Alzheimer's in any patient with slowly progressive intellectual impairment occurring in middle or late life" (Reisberg, p. 77).

GRAPH OF BRAIN

Areas of Brain Most Frequently Affected



Emv

CHAPTER III

GOVERNMENTAL REGULATIONS

Governmental regulations cover all types of public services. The health care professions must comply with a long list of rules and regulations. These regulations range from bookkeeping to the wiring of the facilities. All of the necessary regulations must be met before you are approved by the government to operate and offer your services to the public.

Several things must be done before one can open an Alzheimer's Unit. First, you must submit an application for a new service with the appropriate Federal and State government agencies. Once the application has been filed, the facility will be open for inspections by all local government agencies. These inspections are designed to ensure the facility is properly constructed. The building, electric, plumbing and fire inspectors have to give the facility approval prior to opening for business. Also, the Department of Health will inspect the facility for compliance with all health matters. This department regulates the cleanliness, safety and entire plan for patient safety and welfare. The department needs to be assured that patients will be well cared for, as well as the safety of other patients and staff. One can get information about governmental rules and regulations by calling or writing to your local Division on Aging or the Division of Family Services. These rules and regulations differ from one another by the level of skill or care provided by an agency. A booklet which lists the rules health care providers must comply with may also be available from the Department of Aging. The "providers" are the health care companies/agencies that give direct care to patients. An agency must also provide the client or patient with a list of

patients' rights. A list of patients' rights must be displayed for public view within the facility. The Federal and State agencies are strict with enforcing these rules. The Bill of Rights were developed by the Department of Health, Education and Welfare in 1974. Many of these rules and regulations provide and protect Alzheimer's diseased patients while in a health care facility also. Therefore, family members can rest more easily, knowing that there are others who care about their loved ones while in a health care facility. Also, because of Alzheimer's patients not being able to fully protect themselves, there have been legislative bills designed to protect them. These patients can have their needs known to Federal, State or local policy makers. This can be done with assistance of the Alzheimer's Association. The Association presents legislators and presidential representatives with plans of action almost annually. There has been action supporting research, services and long-term care financing. What is important is to keep the cost of care and services affordable to many if not all Alzheimer's Disease patients and their families.

Most recently the Alzheimer's Association had several different Bills presented during the 1990 Legislative Session. There were three Bills introduced. The list included:

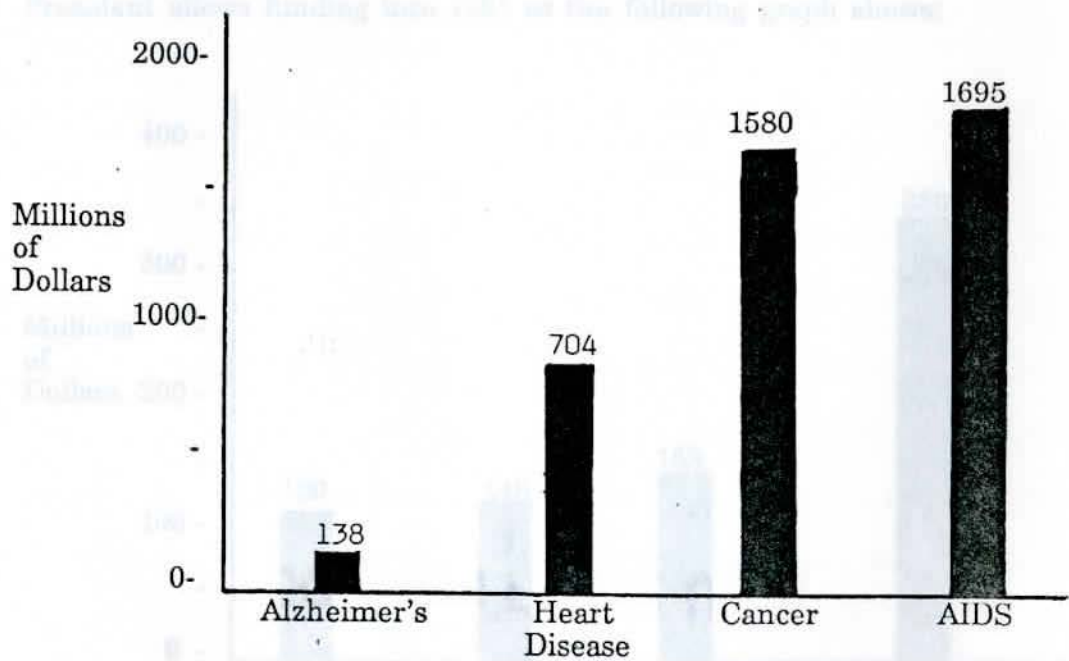
- A. HB 1323 - Alzheimer's Advisory Council -- SB Companion Bill. This Bill would allow for the establishment of an Alzheimer's Advisory Council that would:
1. Provide State wide information on the issues that relate to the Alzheimer's Disease patients.
 2. Provide a link between family and professionals.

3. Promote training within community agencies.
 4. Continue predetermined plans by the Missouri Task Force on Alzheimer's. (Missouri Alzheimer's Association, April 1990, Volume XVII, #16)
- B. SB 508 - Health Care Surrogate. This Bill would allow for the designation of a "surrogate" (caregiver/family member) to make the necessary health care decisions for an adult Alzheimer's Disease patient, either through a living will, power of attorney, or by legal documents, if necessary. (Missouri Alzheimer's Association, April 1990, Volume XVII, #16)
- C. Also, HB 1174 - Protective Services Bill, set out to provide for:
1. Requires professionals to report suspected abuse or neglect of persons over the age of 60. Any person who fails to report any action of this type will be guilty of a Class A misdemeanor.
 2. This Bill also provided immunity from liability, civil or criminal action, of any official, person or institution reporting abuse or neglect of a patient. (Missouri Alzheimer's Association, April 1990, Volume XVII, #16)

The Alzheimer's diseased patients need these protective devices available to them. Unfortunately, the Health Care Surrogate was defeated in the Senate; the Advisory Council and Protective Services remain in Committee. One must remember that these services are to protect patients who can't protect themselves because of the debilitating affect that Alzheimer's has over them. Other legislation that will be addressed are patients' rights to self-determination, dealing with issues such as living wills, health care cost

and patient rights. Currently, Alzheimer's Disease research receives less than other illnesses.

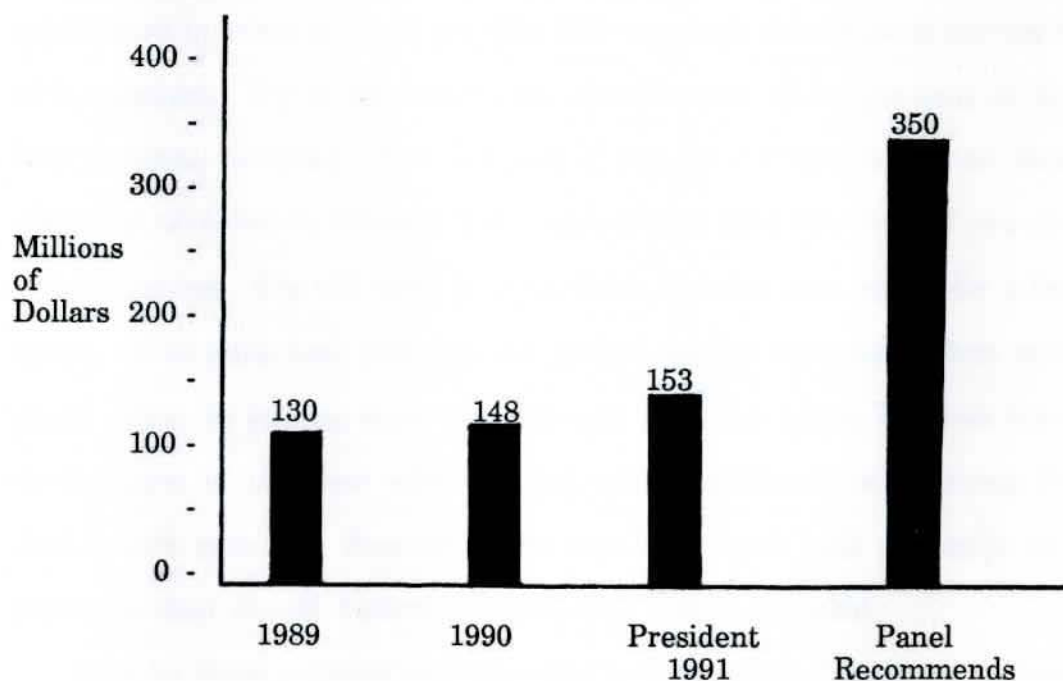
Alzheimer's researchers receive a small amount of Federal funding when compared with the disorders. Currently, heart ailments, Cancer and AIDS research receive larger portions of Federal assistance for their research. Alzheimer's will receive approximately \$138 million for fiscal year 1991 and AIDS will receive approximately \$169.5 million. The funding for Alzheimer's is minute when you think about the vast numbers of Americans being affected by Alzheimer's Disease.



From A.D. - 1990 June

It would be unsympathetic for me to say that AIDS doesn't need all the allocation it receives for research, but realistically I feel Alzheimer's Disease needs a comparable amount of funding to find a cure for Alzheimer's Disease.

Federal support for research on Alzheimer's Disease has had a small increase since the 1989 projected budget. Federal support is necessary with all major illnesses. However, major illness here should represent any illness that affects 15 percent of American people. The support that the Federal government is allowing is: \$130 million for 1989, \$148 million for 1990. The President allows funding into 1991 as the following graph shows:



From A.D. - 1990 June

The graph presents the continued need for Federal funding for research directed toward a cure for Alzheimer's Disease. The Alzheimer's Panel suggests twice as much funding as the President is allocating for the year 1991. The funding needs to continue on an as needed basis until a cure has been found. We, as Americans, don't want to see loved ones suffering from this dreaded disease.

There are many private care facilities across the country that assist Alzheimer's patients. These companies will give you a list of facilities in your area and they will also help you find the best one for your loved one. Many of these companies help the patient in their own homes. Some of these companies help the patient in a nursing home, for example, both and also you can be a caregiver. There are also several private individuals that will care for their needs. Due to the rising numbers of Alzheimer's patients being cared for today, caregivers are working at a fast pace. However, because of the special care that these patients need, it's best to research several caregivers before choosing a care provider. One would need to select the best provider that can more closely meet the needs of the patient. Try to also match the overall needs of the patients to the best qualified company. For example, if you have a relative in the later stages of Alzheimer's Disease, don't let a friend care for them if you can get shopping. You will need to visit them in a day care center for a few hours. This gives both you and the patient quality time apart from each other. Also, by getting them out of the house for a few hours, it gives them the care of someone who has had some experience with caring for Alzheimer's patients. Because of the care they need both physically and mentally, they should deserve the best care that is available.

Care for these patients vary according to their needs. There are nursing care facilities, physical therapy, day care centers, skilled care centers and other services available if needed. Each different category of caregivers have

CHAPTER IV

HEALTH SERVICES AVAILABLE TO
ALZHEIMER'S DISEASE PATIENTS

There are many private and public health centers that assist Alzheimer's patients. These companies and groups assist in finding day care centers and care facilities/nursing homes. Many of these companies help the patient do housework, fix meals, bathe and also just be a companion. There are also several private individuals that will care for their needs. Due to the rising numbers of Alzheimer's patients being seen today, companies are evolving at a fast pace. However, because of the special care that these patients need, it's best to research several companies before choosing a care provider. One would need to select the best provider that can more closely meet the needs of the patient. Try to also match the overall needs of the patients to the best qualified company. For example, if you have a relative in the later stages of Alzheimer's Disease, don't let a friend care for them if you are gone shopping. You will need to place them in a day care center for a few hours. This gives both you and the patient quality time apart from each other. Also, by putting them into day care for a few hours, it places them in the care of someone who has had some experience with caring for Alzheimer's patients. Because of the care they need both physically and mentally, they should deserve the best care that is available.

Care for these patients vary according to their needs. There are nursing care facilities, physical therapy, day care centers, skilled care centers and other services available if needed. Each different category or caregivers have

special services that are available for most Alzheimer's patients. Others may need a skilled care facility to give them care 24 hours a day. One may choose to just have a respite care provider.

Check List for Selecting a Nursing Home

Selecting a good nursing home for a loved one or yourself can be very upsetting. However, if you know what to look for and what to ask you can decrease the anguish. Follow these steps when choosing a facility. By following these steps you can rest assured that all the major considerations have been addressed.

You would want to compare the responses from several institutions. This will allow one to choose the most qualified facility to meet your needs.

- A. Does the facility and administrator have licenses to operate?
- B. What is approximate amount of time to wait for placement in each facility?
- C. What are the costs of care?
- D. Are they certified to offer Medicaid?
- E. Ask if it's a Residential Care facility, Intermediate Care or Skilled Care institution.
- F. What is nurse-patient ratio? (How many nurses to care for how many patients per unit?)

The next step will be to make a visit to the institutions.

- A. Are there odors and is facility clean when you arrive?
- B. Are there appropriate areas and how are they furnished? Check dining area, rest areas, bedrooms and recreational areas.
- C. Make sure there are fire extinguishers and other emergency exits.

D. Does the institution have safety equipment installed in halls and patient use areas? (Handrails, emergency call buttons, bath mats, side rails and fire alarm switches in compliance with State and Federal regulations)

Finally, before one places a family member or relative in a facility, ask the following questions:

Narrow your choices down to those you are comfortable with. Call to make appointment to speak with the Facility Operators, Administrator, Nursing Director, admission staff and dietary staff, if needed. Remember, this institution will be caring for someone you love. Don't be afraid to ask questions. If you should forget, call the institution and ask your question. Don't go on blind assumptions. You should ask about the policies and procedures for visiting, complaints and nursing staff. Is the facility monitored by State and Federal authorities? If so, ask to see a copy of the last inspection report -- this is available upon request. This report will give you an insight as to how the institution operates overall.

Nursing Care

When and if you decide you need a nurse to care for your family member, you must make sure he/she has had prior experience working with Alzheimer's patients. Nurses must be well educated for this specialized area. The nurses must be aware of the continual change in these patients. The nurses must be attentive enough to see the sudden changes that can occur and be able to respond to the patients while in this transition. The patient will need to be brought back to reality and one must be careful not to embarrass the patient in any way. Once a patient feels uncomfortable,

he/she will lose confidence in the nursing care system. These patients need to be supervised at all times.

Some Alzheimer's patients will put on numerous articles of clothing. They will unconsciously put on two or three shirts or three or four pair of undergarments. The person may have a feeling of fear. They will wear most, if not all of their personal belongings. Fear of being robbed or of being left alone are some of the more common fears a patient may experience. The nurse must also be open minded and not make a big issue over patient activities. Because of the patient's unpredictability, the medical professionals must be understanding. This understanding must not only be for the patient, but also for the process that causes this condition of Alzheimer's.

Long-Term Care

The long-term care of Alzheimer's patients will vary with the stage of the patient's illness. For example, in the early and middle stage the patient will need minimal care or assistance. However, in the later stage of the disease, patients will need total care. This care will include feeding, bathing and dressing daily. Generally in the later stage, most patients have a hard time coping. Their lives have changed drastically. They have been independent and now they have to depend on others to do everything for them. The cost for this kind of care can be quite high. One must also provide "necessary" care for all patients. For example, establishing and maintaining a program of physical exercise for patients. Walking, jogging,

swimming and dancing are activities that are advantageous for an Alzheimer's patient. The program must be kept at a tolerable level as not to bore the patient. They must be made to feel needed.

In the later stage, these patients will, "have multiple physical illnesses that incapacitate them and often severely limit their activities. However, certain exercises can be done in a bed or wheelchair or maintain body tone and circulation" (Cohen, Eisdorfer, p. 103).

Long-term care must be maximized, because these patients are more susceptible to infection, poor circulation and bed sores. This care must also be directed at rehabilitation and diet. When rehabilitating the patients, we must look at the patient's condition and what would be a reality goal. Don't place false goals on the patients. For example, don't tell a bedridden, constricted patient that he/she will walk in two or three weeks. This is totally unrealistic for them.

When planning the long-term patient's diet, we must also determine the patient's ability and activities. Is the patient somewhat active or totally bedridden? The diet must be high fiber quality. These are just a few of the areas of concern for long-term care patients.

Care providers must provide a safe facility with a caring environment for the Alzheimer's patient; whereby allowing a patient to maintain dignity and to continue as full a life as possible. We must feel this is a goal that can be accomplished.

Once that mission is planned, one needs to organize the project. There are a number of other forces that would have an impact on this project/mission. For example:

- A. Philosophy and conduct of ownership and management;
- B. Quality of professional staff and management of patient care;
- C. Range of activities and programs;
- D. Patient participation and involvement;
- E. Resident/staff relations;
- F. Physical plant and housekeeping;
- G. Food services;
- H. Design and accessibility;
- I. Community ties;
- J. Professional affiliates;
- K. Cost of operation.

These are some of the organizational factors that were readily identifiable when trying to organize the project which must be fully analyzed before implementing.

Next it is necessary to have a staff that is willing to explore the possibilities of providing this service. Once we have the major short and long-range goals "bug free," we must organize all levels that this service will have an effect on -- such as Directors, Nursing Staff, Security, Food Services, and Housekeeping. Every division of the facility must be advised of the plans for the service. Once everyone has been informed of the plans, each department should submit a detailed report of what they will need and do to successfully carry out their part of the new plan.

The staff must be assured that the new services are of great importance if their facility is to remain competitive in the health industry. Budget and cost personnel must be available for input on expenses and profit matters.

Next we concern ourselves with market strategies to attract the clientele to the services. If one of our functional areas fails to do its part in the planning, the entire venture could be in great danger of folding.

Safety

Safety is a major area of concern for everyone. The patients must be protected from the surrounding environment and from themselves. For example, a patient in a near normal state may drink his/her coffee somewhat hot; this person is able to control the cup and their actions. On the other hand, if a patient is in a later stage, he/she may have to be served slightly warm coffee, as they may not be able to hold or handle a hot cup. Safety comes with preventing these patients from becoming victims of burns or other injuries. If a patient walks on a wet floor they are likely to be injured. Fractured hips, broken arms and/or legs are frequent types of injuries these people suffer. The unsteadiness and shaking that the disease creates is a great danger in itself. The hands and body are severely unsteady in the Alzheimer's patients. They can go from a mild jerking of the hand and head to spastic signs of advanced stages. These patients must be on a "locked" unit. This will prevent people from wandering and becoming lost. These kinds of patients have been known to leave a facility and be found several miles away from home. Loss of memory is a characteristic that aids in the unsafe manner in which these patients live.

Therapy and Activities

To help keep these patients willing to remain motivated, we must have planned activities for them. They must continue to socialize and do as much as they can to entertain themselves. They must be mobile and be with

other patients. They can play cards, bingo or other games to keep their minds busy. They need to go on daily walks, or watch a movie the facility would show for all their residents. The exercising of the mind and body is an important part of the patient's rehabilitation and to help them cope with their individual situations. All these things need to be part of the overall plan of the patient.

There are many community groups that provide services to those prospective patients. These groups will provide nursing care, cooking and other meaningful activities. The major goal is to provide the best care for the client. There are day care services for adults that will "watch" or care for your Alzheimer's services level user. The day care center provides social activities for all their clients. There is also private care services, live-in services, educational services and institutional services. The community offers a number of choices to the patient and their family. Depending on the level of need of each individual, one must choose the fitting type of care.

Private Care

Private care services are available if family or patient want to remain in their own homes. These services are provided by private, public and institutions that give care to Alzheimer's patients. Whenever a patient contracts for private care, they are the one who decides upon their own care.

CHAPTER V

COMMUNITY SERVICES AVAILABLE TO
ALZHEIMER'S DISEASE PATIENTS AND FAMILIESCommunity Services

Within one's own community there are several organizations that can assist an Alzheimer's patient. These organizations can provide one with service providers with experience on Alzheimer's Disease. One can call your local religious affiliation or parish and express an interest in getting help. If someone within your church can't help, they may be able to contact others who can. One should remember that there is assistance and help available if you pursue your leads. It can be a long and tiring process. Whatever happens, keep seeking help until you find what help is required.

There are many community groups that provide services to these prospective patients. These groups will provide nursing care, cooking and other meaningful chores. The major goal is to provide the best care for the client. There are day care services for adults that will "watch" or care for your Alzheimer stricken loved ones. The day care center provides social activities for all their clients. There is also private care services, live-in services, educational services and institutional services. The community offers a number of choices to the patient and their family. Depending on the level of need of each individual, one must choose the fitting type of care.

Private Care

Private care services are available if family or patient want to remain in their own homes. These services are provided by private, public and institutions that give care to Alzheimer's patients. Whenever a patient contracts for private care, they are the one who decides upon their own care.

Most private care patients are in the early stages of Alzheimer's Disease. The largest majority of these people just want someone to be with them. Because of the episodes of forgetfulness, the patients begin to have fears. These clients usually will do something and then wonder why they did it in the first place. They are known for calling a friend or family member, then they will ask the other person why they have called them (the Alzheimer's patient). When this starts to happen, the family begins to show some concern. The private care provider can have a worker come to sit with a patient while the family is away. The worker can take the patient for a walk, do some household chores or just be a friend for the patient if that's what is needed.

This type of care can be more expensive than other types of care, so the private care payee should get the most service possible for their dollar. When contracting for private care services, one must make sure that the care providers are familiar with Alzheimer's patients and their needs. Many of the private care providers will base their services on the stage of the disease the patient is in. Of course, the more care that is required, the higher the cost. For example, private providers may have requirements for their services. The client must:

- A. Be able to ambulate;
- B. Be able to feed themselves;
- C. Be able to participate in activities;
- D. Be able to go to the rest room without assistance; and
- E. Be non-combative.

These are just a few possible restrictions a private provider may insist upon before giving care to a patient. In St. Louis alone, there are 50 to 75 private care providers. Each has different missions. When selecting a private care provider, one should get all the information available about the provider. Don't be afraid to ask questions about the type of care they will give. Remember your loved one will be the recipient of such care.

The cost will fluctuate with the level of and the length of care provided per day. There will also be a difference in price between organizations providing the care (See Table 1 for providers of in-home care). The private or institutional care provider may be selected for giving services. The family will need to consider the patient's stage of Alzheimer's before choosing a provider. One may want private care so the patient can remain in a home setting. There are quite a growing number of patients choosing private care services for this reason throughout the State of Missouri. The care providers will respond to the overall need of the client, such as:

- A. Provide a single meal
- B. Take combative clients
- C. Take incontinent clientele
- D. Provide counseling and support
- E. Provide workshops
- F. Provide games and activities

The private care workers are not as experienced as institutional providers, however they do provide services for many Alzheimer's clients.



A SAMPLE OF IN-HOME RESPIRE SERVICES AVAILABLE



ST. LOUIS CHAPTER

A SAMPLE OF ST. LOUIS HOME HEALTH AGENCIES:		MEDICARE CERTIFIED	MEDICAID CERTIFIED	YEARS SERVING ST. LOUIS	GEOGRAPHIC AREAS SERVED					RESPIRE SERVICES AVAILABLE (PRICES SUBJECT TO CHANGE)				CARE EVALUATION BY RN OR MSW	EMERGENCY CALL-IN AVAILABLE	REFERENCE CHECK	POLICE RECORD CHECK	MALPRACTICE/LIABILITY COVERAGE	BONDING	WORKMEN'S COMPENSATION	EMPLOYER TAXES	LICENSING OR CERTIFICATION IF CARE PROVIDERS	EXPERIENCE WITH DEMENTIA	TRAINING ON DEMENTIA		
					ST. LOUIS CITY	ST. LOUIS COUNTY	ST. CHARLES COUNTY	JEFFERSON COUNTY	FRANKLIN COUNTY	METRO-EAST ILLINOIS	PERSONAL CARE (Bath Service, etc.)	HOMEMAKING	COMPANION												LIVE-IN	
											COST/HOUR MIN. HOURS	COST/HOUR MIN. HOURS	COST/HOUR MIN. HOURS												COST/DAY	
AFFILIATED HOME HEALTH CARE 652-8060	1129 MACKLIND 63110		*	8	*	*	*	*			\$15 FOR 1 HR. \$9-4 HR. MIN.	\$9 4 HR. MIN.	\$9 4 HR. MIN.	\$80	*	*	*	*	*	*	*	*	*	*	*	*
ALWAYS-CARE HEALTH CARE 993-2273	9312 OLIVE ST. RD. 63132	*	*	16	*	*	*				\$14 FOR 1 HR. \$7.25-7.75-5 HR. MIN.	\$8 2 HR. MIN.	\$7.25-\$7.75 5 HR. MIN.	\$76	*	*	*	*	*	*	*	*	*	*	*	*
CARDINAL RITTER INSTITUTE 652-3600	4483 LINDELL BLVD. 63108	*	*	24	*	*	*	*			\$14 FOR 1 HR. \$7.50-3 HR. MIN.	\$7.50 3 HR. MIN.	\$7 3 HR. MIN.	REFERRAL SERVICE \$55-\$65/DAY	*	*	*	*	*	*	*	*	*	*	*	*
CARING LIVE-INS 721-0862	7603 FORSYTHE BLVD. SUITE 200, 63105			5	*	*								MIN. \$675/ MONTH	*									*		
COMPLETE HEALTH CARE 576-4000	11960 WESTLINE IND. DR. 63146		*	6	*	*	*	*	*		\$12.95 FOR 1 HR. \$8.95-2 HR. MIN.	\$8.50 NO MIN.	\$8.50 NO MIN.	\$90	*	*	*	*	*	*	*	*	*	*	*	*
DEACONESS HOME HEALTH 534-4202	6150 OAKLAND 63139	*	*	11	*	*					\$21 FOR 2 HR. \$9.50-4 HR. MIN.	\$8.50 4 HR. MIN.	\$8.50 4 HR. MIN.	\$100	*	*	*	*	*	*	*	*	*	*	*	*
EXTRA CARE (JEWISH HOSPITAL) 454-8000	4949 FOREST PARK 63108			2	*	*					\$15 FOR 1 HR. \$9.10-4 HR. MIN.	\$8.15-\$9.50 4 HR. MIN.	\$8.15-\$9.50 4 HR. MIN.		*	*	*	*	*	*	*	*	*	*	*	*
HOME CARE PLUS 993-5649	9666 OLIVE 63132	*	*	4	*	*	*	*	*		\$28-\$32 FOR 2 HR. \$9.25-11.25-3HR. MIN.	\$8.50-\$11.25 3 HR. MIN.	\$8.50-\$9.75 3 HR. MIN.	\$95-\$126	*	*	*	*	*	*	*	*	*	*	*	*
KIMBERLY-QUALITY CARE 432-4800	11500 OLIVE 63141	*	*	15	*	*	*		*		\$9.75 4 HR. MIN.	\$9.50 4 HR. MIN.	\$9.50 4 HR. MIN.		*	*	*	*	*	*	*	*	*	*	*	*
LUTHERAN GOOD NEIGHBOR PROGRAM 966-2082	505 SOUTH KIRKWOOD 63122			12	*	*					SUGGESTED \$5 4 HR. MIN.	SUGGESTED \$5 4 HR. MIN.	SUGGESTED \$5 4 HR. MIN.		*	*								*	*	*
MEDICAL PERSONNEL POOL 432-7777	763 SOUTH NEW BALLAS 63141	*	*	18	*	*	*	*	*		\$9.25-\$10 NO MIN.	\$8.25-\$10 3 HR. MIN.	\$7.25-\$10 NO MIN.	\$114	*	*	*	*	*	*	*	*	*	*	*	*
NATIONAL HOMECARE SYSTEMS 531-5635/281-1831	4144 LINDELL BLVD. SUITE 408 63108		*	11	*	*	*	*	*		\$7.70 2 HR. MIN.	\$7.70 2 HR. MIN.	MAX. \$5.50/HR. 4 HR. MIN.	VARIES	*	*	*	*	*	*	*	*	*	*	*	*

* LIMITED COVERAGE

ADDRESS: 9378 OLIVE STREET ROAD, SUITE 110
ST. LOUIS, MISSOURI 63132
(314) 432-3422

A SAMPLE OF ST. LOUIS HOME HEALTH AGENCIES:

AGENCY NAME & PHONE	ADDRESS	MEDICARE CERTIFIED	MEDICAID CERTIFIED	YEARS SERVING ST. LOUIS	GEOGRAPHIC AREAS SERVED						RESPIRE SERVICES AVAILABLE (PRICES SUBJECT TO CHANGE)				CARE EVALUATION BY RN OR MSW	EMERGENCY CALL-IN AVAILABLE	REFERENCE CHECK	POLICE RECORD CHECK	MALPRACTICE/LIABILITY COVERAGE	BONDING	WORKMEN'S COMPENSATION	EMPLOYER TAXES	LICENSING OR CERTIFICATION & CARE SOURCE	EXPERIENCE WITH DEMENTIA	TRAINING ON DEMENTIA		
					ST. LOUIS CITY	ST. LOUIS COUNTY	ST. CHARLES COUNTY	JEFFERSON COUNTY	FRANKLIN COUNTY	METRO-EAST ILLINOIS	PERSONAL CARE (Bath Service, etc.)	HOMEMAKING	COMPANION	LIVE-IN													
											COST/HOUR MIN. HOURS	COST/HOUR MIN. HOURS	COST/HOUR MIN. HOURS	COST/DAY													
NORRELL HEALTH CARE 862-5333	165 NORTH MERAMEC SUITE 430 63105			7	*	*	*	*	*	*	\$18 FOR 1 HR. \$9-4 HR. MIN.	\$9 4 HR. MIN.	\$9 4 HR. MIN.	\$108	*	*	*	*	*	*	*	*	*	*	*	*	*
OLSTEN OF ST. LOUIS 647-0200	7930 CLAYTON RD. SUITE 301 63117	*	*	8	*	*	*	*	*	*	\$8.50-\$8.95 4 HR. MIN.	\$8.50-\$8.95 4 HR. MIN.	\$8.50-\$8.95 4 HR. MIN.	\$102	*	*	*	*	*	*	*	*	*	*	*	*	*
PATIENT CARE SERVICES 993-3870	510 N. TRUMAN BLVD. CRYSTAL CITY 63019	*	*	1				*			\$12 FOR 1 HR. \$5.75-\$7-4 HR. MIN.	\$7 2 HR. MIN.	\$4.50-\$6 4 HR. MIN.	VARIES	*	*	*	*	*	*	*	*	*	*	*	*	*
PERSONAL TOUCH 863-6011	7912 BONHOMME AVE. 63105	*	*	5	*	*	*	*	*	*	\$12-\$14 FOR 1 HR. \$8-\$9-4 HR. MIN.	\$8-\$9 4 HR. MIN.	\$8-\$9 4 HR. MIN.	\$85-\$95	*	*	*	*	*	*	*	*	*	*	*	*	*
PROFESSIONAL HOME HEALTH 256-6630	331 CONSORT DR. MANCHESTER 63011	*	*	4	*	*			*		\$15 FOR 45 MIN. \$10-4 HR. MIN.		\$9.50 4 HR. MIN.		*	*	*	*	*	*	*	*	*	*	*	*	*
ST. ANDREWS HOME SERVICES 961-6666	8764 MANCHESTER SUITE 204 63144	*	*	7	*	*	*	*	*		\$18 FOR 1 HR. \$8.75-\$9.25-4 HR. MIN.	\$8-\$8.50 4-HR. MIN.	\$7.50 \$8 4 HR. MIN.		*	*	*	*	*	*	*	*	*	*	*	*	*
ST. ANTHONY'S HOME CARE 525-1799	10010 KENNERLY RD. 63128	*	*	3	*	*	*	*			\$8.75 FOR 1 HR.	\$9.25 2 HR. MIN.	\$9.25 2 HR. MIN.		*	*	*	*	*	*	*	*	*	*	*	*	*
ST. LOUIS SENIOR HOME SERVICE 353-4960	6322 MINNESOTA 63111			1	*	*					\$6 3 HR. MIN.	\$6 3 HR. MIN.	\$6 3 HR. MIN.		*	*	*	*	*	*	*	*	*	*	*	*	*
SARA CARE SERVICES 469-7272	245 KINGSHILL 63141			3	*	*	*	*			MIN. \$5 4 HR. MIN.	MIN. \$5 4 HR. MIN.	MIN. \$5 4 HR. MIN.	\$75	*	*	*	*	*	*	*	*	*	*	*	*	*
UPJOHN HEALTH CARE SERVICES 721-3311	1034 SOUTH BRENTWOOD 63105	*	*	7	*	*	*	*	*		\$9.50 4 HR. MIN.	\$8.50 4 HR. MIN.	\$8.50 4 HR. MIN.		*	*	*	*	*	*	*	*	*	*	*	*	*
V.I.P. NURSES DIRECTORY 868-3063	1740 EMERY DR. 63135			8	*	*	*	*			\$6.75 4 HR. MIN.	\$6.75 4 HR. MIN.	\$6.75 4 HR. MIN.	\$81	*	*	*	*	*	*	*	*	*	*	*	*	*
VERA'S SITTERS 947-4407	104 BLANCHE DR. ST. CHARLES 63303			3	*	*	*	*			\$6 4 HR. MIN.	\$6 4 HR. MIN.	\$6 4 HR. MIN.	\$60	*	*	*	*	*	*	*	*	*	*	*	*	*

* LIMITED COVERAGE

THIS SAMPLE OF HOME HEALTH AGENCIES IS FOR INFORMATIONAL PURPOSES ONLY AND IN NO WAY REPRESENTS A RECOMMENDATION OF SERVICES BY THE ADRDA. 10/88.

Day Care

Day care for Alzheimer's patients range in price from \$6 an hour to about \$18 per hour. In these day care centers, the provider gives personal care, if needed, companionship and medical treatment. In these centers the clients will be involved in many activities. Clients work their minds, their fine motor skills, and try to strengthen their future goals. While in a day care center, the patient can play ball (catch), exercise their extremities, and play checkers or other activities that require use of their limbs. Although many Alzheimer's clients have memory loss, these type of activities do require thought. Having the clients exercise their minds makes it less debilitating when they forget something.

Many day care centers will not accept combative patients (See Table 2 for requirements for day care centers and list of perspective providers). They fear for the safety of others in the center. The combative clients are those found in nursing homes or in Alzheimer's Disease wards. These wards are usually "locked" so the client can't wander off or hurt others. Some day care centers like their clients to be able to use rest rooms and care for themselves in personal matters. Forgetfulness, wandering and fear are a natural part of the Alzheimer's process. I feel these day care centers do provide a caring environment for the patient, however, they need to provide a broader range of activities to include sewing, dance and other age associated recreation.

The patient and/or family should review the following areas for selecting a day care facility: capacity, days/hours available, level of care, fees, transportation, percent of Alzheimer's Disease patients, funding, and types of programs available (see Chart).

NAME OF FACILITY	ADDRESS AND PHONE NUMBER	CAPACITY	DAYS/HOURS	LEVEL OF CARE	FEES	TRANSPORTATION	PERCENT OF AD PATIENTS	FUNDING	PROGRAMS
CLAYTON HOUSE HEALTHCARE ADULT DAY CARE	13995 CLAYTON BALLWIN, MO. 63011 227-5070	14	M - F 8 A.M. - 5 P.M.	NO INCONTINENCE UNLESS CAN TEND TO OWN NEEDS. PATIENT MUST BENEFIT FROM ACTIVITIES	\$21/DAY \$12/4 HRS. OR LESS (NO LUNCH)	"CALL A RIDE" WITHIN 5 MILE RADIUS \$1.00 EACH WAY	75%	PRIVATE PAY	SOCIAL PROGRAMS
CLAYWEST ADULT DAY CARE	2840 W. CLAY ST. CHARLES, MO. 63301 946-6100	16	M - F 6 A.M. - 6 P.M.	INCONTINENCE OK WHEELCHAIRS OK TRIAL PERIOD FOR FOR COMBATIVE	\$3.25/HR. INCLUDES HOT LUNCH & TWO SNACKS; BREAKFAST & DINNER \$1.75 EA.	NO	50%	PRIVATE PAY	SOCIAL PROGRAMS SUPPORT GRUOP
COORDINATED DAY SERVICE PROGRAM	6 MILLSTONE CAMPUS ST. LOUIS, MO. 63146 872-7159	34	M - F 8 A.M. - 4 P.M. SUN 11 A.M. - 4 P.M.	INCONTINENCE OK WANDERING OK	SLIDING SCALE \$27/DAY MAXIMUM	WITHIN 10 MILES INCLUDED IN FEE	40-45%	MEDICAID PRIVATE PAY SCHOLARSHIPS	SPECIAL AD ROOM POSITIVE INTER-ACTION & INTER-GENERATION PROGS SUPPORT GRUOP
ELDERCARE CENTER - UNIV. OF MO. ST. LOUIS	8351 SOUTH FLORISSANT ST. LOUIS, MO. 63121 524-0155	40	M - F 7:15 A.M. - 5:30 P.M.	VERY FLEXIBLE INCONTINENCE OK	SLIDING SCALE \$25/DAY MAXIMUM	OATS PROVIDES LIMITED TRANSPORTATION WITHIN 5 MILE RADIUS	50%	MEDICAID PRIVATE PAY SCHOLARSHIPS	VAUDATION THERAPY SOCIAL PROGRAMS
JEFFCO SENIOR ADULT DAY PROGRAM - COMTREA	MAIN & MILL P.O. BOX 519 FESTUS, MO. 63028 942-3730	12	M & TH 8:30 A.M. - 2:30 P.M.	INCONTINENCE OK WHEELCHAIRS OK MINIMAL COMBATIVENESS OK	SLIDING SCALE	NO	LOW	MEDICAID PENDING PRIVATE PAY SCHOLARSHIPS	MENTAL HEALTH SERVICES
JEWISH CENTER FOR THE AGED	13190 SOUTH OUTER 40 ROAD CHESTERFIELD, MO. 63017 434-3330	8	M - F 8 A.M. - 4:30 P.M. VARIABLE DAYS FOR AD CUJENTS	MINIMUM ASSIST PROVIDED FOR FEEDING, TOILETING, AND AMBULATION	SLIDING SCALE \$27/DAY MAXIMUM	INCLUDED IN FEE	35%	MEDICAID MEDICARE/THERAPY PRIVATE PAY SCHOLARSHIPS	OCCUPATIONAL & PHYSICAL THERAPY MEDICAL DIETARY AND SOME PERSONAL CARE SERVICES
ST. ELIZABETH ADULT DAY CARE CENTER	3401 ARSENAL ST. LOUIS, MO. 63118 772-5107	36	M - F 7 A.M. - 6 P.M. FRI EVE - 11 P.M. SAT. 8:30 AM - 5 PM LAST SUN. OF MO. 8:30 A.M. - 5 P.M.	VERY FLEXIBLE INCONTINENCE OK	SLIDING SCALE	WITHIN CITY LIMITS	68%	MEDICAID PRIVATE PAY SCHOLARSHIPS	BATHING PROGRAM OVERNIGHT PROGRAM SUPPORT GROUP
ST. ELIZABETH EAST	3227 SO. NINTH ST. LOUIS, MO. 63118 771-1591	40	M - F 6:30 A.M. - 6 P.M.	VERY FLEXIBLE INCONTINENCE OK	SLIDING SCALE	WITHIN CITY LIMITS	68%	MEDICAID PRIVATE PAY SCHOLARSHIPS	BATHING PROGRAM OVERNIGHT PROGRAM

TABLE 2



ADULT DAY CARE FACILITIES

ST. LOUIS CHAPTER

NAME OF FACILITY	ADDRESS AND PHONE NUMBER	CAPACITY	DAYS/HOURS	LEVEL OF CARE	FEES	TRANSPORTATION	PERCENT OF AD PATIENTS	FUNDING	PROGRAMS
AMERICAN RED CROSS CITY NORTH	RELOCATING 1/90	50	M - F 7 A.M. - 6 P.M.	INCONTINENCE OK WHEELCHAIRS OK NO COMBATIVENESS	SLIDING SCALE \$27/DAY MAXIMUM	WITHIN 5 MILE RADIUS INCLUDED IN FEE	30-35%	MEDICAID PRIVATE PAY SCHOLARSHIPS	OCCUPATIONAL THERAPY
AMERICAN RED CROSS CITY SOUTH	2220 LEMP ST. LOUIS, MO. 63104 771-6656	35	M - F 7 A.M. - 6 P.M.	INCONTINENCE OK WHEELCHAIRS OK NO COMBATIVENESS	SLIDING SCALE \$27/DAY MAXIMUM	WITHIN 5 MILE RADIUS INCLUDED IN FEE	30-35%	MEDICAID PRIVATE PAY SCHOLARSHIPS	OCCUPATIONAL THERAPY
AMERICAN RED CROSS CITY WEST	5615 PERSHING ST. LOUIS, MO. 63112 454-3941	35	M - F 7 A.M. - 6 P.M.	INCONTINENCE OK WHEELCHAIRS OK NO COMBATIVENESS	SLIDING SCALE \$27/DAY MAXIMUM	WITHIN 5 MILE RADIUS INCLUDED IN FEE	30-35%	MEDICAID PRIVATE PAY SCHOLARSHIPS	OCCUPATIONAL THERAPY SUPPORT GROUP
AMERICAN RED CROSS NORTH COUNTY	1625 WASHINGTON FLORISSANT, MO. 63033 921-5118	24	M - F 7 A.M. - 6 P.M.	INCONTINENCE OK WHEELCHAIRS OK NO COMBATIVENESS	SLIDING SCALE \$27/DAY MAXIMUM	WITHIN 5 MILE RADIUS INCLUDED IN FEE	65%	MEDICAID PRIVATE PAY SCHOLARSHIPS	OCCUPATIONAL THERAPY SUPPORT GROUP
BETHESDA DILWORTH ADULT DAY CARE	9645 BIG BEND WEBSTER GROVES, MO. 63119 968-5460	30	M - F 8 A.M. - 5:30 P.M.	NO INCONTINENCE NO WANDERING NO COMBATIVENESS	\$18/DAY	NO	65%	PRIVATE PAY	PHYSICAL OCCUPATIONAL AND SPEECH THERAPY
CARDINAL RITTER ADULT DAY CARE MID-CITY	4483 LINDELL ST. LOUIS, MO. 63108 652-3600	20	T & T 8:30 A.M. - 4 P.M.	INCONTINENCE OK WHEELCHAIRS OK NO COMBATIVENESS	SLIDING SCALE \$18/DAY	WITHIN 6 MILE RADIUS \$4/DAY FEE	NEW	MEDICAID PENDING PRIVATE PAY SCHOLARSHIPS	RN AND ACTIVITY DIRECTOR
CARDINAL RITTER ADULT DAY CARE SHREWSBURY	7677 WATSON RD. SHREWSBURY, MO. 63119 962-0969	14	M / W / F	INCONTINENCE OK WHEELCHAIRS OK NO COMBATIVENESS	SLIDING SCALE \$18/DAY	WITHIN 6 MILE RADIUS \$4/DAY FEE	NEW	MEDICAID PENDING PRIVATE PAY SCHOLARSHIPS	RN AND ACTIVITY DIRECTOR

Live-In

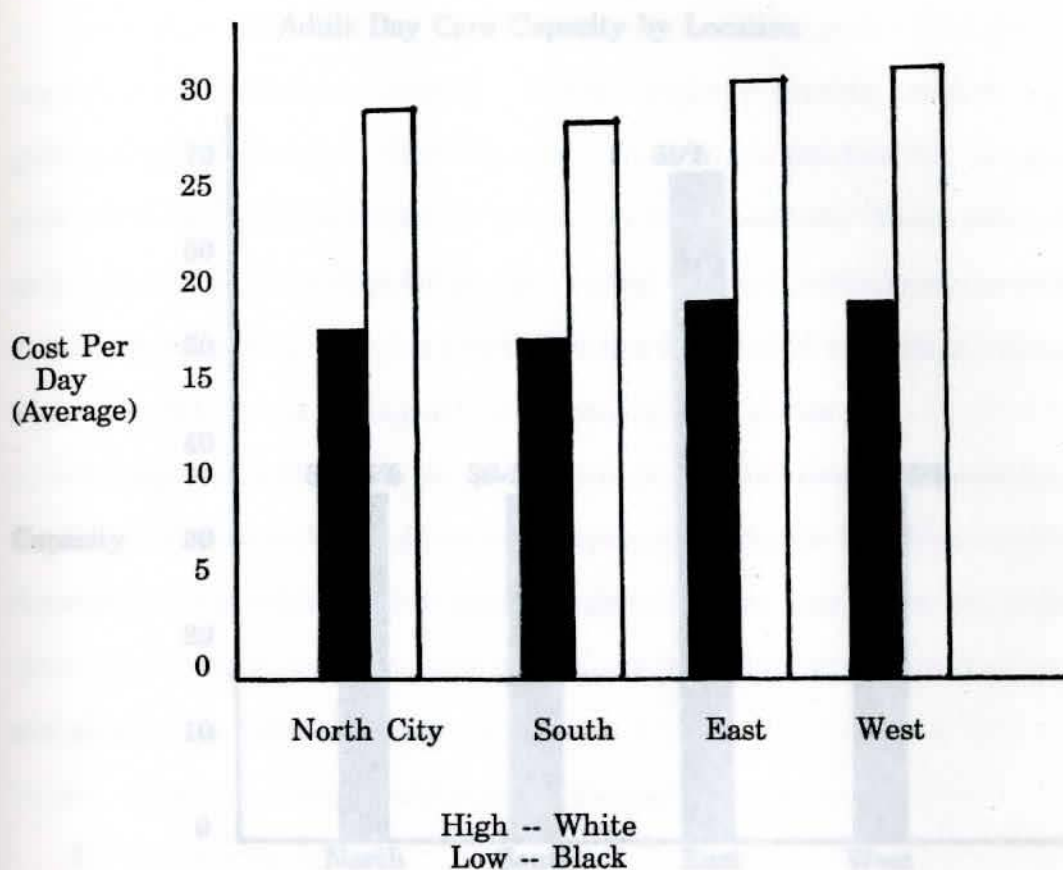
Live-in services are also available to Alzheimer's patients. When these people need live-in assistance, they are generally in the later stages of the disease. These clients don't go outside the home often. If they do, they are virtually lost. They can't remember their way back home. Most live-in care providers are experienced with the behavior of Alzheimer's clients and can help them remain active in the home. Live-in's will help them cook, clean, bathe and continue their daily activities. The cost of live-in care can be high. Prices range from \$55 per day to \$120 per day, depending on the care needed. The client is able to stay in their homes and familiar environments, which allows the client less fear of the outside world. The major goal of live-in caregivers is to allow the patient/client to live as independent a life as possible. Live-in care is a good service, however, the end result is still the same . . . institutionalization.

High - White
Low - Black

As you can see, the cost for day care services are comparable. However, the rate per hour and level of staff needed may be considerably more. A schedule of adult day care centers can be obtained from writing or calling:

Alzheimer's Association Chapter Office
1078 Olive Street, Suite 110
St. Louis, Missouri 63101
(314) 435-3432

(This information is given only for the purpose of assisting Alzheimer's patients or their families to secure appropriate care.)



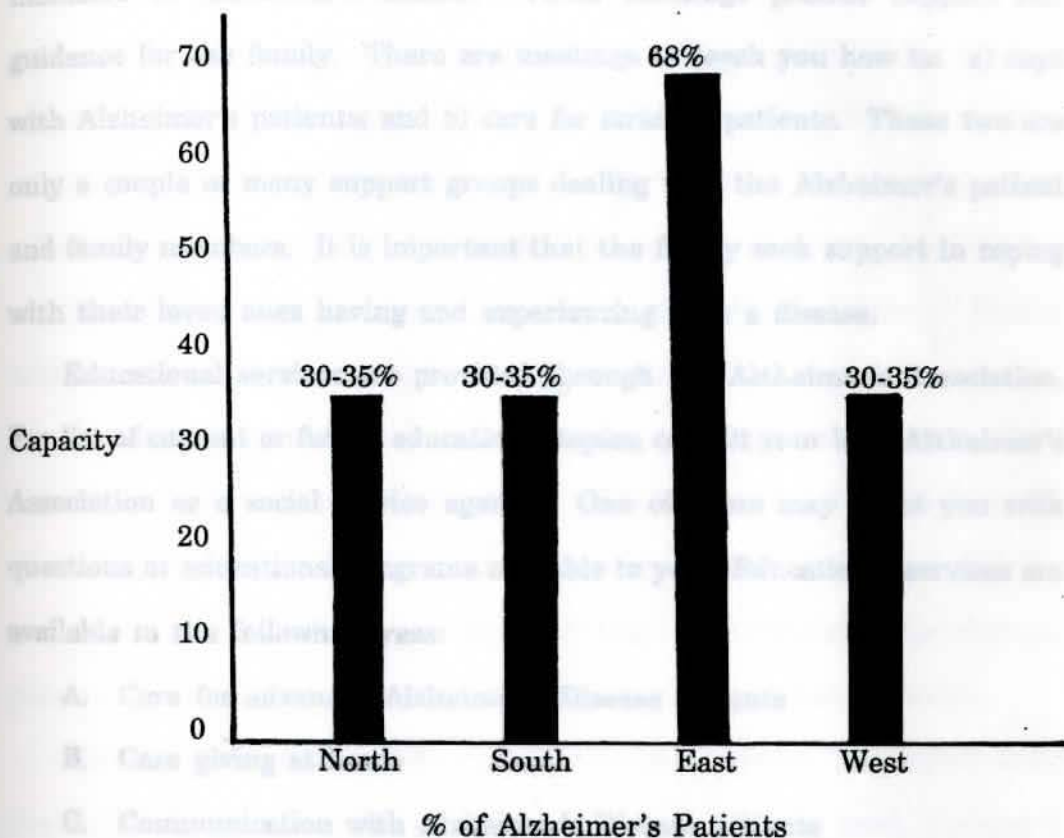
As you can see, the cost for day care services are comparable. However, the rate per hour and level of skill needed may be considerably more. A schedule of adult day care centers can be obtained from writing or calling:

Alzheimer's Association Chapter Office
9378 Olive Street Road, Suite 110
St. Louis, Missouri 63132
(314) 432-3422

(This information is given only for the purpose of assisting Alzheimer's patients or their families to secure appropriate care.)

Educational Services

Adult Day Care Capacity by Location



These percentages are a random sample of facilities with varying capacity but also with varying percentages of Alzheimer's patients in different locations. This doesn't imply that more Alzheimer's patients live in the East.

Institutional providers are the most up-to-date with the Alzheimer's research. These providers will be the ones to have the latest in quality care. If they find that starches is unproductive, they will ditch it. If cost gains are not good for the patient's memory they will eliminate them.

Educational Services

There are also educational and informative meetings for the family members of Alzheimer's clients. These meetings provide support and guidance for the family. There are meetings to teach you how to: a) cope with Alzheimer's patients; and b) care for stricken patients. These two are only a couple of many support groups dealing with the Alzheimer's patient and family members. It is important that the family seek support in coping with their loved ones having and experiencing such a disease.

Educational services are provided through the Alzheimer's Association. For list of current or future educational topics, consult your local Alzheimer's Association or a social service agency. One of these may assist you with questions or educational programs available to you. Educational services are available in the following areas:

- A. Care for advanced Alzheimer's Disease patients
- B. Care giving at home
- C. Communication with Alzheimer's Disease patients
- D. Financial services you may need
- E. Coping with Alzheimer's Disease patients

(Alzheimer's Association, April 1990, Volume XVII, Number 16)

These are just a few of the services available to you and your loved one.

Institutional Care

Institutional providers are the most up-to-date with the Alzheimer's research. These providers will be the ones to have the latest in quality care. If they find that exercise is nonproductive, they will abolish it. If card games are not good for the patient's memory they will discontinue them.

However, institutions are readily available to make changes if it's best for quality care. Institutions want the very best for each of their clients. Institutional units may have more staff that can keep the clients of Alzheimer's active throughout their stay. Alzheimer's patients need to remain active. If the client is left to wander about aimlessly without stimulation, the client will become internally oriented, meaning the client refuses or won't respond to stimuli provided by the caregivers. Institutions, on the other hand, are trained to break that silent barrier. Reality orientation is best for the Alzheimer's patients.

In the institution there is a constant supply of reality orientation. This orientation reinforces the client's ability to think clearly. It also allows the client to actively participate in their actions. This activity requires the patient to think before they act and once they have completed the thought process, they will respond to the situation in an appropriate manner.

While in the institution the clients can wander about. This allows them the ability to remain active as long as possible. This is good, because it allows the clients to have good cardiovascular circulation, prevents decubitus and overall keeps the body in functioning order. If the client was confined, it would prevent them from having a good exercise program. Furthermore, if confined, they're more prone to pneumonia and other respiratory and circulatory problems. Many institutions are known for their excellence in Alzheimer's care. A list of special care units are provided (See Table 3). There are many of these facilities throughout St. Louis and California. These institutions, like many others, require excellence in Alzheimer's care.

NAME OF FACILITY	ADDRESS & PHONE NUMBER	CONTACT PERSON	FEES	LEVEL OF CARE	SPECIAL UNIT AVAILABLE?	MIN./MAX. STAY	ADMISSION PROCEDURE	CALL IN ADVANCE
DELMAR GARDENS NORTH	4401 PARKER RD. FLORISSANT, MO. 63033 355-1516	KATHY RUSS	\$75/DAY (SEMI-PRIVATE) \$105/DAY (PRIVATE)	NO COMBATIVENESS NO WANDERERS	NO (KEEP AD PATIENTS TOGETHER)	2 WEEKS MINIMUM 1 MONTH — MAXIMUM	MEDICAL INFO ASSESSMENT INTERVIEW	1 DAY
DELMAR GARDENS WEST	13550 SO. OUTER 40 CHESTERFIELD, MO. 63017 878-1330	MORA MARXER	\$75/DAY (SEMI-PRIVATE) \$95/DAY (PRIVATE)	NO COMBATIVENESS NO WANDERERS	NO	NO	MEDICAL INFO RECENT PHYSICAL DEPOSIT IN ADVANCE	1 DAY
GARDEN VIEW CARE CENTER	700 GARDEN PATH O'FALLON, MO. 63366 441-5432	SUSAN WESTHOFF	\$100/DAY UNDER 10 DAYS (SEMI-PRIVATE ONLY)	ANY STAGE	NO	10 DAYS — MINIMUM	MEDICAL INFO RECENT CHEST X-RAY	1 DAY
JEWISH CENTER FOR AGED	13190 SO. OUTER 40 CHESTERFIELD, MO. 63017 434-3330	ZONNEL WESTLAKE	\$70/DAY (SEMI-PRIVATE) \$82/DAY (PRIVATE)	ANY STAGE	YES	1 WEEK — MINIMUM 6 WEEKS — MAXIMUM	MEDICAL INFO ASSESSMENT INTERVIEW	2 WEEKS
MARQUETTE MANOR	3419 GASCONADE ST. LOUIS, MO. 63118 351-7512	JOYCE ASHBURN	\$50/DAY (PRIVATE)	NO WANDERERS NO TUBES OR OPEN SORES	NO	2 WEEKS — MINIMUM	MEDICAL INFO ASSESSMENT INTERVIEW	10 DAYS
ST. JOSEPH'S HOSPITAL	1515 MAIN ST. HIGHLAND, IL. 62249 618-654-7421	LUCILLE RAYKERS	\$65/DAY (SEMI-PRIVATE) \$75/DAY (PRIVATE)	ANY STAGE	NO	FLEXIBLE	MEDICAL INFO RECENT PHYSICAL	FLEXIBLE
RIVER BLUFFS CARE CENTER	3354 JEROME LANE CAHOKIA, IL. 62249 618-337-9823	PHYLLIS EVANS	\$41/DAY (SEMI-PRIVATE)	ANY STAGE	NO	1 WEEK — MINIMUM	MEDICAL INFO RECENT PHYSICAL	2-3 WEEKS
ST. PETER'S MANOR CARE CENTER	150 SPENCER RD. ST. PETERS, MO. 63376 441-2750	BONNIE HUNT	\$53/DAY (SEMI-PRIVATE) \$58/DAY (PRIVATE)	ANY STAGE	NO (KEEP AD PATIENTS TOGETHER)	FLEXIBLE	MEDICAL INFO RECENT PHYSICAL CHEST X-RAY	1 DAY

THIS LISTING OF SHORT-TERM RESIDENTIAL FACILITIES IS FOR INFORMATIONAL PURPOSES ONLY AND IN NO WAY REPRESENTS A RECOMMENDATION OF SERVICES BY THE ADRDA. ALL INFORMATION IS SUBJECT TO CHANGE. 11/89



SHORT-TERM RESIDENTIAL CARE FACILITIES

NAME OF FACILITY	ADDRESS & PHONE NUMBER	CONTACT PERSON	FEES	LEVEL OF CARE	SPECIAL UNIT AVAILABLE?	MIN./MAX. STAY	ADMISSION PROCEDURES	CALL IN ADVANCE
AUVENTINE	1 ARBOR TERRACE FENTON, MO. 63021 343-0016	BARBARA WALLACE	\$50.25/DAY (SEMI-PRIVATE) \$901 DAY (PRIVATE)	EARLY STAGE (MUST FOLLOW PATH TO SAFETY)	NO (KEEP AD PATIENTS TOGETHER)	WEEKEND — MINIMUM	MEDICAL INFO TOUR FACILITY	1 DAY
BROOKING PARK	307 SO. WOODSMILL CHESTERFIELD, MO. 63017 576-5545	HARRIET GOLDBERG	\$1800/MONTH (SEMI-PRIVATE) \$2300/MONTH (PRIVATE) — PRO-RATED	EARLY STAGE (MUST FOLLOW PATH TO SAFETY)	NO	2 WEEKS — MINIMUM	MEDICAL INFO RECENT PHYSICAL ASSESSMENT INTERVIEW	3 DAYS TO 1 WEEK
CAMELOT RESIDENCE	265 SPENCER ST. PETERS, MO. 63376 447-3430	BERNIECE WIGGEN	\$41/DAY (SEMI-PRIVATE) \$51-55/DAY (PRIVATE)	EARLY STAGE (MUST FOLLOW PATH TO SAFETY)	NO	WEEKEND MINIMUM	MEDICAL INFO RECENT PHYSICAL PAY IN ADVANCE	1 WEEK
CARROLTON MANOR	12630 GIST RD. BRIDGETON, MO. 63044 291-6060	MARLENE RHODES	\$31/DAY (TRIPLE) \$40-43/DAY (SEMI-PRIVATE) \$50/DAY (PRIVATE)	EARLY AND MIDDLE STAGE	NO	FLEXIBLE	MEDICAL INFO RECENT PHYSICAL ASSESSMENT INTERVIEW	1 DAY
CEDARCROFT	110 HIGHLAND AVE. VALLEY PARK, MO. 63088 225-5144	KATHY MCHUGH	\$56/DAY (MEN'S WARD) \$68/DAY (SEMI-PRIVATE) \$78/DAY (PRIVATE)	ANY STAGE	NO	FLEXIBLE	MEDICAL INFO RECENT PHYSICAL	1 DAY
CLAYTON HOUSE	13995 CLAYTON BALLWIN, MO. 63011 227-5070	NANCY KAUFMANN	\$80/DAY (SEMI-PRIVATE) \$115/DAY (PRIVATE)	MUST BE AMBULATORY AND ABLE TO PARTICIPATE	YES	FLEXIBLE	RECENT PHYSICAL RECENT CHEST X-RAY OR TB TEST ASSESSMENT INTERVIEW	5-7 DAYS
DELMAR GARDENS CHESTERFIELD	14855 NO. OUTER 40 CHESTERFIELD, MO. 63017 532-0150	ANN GROSSBERG	\$72/DAY (SEMI-PRIVATE) \$100/DAY (PRIVATE)	ANY STAGE	YES	FLEXIBLE	MEDICAL INFO RECENT PHYSICAL	1 DAY

Some of the services these institutions provide are:

- A. In-service training for employees
- B. Family support groups
- C. Workshops
- D. Printed information
- E. Respite care services
- F. Occupational therapy
- G. Speech therapy

Institutions take the families into consideration and expect them to actively participate in the client's care. I believe institutions are very client-oriented in terms of Alzheimer's. These units are an asset to any health care provider. I feel those who provide care for Alzheimer's patients will remain competitive in the health care industry.

Respite Care

Respite care is "time off" for a caregiver. This service allows caregivers to get relief from an Alzheimer's patient. This allows the family caregiver time to be alone and do things necessary to them. Because of the many providers available, it is important to select the respite care provider that best fits the client's needs. Refer to Table 1 for list of providers and cost of fee. An Alzheimer's Association can provide counseling and information to patients and families, if needed. Also, there is short-term care provided in residential care facilities for one to two weeks (See Table 4). A patient may also be placed in a residential care facility for months at a time while the caregiver tends to necessary duties. There are assistance programs available to Alzheimer's patients. These programs will provide financial assistance up

OVERVIEW OF SPECIAL CARE UNITS

FACILITY	ASSESSMENT FOR APPROPRIATENESS	CRITERIA FOR DISCHARGE *	LEVEL OF FUNCTIONING **	BEHAVIOR MGMT.	PROGRAMS TO INTEGRATE FAMILY	PROGRAM & ACTIVITIES WITH OTHER RESIDENTS	STAFF RATIO	SPECIAL TRAINING FOR STAFF	ENVIRONMENTAL ADAPTATIONS	PAY DIFFERENTIAL /COST
CLAYTON HOUSE 227 - 5070	Diagnosis by a Physician Amb. or require little assistance Pre-admission Interview	Physical Condition Deteriorates Harmful to Self or Others No Longer Ambulatory Requires 24hr Restraints	Any Stage of the Disease	Minimum Use of Phys. & Chem. Restraints Daily Structured Activities Two Full Time Activity Dir. Dr. Hooyman Consultant	Family Night Once a Month Monthly Support Group	Intergrated on the Basis of Level of Functioning	Day Shift 2 Nurses 3 Aides Activity Director Evening 1 Nurse 2 Aides Activity Director Night 1 Nurse 1 Aide	Monthly Inservice Trainings	Secured Unit Separate Dining & Activity Rooms Separate from Other Areas of Facility	\$70/Day 6 Medicaid Beds
DELMAR GARDENS SOUTH 842 - 0588 CHESTERFIELD 532 - 0150	Diagnosis by a Physician Pre-admission Interview	Physical Condition Deteriorates	Any Stage of the Disease	Minimum Use of Phys. & Chem. Restraints Daily Structured Activities Recreational & Music Therapists St. Louis Univ. Team Consult.	Working to Integrate Family	Intergrated on the Basis of Level of Functioning	Day Shift 1 Nurse 5 Aides Evening 1 Nurse 4 Aides Night 1 Nurse 3 Aides	Inservice Trainings	Separate Dining Room, Activity Room, Courtyard & Enclosed Track Separate from Other Areas of Facility	Semi-Private \$80/Day Private \$130/Day Mini-Private \$98/Day Semi-Private (Pod Shaped) \$90/Day
JEWISH CENTER FOR THE AGED 434 - 3330	Diagnosis by a Physician Assessment by Overall Plan of Care Team	Physical Condition Deteriorates Unable to Benefit from Activities	Any Stage of the Disease	Minimum Use of Phys. & Chem. Restraints Daily Structured Activities Full Time Recreational Therapists	Integrated based on Family Participation Monthly Support Group Social Worker Available for Individual Counseling	Intergrated on the Basis of Level of Functioning	Day Shift 1 Nurse 6 SRCA Evening 1 Nurse 1 SRCA 4 Aides Night 1 SRCA 2 Aides	Inservice Trainings Alzheimer's Association How-to-Cope Program	Secured Unit Separate Dining Room, Activity Room, & Enclosed Garden Separate from Other Areas of Facility	\$89/Day Each Bed can become a Medicaid Bed

ADDRESS: ALZHEIMER'S ASSOCIATION CHAPTER OFFICE
9378 OLIVE STREET RD., SUITE 110
ST. LOUIS, MISSOURI 63132
(314) 432-3422

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OVERVIEW OF SENIOR CARE CENTERS

FACILITY	ASSESSMENT FOR APPROPRIATENESS	CRITERIA FOR DISCHARGE *	LEVEL OF FUNCTIONING **	BEHAVIOR MGMT.	PROGRAMS TO INTEGRATE FAMILY	PROGRAM & ACTIVITIES WITH OTHER RESIDENTS	STAFF RATIO	SPECIAL TRAINING FOR STAFF	ENVIRONMENTAL ADAPTATIONS	PAY DIFFERENTIAL /COST
BETHESDA DILWORTH MEMORIAL HOME 968 - 5460	Diagnosis by a Physician Preadmission Interview History and Physical	Physical Condition Deteriorates	Any Stage of the Disease	Minimum Use of Physical & Chemical Restraints Daily Structured Activities Three Full-time Activity Dir.	Integrated on Family Participation Support Group Social Worker Available for Individual Counseling	Integrated on Basis of Level of Functioning	Day Shift 1 Nurse 1 CMT, 2 Aides Evening 1 Nurse, 1 CMT, 1 Aide Night 1 Nurse, 1 Aide	Inservice Training Alzheimer's Assoc. How-to-Cope Program St. Louis Univ. Hospital 12 week Research Program	Secured Unit Residents wear a Beeper Band Separated from Other Areas of Facility Separate Dining & Activity Rooms	Semi-Private \$66/Day Private \$75/Day
CLAY WEST HOUSE 946 - 6100 OR 925 - 1500	Preadmission Interview	Physical Condition Deteriorates Unable to Benefit from Activities Harmful to Self or Others No Longer Mobile	Any Stage of the Disease	Minimum Use of Physical & Chemical Restraints Daily Structured Activities	Invited to Care Plan Meetings Encouraged to Part. in Activities Monthly Support Groups Educ. Forums Pastoral Counseling	Integrated on Basis of Level of Functioning Benefit from Activity	Day Shift 3 Nurses, 1 CMT, 7 Aides Evening 2 Nurses, 5 Aides Night 1 Nurse, 4 Aides	Monthly Inservice Training Alzheimer's Assoc. How-to-Cope Program Involved with Memory & Aging Project	Secured Unit Separated from Other Areas of Facility Separate Dining & Activity Rooms	Semi-Private \$2,050/Month Private \$2,685/Month
OAK KNOLL 521 - 7419 OR 521 - 7422	Preadmission Interview History and Physical	Facility is an ICF so patient is discharged to a SWF when physical condition deteriorates	Any Stage	Minimum Use of Physical & Chemical Restraints Two Structured activities per day Volunteer Family Members help with Activities	Integrated on Family Participation	Integrated on Basis of Level of Functioning	Day Shift 1 CNA Evening 1 CNA Night 1 CNA, Nurse on duty within the facility	Monthly Inservice Training	Secured Unit Separated from Other Areas 2nd Floor Separate Dining Area	Semi-Private \$49/Day 3 Bedroom \$48/Day

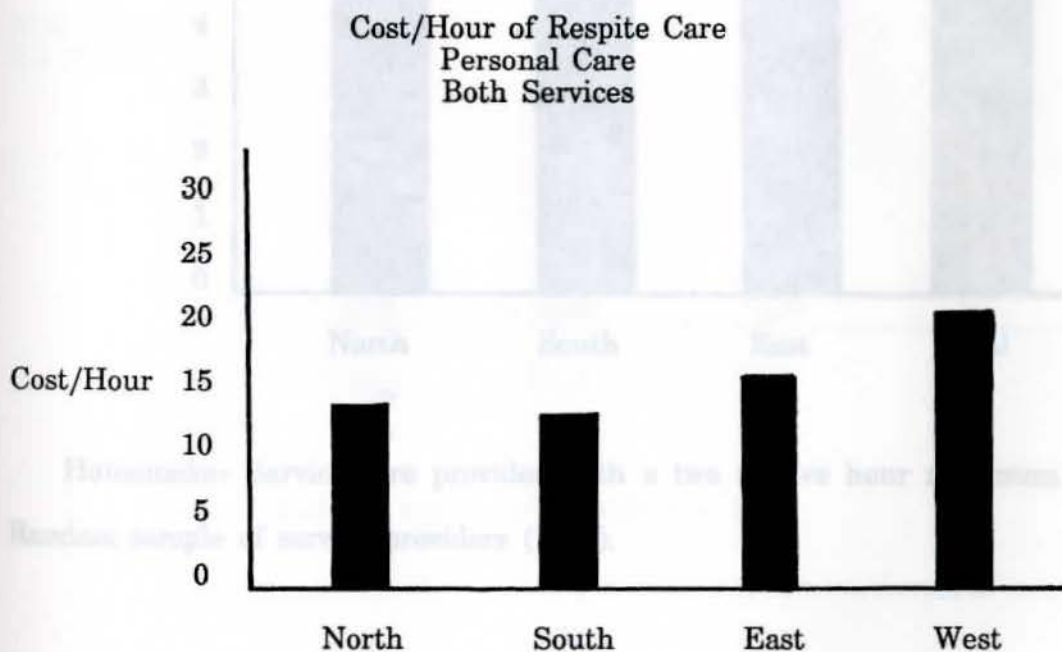
* Patient will be discharged from SCU to the skilled area of the Facility when physical condition deteriorates and patient requires skilled care.

** SCU's primarily take early and middle stage patients. Late stage depends upon physical condition.

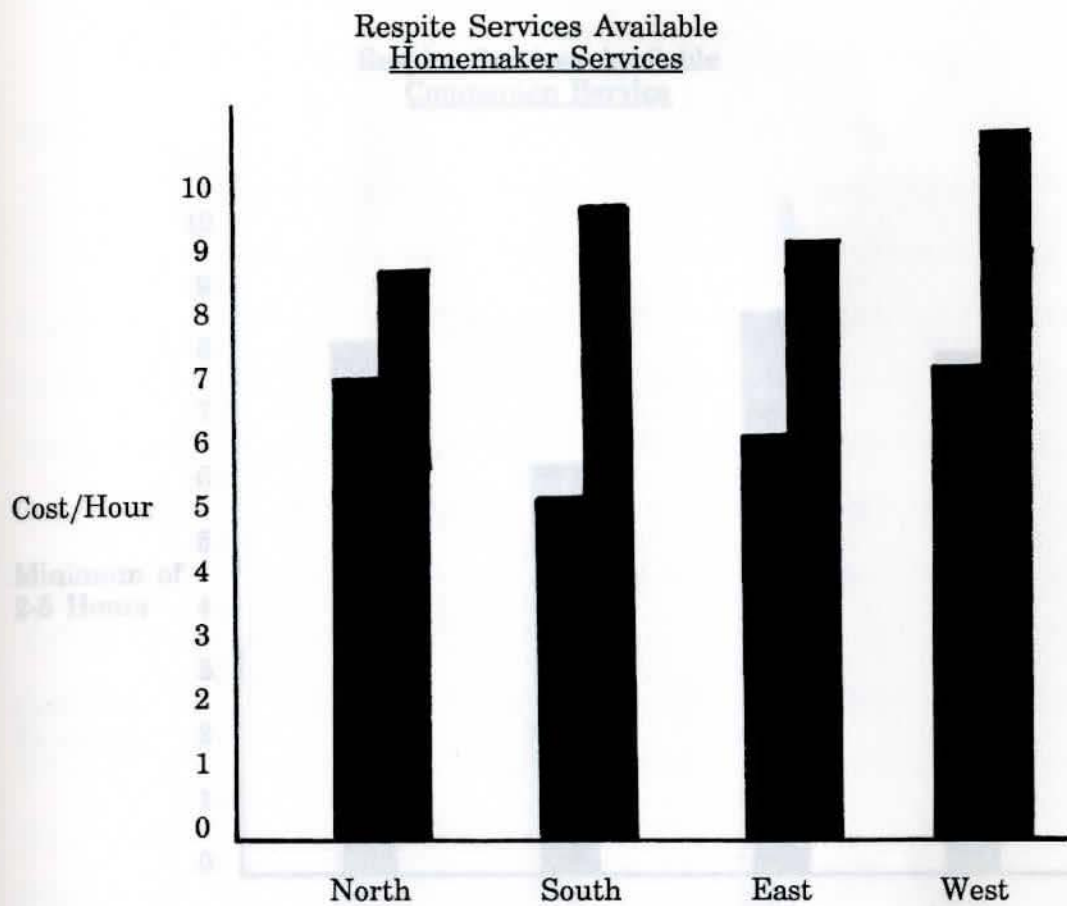
to \$6,000 per year. There are some guidelines that must be followed for assistance. For example:

- A. \$50 allowed each month
- B. Respite services must be verified
- C. Higher amounts can be granted by Respite Care Coordinator only



Those persons eligible are the caregiver and victim. Both must live together, also. The patient must be under the physician's care and have a diagnosis of Alzheimer's disease, must submit statement of need, and use services in the patient's service area.



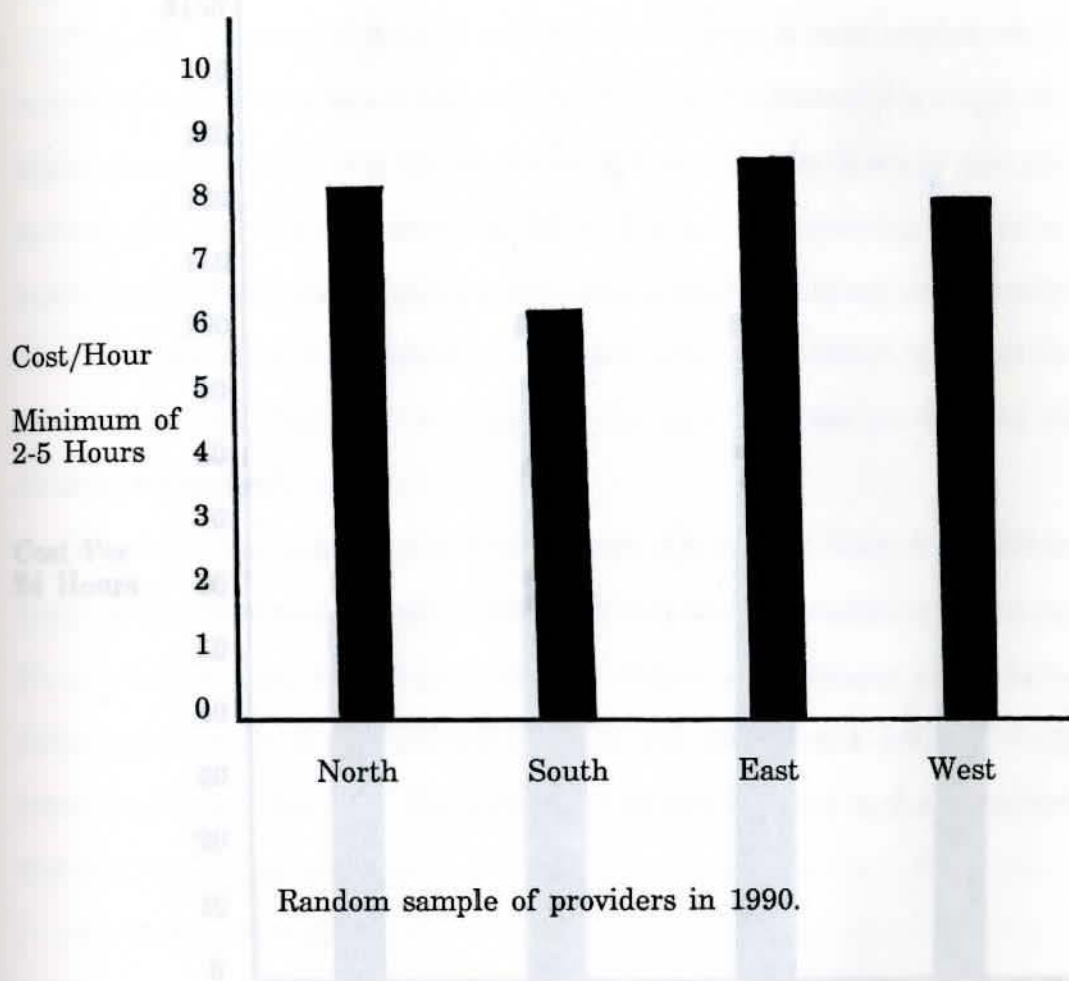
The rate/hour are on estimate of cost. However, many companies have a two to five hour minimum allowed for service (1990).



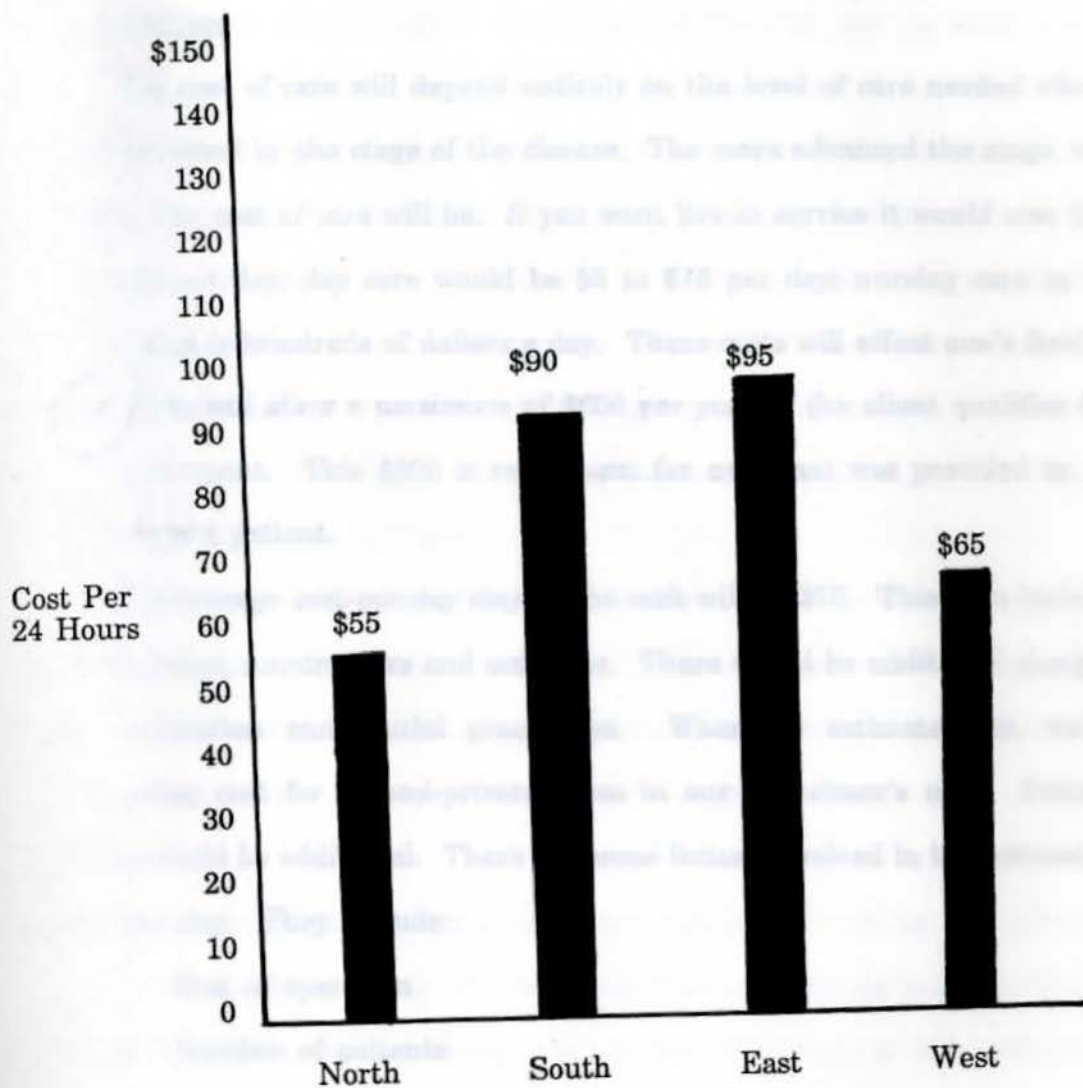
Homemaker Services are provided with a two to five hour minimum.
Random sample of service providers (1990).

 -- Low
 -- High

Respite Services Available
Companion Service



Respite Services Available
Live-In Services



For random sample for live-in services, I have given rate/day for least expensive provider (1990).

CHAPTER VI

COST FOR CARE OF ALZHEIMER'S DISEASE PATIENTS

Cost of Care

The cost of care will depend entirely on the level of care needed which is determined by the stage of the disease. The more advanced the stage, the higher the cost of care will be. If you want live-in service it would cost \$55 to \$120 per day; day care would be \$6 to \$18 per day; nursing care in an institution is hundreds of dollars a day. These costs will affect one's family. The State will allow a maximum of \$600 per year, if the client qualifies for reimbursement. This \$600 is repayment for care that was provided to an Alzheimer's patient.

The average cost-per-day stay in the unit will be \$70. This is to include meals, room, nursing care and activities. There would be additional charges for medication and special procedures. When we estimate cost, we're estimating cost for a semi-private room in our Alzheimer's unit. Private rooms would be additional. There are some factors involved in the estimated cost per day. They include:

- A. Cost of operation
- B. Number of patients
- C. Different activities needed for patients
- D. Stage of advancement
- E. Life expectancy of patient

These are a few of the factors taken into account prior to serving Alzheimer's patients. With strategic planning we could find out how profitable the venture would be on a long-term basis. If it proved

unfavorable for a long-term goal, we could investigate short-term respite care. It may be more advantageous to devise a short-term goal rather than a long-term goal. This would be determined by the staff and the level of care you want to provide.

With the care being cost efficient and long-lasting, this should provide some reassurance for the initial set of goals, "providing quality care." For the facility to be profitable, we must make sure that our expenses and facility costs are less than our rate of returns. We would not want our expenses outweighing our returns. Cost of nursing home care generally includes one or more of the following: room, board, laundry, therapies, medications or other miscellaneous expenses.

It's necessary that the client receive the most for their money. When calculating the cost of long-term care, medications are an added expense. Many long-term care facilities may only calculate the cost of meals, activities and personal care. The more services one needs, the higher their monthly cost.

When designing a program, one must decide what will be cost efficient for the company and client. For example, if we only provide meals, activities and personal care, we may charge \$24 per day. If we were to add medication and telephone calls for patients, we may have to charge \$50 to \$100 per day, per patient. Many companies will take the least-cost method; others may opt for another avenue. This will depend on the company's desire to be cost efficient or not.

The cost of care for these clients will reach \$50 million or more in 1990. The average cost is about \$7 to \$8 per hour of care. This is an enormous

amount of money when you take into consideration that there are 30,000 to 40,000 clients in St. Louis alone. The average cost of care per hour for an Alzheimer's patient can range from \$6 to \$27. Institutional care can be \$400 to \$1,000 per month or more, depending on services required (See Chart next page).

More than 50 percent of all nursing home patients are victims of Alzheimer's Disease or a related disorder. The annual cost of nursing home care ranges between \$24,000 and \$36,000. The financing of care for Alzheimer's Disease . . . including costs of diagnosis, treatment, nursing home care, informal care, and lost wages . . . is estimated to be more than \$80 billion each year. The Federal government covers \$4.4 billion, and the states, another \$4.1 billion. Much of the remaining costs are borne by patients and their families (information taken from Alzheimer's Disease Fact Sheet, 1990)

COST VERSUS LEVEL OF CARE NEEDED BY PATIENT

Total Combative										27
Total Personal Care										24
Minimal Personal Care										18
Companion (incl. snack, full meals, activities and no personal care)										15-16
Companion (incl. snack, full meals, and activities)										14
Companion (incl. snack and full meals)										12
Companion (incl. snack)										8
Companion										6
<u>Level of Care</u>	<u>\$0</u>	<u>5</u>	<u>10</u>	<u>15</u>	<u>20</u>	<u>25</u>	<u>30</u>	<u>35</u>		
	Cost									

Cost increases with added care required.
(Example: Total care higher, companion lower)



Insurance

If the State will provide Medicare and Medicaid beds, we must turn to the government for insurance coverage. This would help in the total operation of the facility. It would offer more services that would ensure prompt payment to cover the operating expenses, thereby making it easier for the company to meet insurance and regulatory requirements. The government will make sure institutional providers comply with all regulations if they're contributing to patient care costs.

Insurance rates will dictate one's care and health cost coverage. Insurance will cover some cost of care for Alzheimer's patients. For example, nursing visits may be covered by a State agency. Homemaker services may be covered by private coverage. As mentioned earlier in the project, some of the cost may be tax deductible under the current tax laws. If you have a private insurance carrier, you should review your policies to see if some cost will be covered under your current plan. One may also consider a special rider for Alzheimer's care. The cost of insurance for an Alzheimer's patient may be expensive. One could research several organizations to see which provides the most health care cost. Health insurance has always been costly, however, we must have it so we can offset some of the cost of care.

Because of the severity of injury with Alzheimer's patients, insurance is somewhat higher than with other services. Recurring falls, cuts, fractures and similar injuries make it necessary to carry higher than normal insurance coverage. One never knows when injury may occur or an operational discrepancy would occur. Insurance not only must cover the patients -- it must cover family members, employees and the general public. If a family



member were to be struck by a patient, the facility would be liable. All aspects must be considered when fulfilling our insurance needs.

Marketing

The marketing will be an important aspect of the plan. We will direct our efforts to the portion of the population most likely to need our services, the elderly population. Elderly, meaning advanced age, 65 and older. We must provide all services. The target group we are drawing at are the Alzheimer's people. This group has been misunderstood by many in years past. Because of our interest in this particular disease, the patient is struck can feel relieved that there are those who know what they are going through. There are several facilities that provide similar services, so we must market our existing care and our service costs. For example, we want to emphasize our specialty in education of the patient. This will make the patient and their family aware of our understanding of the disease and its problems. We will also emphasize our dedication to the disease. We will show the things we would be providing for our patients, such as:

- A. Safety features - locked doors so patients won't wander and get lost or injured.
- B. Meals - not too hot for our patients who can't control their emotions.
- C. Activities - games and exercises to stimulate some otherwise confined areas of the body, arms, hands, etc.
- D. Independence - letting patients participate at their own discretion and making decisions for themselves.

CHAPTER VII

MARKETING

Marketing

Our marketing will be as important as all the other aspects of this venture. We will direct our efforts to the portion of the population most likely to need our service, the elderly generation. Elderly, meaning advanced age, 65 and older. We must provide all services. The select group we are directing at are the Alzheimer's people. This group has been misunderstood by many in years past. Because of our interest in this particular disease, the patient so stricken can feel relieved that there are those who know what they are going through. There are several facilities that provide similar services, so we must market our nursing care and our service costs. For example, we want to emphasize our specialty in education of the nurses. This will make the patient and their family aware of our understanding of the disease and its problems. We will also emphasize our dedication to the disease. We will show the things we would be providing for our patients, such as:

- A. Safety factors -- locked doors so patients won't wander and get lost or injured.
- B. Meals -- not too hot for our patients who can't control their motions.
- C. Activities -- games and exercises to stimulate some otherwise confined areas of the body, arms, hands, etc.
- D. Independence -- letting patients participate at their own discretion and making decisions for themselves.

These are some areas of our marketing interest. They will only be effective if management sticks to them.

The costs of the service will probably be the most important factor for the patient and their family. If the costs are too high, the family may not be able to afford the service no matter how good it would be for the patient. We must keep the cost to the patient and their family as low as possible while at the same time earn enough to keep the operations at a quality level.

Following are two cases that really come to mind when I recall my visits. Each of the Case Studies are examples of what Alzheimer's patients and their families deal with each day. Alzheimer's Disease is a devastating condition that needs an immediate response.

Case Study 1

In this observational study, I found an 80-year-old male. He had been diagnosed as having Alzheimer's Disease approximately seven to eight years ago that being when he was in his late 70's. I found this patient to be confined to a Geriatric. This chair has a trap on top which prohibits his movement about. He constantly wrinkles and picks at his clothing. At the sign of cold, the client/patient doesn't remember my name, his name or where he is. The client asked me how deep the water was. It was actually in the 70 degree range that particular day. When I asked him where he was, he said it's day camp. As time passed, I noticed the patient had

CHAPTER VIII

CASE STUDIES

When this project started, I felt it would be necessary to visit an institution that cares for Alzheimer's patients. I visited several facilities to observe their individual care procedures. Each facility had a very professional staff that gave quality care. On each Alzheimer's unit I visited, we had to enter a locked unit. Once inside, the door locked behind us immediately. On the inner and outer walls there were numerical panels that had to be accessed to enter and leave the unit. The patients were roaming about as Alzheimer's patients have been noted to do. Once the patients were in view, one could see sign of Alzheimer's Disease in these patients.

Following are two cases that readily come to mind when I recall my visits. Each of the Case Studies are examples of what Alzheimer's patients and their families deal with each day. Alzheimer's Disease is a devastating condition that needs an immediate cure.

Case Study I

In this observational study, I found an 86-year-old male. He had been diagnosed as having Alzheimer's Disease approximately seven to eight years ago; that being when he was in his late 70's. I found this patient to be confined to a Geri-chair. This chair has a tray on top which prohibits his movement about. He constantly mumbles and picks at his clothing. As the signs unfold, the client/patient doesn't remember my name, his name or where he is. The client asked me how deep the snow was. It was actually in the 70 degree range that particular day. When I asked him where he was, he said it's day time. As time passed, I noticed the patient had

urinated in his pants. He had never asked to use the rest room. Once he was changed (immediately) by the staff, he said he wanted to go to the bathroom. When he was taken, he never used the toilet. What he did was try to take his shoes off. The patient was returned to his chair and secured in it. The patient was constantly responding to questions inappropriately. He was forgetful when asked the same questions at different intervals. He actually became combative toward one lady. She had tried to help untie his Posey Vest. A Posey Vest is a device used to confine a patient to bed or a chair. The vest cannot be applied without a physician's consent or in case of emergency situations. However, this gentleman was on a skilled nursing visit. The visit was for Alzheimer's patients. There were no doors or windows without warning devices on them, in case a patient wandered off. On this visit, the patient would have 24 hour observation and health care.

Case Study II

This case is about a 64-year-old female. She was confined to a locked unit also. She was up and about as she felt. This patient would aggravate the other patients. She had taken another patient's shoe. With another patient she kept telling him to shut-up. She had taken other cups and bowls they had. Suddenly this lady disappeared from the room. When I looked for her, I found her in another patient's room hiding the cups. She had put them in the patient's clothes drawer. Suddenly she saw me and she acted as if she was going to sleep. She took her shoes off and laid on the other patient's bed. She was restless, because she would sit down for a few minutes then she would wander about again. Whenever a person came on the unit she would stop right in front of them and just stare at them. She

appeared to be confused at times, also. When I talked with her she was disoriented to person, place and time. She once said it was morning -- it was really five o'clock in the afternoon. She said she was the manager. The staff told me she had been a school teacher most of her life.

In these cases, I feel that both patients could be categorized as have Alzheimer's. However, actual diagnosis is confirmed on autopsy. I also want to say that some of these signs and symptoms are seen or associated with other illnesses. It's important to have the patient seen by a physician if one fears signs and symptoms of Alzheimer's. Therefore, if one has concerns or questions on Alzheimer's Disease, consult your physician or contact the Alzheimer's Association in your area.

CHAPTER IX

FUTURE OUTLOOK -- PERSONAL VIEW

Alzheimer's Disease has affected many people. Those affected are the cure for the future. Unfortunately, there has to be someone suffer for the cure of others. Actually, I feel the future will hold positive results for a cure. Maybe there will be a simple solution to a cure. Whatever the cause of the disease, we must find the cause. I feel that the government will need to allocate more research grants. Don't waste the money on something else. I also suggest that the researchers stop collecting all the specimens for research. If they know what plaque builds up in the brain, why do they still need more specimens? They should do cross-sections of many of them and find a common link. Concentrate on care for the stricken patients we see today. Care must be perfected. All of the laboring with blood work will show positive results someday. Unfortunately, we must struggle until we find a cure. We, as health care providers, would be glad to see this disease controlled quickly. It is having an adverse effect on all of us. It requires too much of our time that could be focused in other areas of health care. Personally, I feel that a cure will not be found until into the Twenty-first Century. I think the disease has caught the health care profession off guard per se. If we had actually known about Alzheimer's ten to fifteen years ago, why did we wait until now to try to combat the disease?

Medicine is important to these patients also. Alzheimer's patients often forget to eat. Caregivers need to remind patients that food can be hot, warm or cold, and assist them in maintaining their dignity. These patients need reassurance and help at mealtimes.

CHAPTER X

RECOMMENDATIONS

Because of the process of Alzheimer's Disease, we need to allocate more money for research and finding a cure. In addition, we need to provide those affected with more care to offset the tremendous cost these patients will have for care . . . provide more voluntary clinics . . . in the area of nursing care, try to provide more reality orientation . . . be more tolerant of the patient and the disease . . . be more receptive of client's conditions and be sympathetic to family, also. The family needs more coaching when visiting loved ones in care institutions. One should assist the family in dealing with their grief. Talk to the family about the expectations of the patient. The family should be able to effectively communicate with the patient. Don't talk loudly to the patient -- it may upset them. One should remember the following when talking to an Alzheimer's patient:

- A. Speak slowly
- B. Use short simple sentences
- C. Ask only one question at a time
- D. Give positive reinforcement

Maintaining good eye contact and lightly touching patient on shoulder or hand may maintain the patient's attention span. Do not force a patient to complete a task. One needs to be truthful when speaking with patients.

Mealtime is important to these patients also. Alzheimer's patients often forget to eat. Caregivers need to remind patients that food can be hot, utensils sharp, and assist them in maintaining their dignity. These patients need reassurance and help at mealtimes.

Families should seek appropriate counseling on the different changes that the patients go through. Many family members have trouble coping with Alzheimer's patients. Families should seek care for Alzheimer's patients. Do not abuse an Alzheimer's patient. The patient doesn't know what they are doing from one minute to the next. They can't predict what their next mood change will be. Families must be tolerant of Alzheimer's Disease patients -- seek respite care for your well-being. Protect yourself at all times. Don't be unrealistic about the health of a family member. Building false hopes will cause you more anguish than is necessary. Be true to yourself and to the patient. If you have a loved one with Alzheimer's Disease, get them all the necessary health care they need. Attend meetings and seminars on the care, safety and health of Alzheimer's patients. Participate in research projects if possible. Get the Alzheimer's patient an identification bracelet. This may help the police or authorities in safely returning an Alzheimer's patient.

CONCLUSION

Because of modern medical advances, it is possible to live longer. Such advances as the CT scan (computerized Tomography) can detect many illnesses in their early stages and treatment can be started before the illness gets too advanced for successful treatment. Many advances have been discovered by initiating similar types of programs, like the Alzheimer's unit. Once we have discovered similar signs and symptoms we can provide better services. So it's necessary to remain competitive in the development of health services. Society expects a choice in where and how they are able to get treatment for any and all their illnesses. If we can't give the consumer what they are looking for, we will not survive as product or service.

Women and men alike are living longer than the expected norm. It was noted that at today's rates, women live to be approximately 73 years of age, men a little less. There are other factors that would have an impact on the life expectancy of a person. For example, smoking and drinking. If one smokes, he/she would not be expected to live as long as a person who does not smoke. Drinking may have the same type of effect on a person's life expectancy. You could drink years off your life expectancy rate.

Because the American people are living longer, it is necessary to provide more services to them. The type of service should be consistent with the discoveries of modern medicine. Whatever the service is, the provider must remain competitive to succeed. If you would not change your services to include the new discoveries of treatment and care, people would not consider any of your services. Flexibility is necessary to keep up the pace. With the number of Alzheimer's patients steadily increasing, it's important to

introduce these services to the community. If the service benefits enough of the population, perhaps the health care providers could find a cure for this dreaded disease.

Although there are many service providers, providing good quality care, this service area should definitely be broadened to include more State facilities. I feel the State should get more involved with this disease. There needs to be more allocation and appropriation of funds. Research and long-range goals need to be set. I feel the cost of care will steadily rise. The number of Alzheimer's clients will continue to rise and the need for more facilities will also grow with the populations in this category. The long-term reality is that this disease will affect most of us sooner than we expect. Since the real diagnosis of Alzheimer's comes on an autopsy, it is necessary that we find a cure soon so we can live more productive lives.

REFERENCES

- Alzheimer's Association Newsletter—Someone to Stand by You. February 1990, Volume XV, Number 14.
- Alzheimer's Association Newsletter—Someone to Stand by You. April 1990, Volume XVII, Number 18.
- Alzheimer's Association Newsletter—Someone to Stand by You. June 1990, Volume XIV, Number 18.
- Alzheimer's Association Newsletter—Someone to Stand by You. July 1990, Volume XX, Number 19.
- Alzheimer's Association Newsletter—Someone to Stand by You. Summer 1996, Volume VIII, Number 47.

REFERENCES

- Alzheimer's Disease. (1987). An Overview. Chicago, IL: Alzheimer's Disease and Related Disorders Association, Inc. Alzheimer's Association—Someone to Stand by You.
- Alzheimer's Disease Fact Sheet. (1990). Chicago, IL: Alzheimer's Disease and Related Disorders Association, Inc. Alzheimer's Association—Someone to Stand by You.
- Alzheimer's Disease Statistics. (1990). Chicago, IL: Alzheimer's Disease and Related Disorders Association, Inc. Alzheimer's Association—Someone to Stand by You.
- Cohen, Ph.D., D. & Rindorfer, Ph.D., M.D., C. (1986). The Loss of Self: A Family Resource for the Care of Alzheimer's Disease and Related Disorders. 018285. New York: W. W. Norton & Company.
- Long-Term Care Facility Regulations and Licensure Law. (1986). State of Missouri Department of Social Services, Division of Aging. For Residential Care Facilities I, II, Intermediate Care Facilities, Skilled Nursing Facilities.
- Long-Term Care Facility Regulations and Licensure Law. (1986). State of Missouri Department of Social Services, Division of Aging. For Residential Care Facilities I & II, Intermediate Care Facilities, and Skilled Care Facilities.
- Reisberg, M.D., B. (1981). A Guide to Alzheimer's Disease for Families, Neighbors, and Friends. #018296. New York: The Free Press - A Division of MacMillan, Inc.
- A Special Thanks to: St. Louis Alzheimer's Association
St. Louis, MO 63122
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REFERENCES

- Alzheimer's Association Newsletter--Someone to Stand by You. February 1990, Volume XV, Number 14.
- Alzheimer's Association Newsletter--Someone to Stand by You. April 1990, Volume XVII, Number 16.
- Alzheimer's Association Newsletter--Someone to Stand by You. June 1990, Volume XIV, Number 18.
- Alzheimer's Association Newsletter--Someone to Stand by You. July 1990, Volume XX, Number 19.
- Alzheimer's Association Newsletter--Someone to Stand by You. Summer 1998, Volume VIII, Number 17.
- Alzheimer's Disease. (1987). An Overview. Chicago, IL: Alzheimer's Disease and Related Disorders Association, Inc. Alzheimer's Association--Someone to Stand by You.
- Alzheimer's Disease Fact Sheet. (1990). Chicago, IL: Alzheimer's Disease and Related Disorders Association, Inc. Alzheimer's Association--Someone to Stand by You.
- Alzheimer's Disease Statistics. (1990). Chicago, IL: Alzheimer's Disease and Related Disorders Association, Inc. Alzheimer's Association--Someone to Stand by You.
- Cohen, Ph.D., D. & Eisdorfer, Ph.D., M.D., C. (1986). The Loss of Self. A Family Resource for the Care of Alzheimer's Disease and Related Disorders, 616.83. New York: W. W. Norton & Company.
- Long-Term Care Facility Regulations and Licensure Law. (1988). State of Missouri Department of Social Services, Division of Aging. For Residential Care Facilities I, II, Intermediate Care Facilities, Skilled Nursing Facilities.
- Long-Term Care Facility Regulations and Licensure Law. (1989). State of Missouri Department of Social Services, Division of Aging. For Residential Care Facilities I & II, Intermediate Care Facilities, and Skilled Care Facilities.
- Reisberg, M.D., B. (1981). A Guide to Alzheimer's Disease for Families, Spouses and Friends. #616.898. New York: The Free Press -- A Division of MacMillan, Inc.
- A Special Thanks to: St. Louis Alzheimer's Association
St. Louis, MO 63132
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Because of the closeness of signs and symptoms of Alzheimer's Disease you must consult a physician for true confirmation of the disease. Although I have worked with Alzheimer's patients, I cannot honestly say that because you have one or more of these signs or symptoms that you have Alzheimer's. Therefore, I disclaim any and all allegations of liability for one's interpretation of this information. If you have questions about Alzheimer's Disease, consult your physician or your local Alzheimer's Association for information.