WHAT IS ALZHEIMER’S DISEASE?

Alzheimer’s Disease was first discovered in 1906 by a German doctor named Alois Alzheimer. It is a disorder of the brain, causing damage to brain tissue over a period of time. Alzheimer’s accounts for more than half of all organically caused memory loss and it is the fourth leading cause of death in the aged following heart disease, cancer, and stroke. At present there is no known cause or cure. The disease can linger from two to 25 years before death results.

Alzheimer’s shows up differently from one person to the next. Initial symptoms are subtle; the person may show signs of personality change, memory loss, poor judgement, have less initiative, be unable to learn new things, have mood swings or become easily agitated. Gradually, as the disease progresses, the victim develops speech and language problems, movement and coordination difficulties, total confusion and disorientation, and will ultimately rely completely on a caregiver for daily functioning.

Although in the early stages of Alzheimer’s the victim may appear completely healthy, the damage is slowly destroying the brain cells. This hidden process damages the brain in several ways:

- patches of brain cells degenerate
- nerve endings that transmit messages within the brain become tangled (neurofibrillary tangles)
- there is reduction in acetylcholine, an important brain chemical
- spaces in the brain (ventricles become larger and filled with granular fluid)
- the size and shape of the brain alters – areas affected include the hippocampal gyrus, frontal lobe, locus coeruleus, and amygdala.

Understandably, as the brain continues to degenerate, there is a comparable loss in mental functioning. Since the brain controls all of our bodily functions, an Alzheimer patient in the later stages will have difficulty walking, talking, swallowing, controlling bladder and bowel functions, etc. They become quite frail and prone to infections such as pneumonia.

To complicate matters further, there are numerous conditions which mimic Alzheimer’s Disease. Conditions such as stroke, vascular diseases, alcohol, depression, toxins, nutritional deficiencies, infections, etc., can all have symptoms that mimic Alzheimer’s. For this reason it is most important that a thorough examination be done in order to rule out any treatable condition.
DIAGNOSING ALZHEIMER’S DISEASE

The diagnosis of Alzheimer’s Disease is one of excluding other conditions that may be responsible for producing the symptoms of memory loss, confusion, personality change, etc. There is no specific “test” to determine Alzheimer’s Disease, the only definitive diagnosis is given after a post-mortem brain autopsy is performed.

Since there are numerous conditions that mimic the symptoms of Alzheimer’s Disease, a thorough evaluation is recommended in order to rule out any condition that may be treatable. A neurologist, memory disorder clinic, or hospital with a specialized geriatric program can do effective evaluations.

A typical evaluation of a patient with suspected Alzheimer’s Disease generally includes the following:

- social/medical history
- sensory/motor exams
- mental status exams
- MRI (can show brain atrophy, shrinkage, tumors, strokes)
- EEG (shows brain wave activity)
- Blood tests
- Neuropsychologist exam (measures memory functioning and depression)

After a thorough evaluation, the physician can usually determine the cause of impairment. When all tests are performed and prove to be negative, a diagnosis of “probable Alzheimer’s “ is made. It is at this point that the caregiver needs to become fully educated regarding Alzheimer’s Disease and seek out a supportive network of family, professionals, and friends.
WHAT IS DEMENTIA?

Dementia is a technical term for describing a memory disorder. The word dementia comes from two Latin words meaning `mind` and `away`. A demented person has to some degree, lost his or her thinking abilities and judgement, resulting in changed behavior and lost abilities to perform routine functions. In less severe cases, this impairment may take the form of inability to manage money or drive safely in more severe cases, it can also manifest itself in loss of abilities such as those required to get dressed or eat with a knife and fork. This person needs assistance from another person to survive.

The most common dementing illness is Alzheimer’s Disease, estimated to affect between 4 million Americans. Almost half of those persons are aged 85 and over, but new information has shown that approximately 10% of all persons age 65 and over are also affected by this disease. (The National Institute of Aging estimates that one half of nursing home patients suffer from it.)

There are other types of dementing illnesses. Multiple-infarct (stroke) occurs in about 35-40% of cases and Lewy-body dementia in about 25% of cases. Other progressive dementias include, frontal lobe & Huntington’s disease, progressive supranuclear palsy and cortical basilar disease. Alzheimer’s disease occurs in about 75% of cases, that is why we hear about this disease more than the others.

“Hardening of the arteries” was once used as catch-all term used incorrectly as a cause of dementing illness. This term really is used instead of the word arteriosclerosis, which is a condition marked by loss of elasticity, thickening and hardening of the arteries. People used to believe that “hardening of the arteries” resulted in decreased blood flow to the brain rather than inadequate circulation that causes the problem.

The economic and social costs of dementia are high for everyone involved – patients, families and caregivers. While the causes of Alzheimer’s disease are unknown and there currently is no cure, there are many other conditions which also produce similar symptoms, some of which are treatable or reversible.
THE GLOBAL DETERIORATION SCALE FOR ASSESSMENT OF PRIMARY DEGENERATIVE DEMENTIA

Level 1 – No cognitive decline
Clinical Characteristics:

No subjective complaints of memory deficit. No memory deficit evident on clinical interview.

Level 2 – Very mild cognitive decline (Forgetfulness)
Clinical Characteristics:

Subjective complaints of memory deficit, most frequently in following area: (a) forgetting where one has placed familiar objects; (b) forgetting names one formerly knew well. No objective evidence of memory deficit on clinical interview. No objective deficits in employment or social situations. Appropriate concern with respect to symptomatology.

Level 3 – Mild cognitive decline (Early Confusional)
Clinical Characteristics:

Earliest clear-cut deficits. Manifestations in more than one of the following areas: (a) patient may have gotten lost when traveling to an unfamiliar location; (b) co-workers become aware of patient’s relatively poor performance; (c) word and name finding deficit becomes evident to intimates; (d) patient may read a passage or a book and retain relatively little material; (e) patient may demonstrate decreased facility in remembering names upon introduction to new people; (f) patient may have lost or misplaced an object of value’ (g) concentration deficit may be evident on clinical testing. Objective evidence of memory deficit obtained only with an intensive interview. Decreased performance in demanding employment and social settings. Denial begins to become manifest in patient. Mild to moderate anxiety accompanies symptoms.

Level 4 – Moderate cognitive decline (Late Confusional)
Clinical Characteristics:

Clear-cut deficit on careful clinical interview. Deficit manifest in following areas: (a) decreased knowledge of current and recent events; (b) may exhibit some deficit elicited on serial subtractions; (c) concentration deficit elicited on serial subtraction; (d) decreased ability to travel, handle finances, etc. Frequently no deficit in following areas: (a) orientation to time and person; (b) recognition of familiar persons and faces; (c) ability to travel to familiar locations. Inability to perform complex tasks. Denial is dominant defense mechanism. Flattening affect and withdrawal from challenging situations occur.
Level 5 – Moderately severe cognitive decline (Early Dementia)
Clinical Characteristics:

Patient can no longer survive without some assistance. Patient is unable during interview to recall a major relevant aspect of their current lives, e.g., an address or telephone number of many years, the names of close family members (such as grandchildren), the name of the high school or college from which they graduated. Frequently some disorientation to time (date, day of week, season, etc.) or to place. An educated person may have difficulty counting back from 40 by 4’s or from 20 by 2’s. Persons at this stage retain knowledge of many major facts regarding themselves and others. They invariably know their own names and generally know their spouse’s and children’s’ names. They require no assistance with toileting and eating, but may have some difficulty choosing the proper clothing to wear.

Level 6 – Severe cognitive decline (Middle Dementia)
Clinical Characteristics:

May occasionally forget the name of the spouse upon whom they are entirely dependent for survival. Will be largely unaware of all recent events and experiences in their lives. Retain some knowledge of their past lives but this is very sketchy. Generally unaware of their surroundings, the year, the season, etc. May have difficulty counting from 10, both backward and, sometimes, forward. Will require some assistance with activities of daily living, e.g., may become incontinent, will require travel assistance but occasionally will display ability to familiar locations. Diurnal rhythm frequently disturbed. Almost always recall their own name. Frequently continue to be able to distinguish familiar from unfamiliar persons in their environment. Personality and emotional changes occur. These are quite variable and include: (a) delusional behavior, e.g., patients may accuse their spouse of being an impostor, may talk to imaginary figures in the environment, or to their own reflection in the mirror; (b) obsessive symptoms, e.g., person may continually repeat simple cleaning activities; (c) anxiety symptoms, agitation, and even previously nonexistent violent behavior may occur; (d) cognitive abulia, i.e., loss of willpower because an individual cannot carry a thought long enough to determine a purposeful course of action.

Level 7– Very Severe Cognitive Decline (Late Dementia)
Clinical Characteristics:

All verbal abilities are lost. Frequently there is no speech at all – only grunting. Incontinent of urine, requires assistance toileting and feeding. Lose basic psychomotor skills, e.g. ability to walk. The brain appears to no longer be able to tell the body what to do. Generalized and cortical neurologic signs and symptoms are frequently present.

Lee Memorial’s Memory Disorder Team coordinates the comprehensive diagnosis and treatment of memory disorders. The clinic draws on the resources and expertise of a multi-faceted team of professionals to accurately diagnose and treat memory disorders:

• Neurologist
• Neuropsychologist
• Psychologist
• Nurse Practitioner
• Case Manager

Arriving at an accurate diagnosis of the cause of memory loss can spare the family the frustration of pursuing inappropriate and ineffective treatments.

The clinic helps patients and loved ones cope with the diagnosis by assisting with a variety of services:

• Counseling/therapy for both patients and family members
• Day Care referrals
• Education
• Community resources
• Caregiver education and support

Lee Memory Care is located in the Medical Office Center at Lee Memorial Health System, Cleveland Avenue. An individual may be self-referred or referral may be made through physicians or family members. For more information and scheduling, please contact (239) 334-5634
LEGAL ISSUES FOR THE FAMILY OF A MEMORY IMPAIRED PERSON

There are two broad issues that need to be addressed when a family member is diagnosed with a memory impairment. The two issues are property management and health care decisions. It is imperative that the memory impaired is drawn into discussions about these issues in the first stages of the disease so that the patient’s wishes are made known.

The memory-impaired person should execute legal documents to prepare for incapacity if the patient is legally competent. Many persons in the early stages of Alzheimer’s and related disorders are competent to execute legal documents. The test of legal capacity or competency is that the person knows his or her surroundings and has an understanding of the legal documents they are executing. This is decided on a case-by-case basis by the attorney interviewing the client.

If the attorney believes the person is competent, the client should execute the following documents: (1) a Last Will and Testament or Trust; (2) a Durable Power of Attorney to Manage Property; and (3) a Designation of Health Care Surrogate and Living Will.

A Last Will and Testament is a legal document which outlines the distribution of real and personal property at the death of the Testator (the person making the Will). A Trust is similar in that it outlines a plan for distribution of property at death, but it also outlines plans for management of property during the lifetime of the Settler (the person making the Trust). In the event that the memory-impaired person owns property in his/her own name but is unable to execute a Trust or Last Will and Testament because they lack legal capacity, all real and personal property will pass to their heirs at the time of their death, and state laws dictate who the heirs at law are.

A Durable Power of Attorney is another legal document that is imperative for the memory impaired person to have. This document allows the person, (the principal) to name a trusted friend or family member as their “agent” to manage all real and personal property during their lifetime. A Durable Power of Attorney lasts during the principal’s incapacity. A General Power of Attorney does not.

The Durable Power of Attorney can include the power to make gifts of property, to apply for government benefits, to sue and defend lawsuits, to sell homestead property and any other power the principal has. It is a powerful document that should only be given to someone who can be trusted. Some Durable Powers of Attorney include the power to make medical decisions, although the preferred choice is to have a separate document regarding medical decisions. In the event that the Durable Power of Attorney is only a property management document, another essential document for a memory-impaired person is the Designation of Health Care Surrogate. The Health Care Surrogate is a legal document that allows you to appoint someone to make all medical decisions for you in the event that you are no longer able to make those

7
decisions on your own. It is important to appoint someone who knows best how you would like to be treated and will carry out your wishes. Your surrogate will have the authority to review all medical records and enforce your Living Will, as well as make all medical decisions if you are incompetent.

It is also critical for the memory impaired person to discuss with family and friends their feelings about medical care, including their preference for or against life prolonging medical intervention. The wishes of the patient regarding life-prolonging procedures should be specifically described in a Living Will.

The best scenario for the family of the memory impaired person is to make sure that all of the above mentioned documents are in place before the person becomes incapacitated. However, many times families are not able to meet with an attorney to have these documents executed and the person enters the middle stages of Alzheimer’s and related disorders without such planning.

Each person’s financial circumstances are different and require analysis by someone well versed in planning for individuals with the disease, and what type of care may be required. A careful review of each asset and a determination of what can be done with that asset is very important. At this stage, the person is not included in any decision making. Due to the terminal nature of Alzheimer’s Disease and related disorders, it is very important that a plan be developed so that assets do not remain titled to the memory impaired person beyond the point where he or she is too incapacitated to deal with them. When property management issues are not resolved before incapacity, it may be necessary to seek guardianship through the court.

In the event that all financial issues are resolved but there are ongoing medical problems and no written designation of a surrogate, through the health care statute, a family or friend can be empowered to make medical decisions for the incompetent person and become that individual’s health care proxy. The attending physician and a second physician must state in writing that the person is not competent to make medical decisions. The two written statements are added to the person’s medical records and a family member or friend can step into place to make medical decisions. This process takes place without court intervention and can be accomplished quickly. A health care proxy should be prepared for all persons who are incompetent and who had never signed a Designation of Health Care Surrogate.

Decision making for a memory-impaired person becomes more difficult as the person enters the late stages of the disease. The primary concern at this stage is the day to day care of the person. Often times this means admission in a skilled nursing facility if total care in the home is not possible. The cost for nursing home care or 24 hour in home care requires additional financial planning and knowledge of the available government benefits.

Medicare may pay some days in the nursing home, but only if there was a three day prior hospitalization. After Medicare coverage is exhausted, the person will be required
to pay privately or apply for Medicaid. The Medicaid eligibility rules are ever changing. Therefore, it is important to clearly understand how and when the person might qualify for Medicaid. Do not rely on unreliable sources. It is necessary that you consult an attorney familiar with these laws as early as possible. The Department of Children & Families are not empowered to counsel you as to how to qualify for Medicaid, nor are financial planners.

Additionally, the issue of life prolonging procedures becomes very important during the end stage of Alzheimer’s and related disorders. If the person did not execute a Living Will it is necessary that friends and relatives who have any knowledge of the person’s wishes regarding having their life artificially prolonged state those intentions in writing. Even if the individual did not make any statements, under current law a family member can make the decision they believe is in the best interest of the individual.

All of these legal issues related to memory impairment are difficult because we often find families guessing what the person might have wanted. The disease is devastating to families and that devastation can be reduced with some planning in the first stages of the disease when the individual can participate in the plan. When choosing an attorney to assist with the plan, make sure you choose someone familiar with the laws affecting the elderly, specifically those affecting the memory-impaired person.

Prepared by: Osterhout & McKinney, P.A.
Elder Law Attorneys
CAREGIVER EDUCATION AND SUPPORT

ALVIN A. DUBIN ALZHEIMER’S RESOURCE CENTER – (239) 437-3007
10051 McGregor Blvd., Suite 101, Ft. Myers, Fl  33919

The Dubin Alzheimer’s Resource Center provides education to the public as well as to the caregiver. The center houses a lending library with a vast variety of material on Alzheimer’s disease and related disorders. Books, videos, pamphlets and articles on all aspects of caring for someone with Alzheimer’s disease or another form of dementia are available. Staff and volunteers are available to help in problem solving and locating resources for the caregiver & family. The Dubin Center facilitates support groups which allow friendships to form between people who are dealing with similar caregiving situations and provides opportunity to learn about the disease process and ways to cope with daily challenges. A social worker is available to help in problem solving and assisting people to find and utilize appropriate services and health centers for long term or respite care. Hope Hospice satellite offices in Cape Coral and Lehigh can be “pick-up places” for educational materials.

LEE MEMORY CARE - OLDER ADULT SERVICES – (239) 334-5884
LEE MEMORIAL HEALTH SYSTEM
Caregiver Education Programs. These classes are provided at no cost in various locations throughout Lee County.

The Caregivers Education program, offers educational and emotional support for people who take care of a dependent loved one at home. A twelve-hour program is presented by health care professionals who will help the family understand behavior changes related to chronic illness and memory impairment.
ALZHEIMER’S SUPPORT GROUPS OF LEE COUNTY

Dubin Alzheimer’s Resource Center
10051 McGregor Blvd., Suite 101
Ft. Myers, Fl 33919
www.alzheimer’sswfl.org
239 437-3007

Please call the Dubin Center to confirm these dates and times.

BONITA SPRINGS
Every 4th Monday at 10:30 a.m.
27200 Riverview Center Blvd.

CAPE CORAL
1st & 3rd Thursdays at 2:00 p.m.
Gulf Coast Village, 1333 Santa Barbara Blvd. Cape Coral

EAST FT. MYERS/ALVA
2nd Thursday of each month at 1:00 p.m.
St. Vincent de Paul
13031 Palm Beach Blvd.

FORT MYERS
2nd and 4th Wednesdays at 9:45 a.m.
Westminster Presbyterian Church
16531 Bass Road & Summerlin

NORTH FORT MYERS
4th Thursday of each month at 2 p.m.
Pine Lakes Country Club
3 ½ miles north of the Shell Factory on US 41

PINE ISLAND
1st Thursday of each month at 10:30 a.m.
Pine Island United Methodist Church
5701 Pine Island Rd, Bokeelia

SAN CARLOS PARK/ESTERO
4th Wednesday of each month at 2 p.m.
Grace Presbyterian Church
7470 Hickory Rd.
SANIBEL
4th Tuesday of each month at 10 a.m.
Ruth Hamann Residence
1515 Bunting Lane
(no meetings during Summer months)

LEHIGH
3rd Monday of each month at 12:30 p.m.
The Community Health Association
9 Beth Stacey Road

ADULT CHILDREN GROUP
1st Tuesday at 6:15 p.m.
Dubin Alzheimer’s Resource Center
10051 McGregor Blvd., Ste. 101, Ft. Myers

LONG TERM CARE ISSUES
Every 2nd Friday at 1:30 p.m.
Dubin Alzheimer’s Resource Center
10051 McGregor Blvd., Ste 101, Ft. Myers

TEEN GROUP
2nd Monday of each month at 4:15 p.m.
Dubin Alzheimer’s Resource Center
10051 McGregor Blvd., Ste 101, Ft. Myers

EARLY STAGE ALZHEIMER’S GROUP
A special program for individuals with early stage dementia
Please call the Dubin Center (239) 437-3007 for more information
SAFETY PROGRAM FOR ALZHEIMER’S PERSONS AND CAREGIVERS

The Alvin A Dubin Alzheimer’s Resource center, Inc. is pleased to offer an important safety program which has been developed with the help of professionals from a variety of different fields with one goal in mind: TO HELP SAVE LIVES

At the Alvin A Dubin Alzheimer’s Resources Center, we are committed to helping caregivers ensure that there loved ones with memory loss have the best possible care in a safe environment. Providing an emergency plan kit and identification bracelet via our safety program is one way we can achieve this goal. With the assistance of many individuals and agencies who are interested in the welfare and safety of our friends and neighbors affected by Alzheimer’s disease, we are able to help caregivers find peace of mind by putting in place an emergency plan for the care of their loved ones.

The emergency plan kit is intended to help eliminate the possibility of a crisis situation if the caregiver of a loved one with Alzheimer’s disease or related disorder requires emergency care. The emergency workers who come to rescue the caregiver may not realize a memory-impaired adult resides in the home, and therefore may leave the person with Alzheimer’s alone when they take the caregiver to the hospital.

The Safety Program universal Symbol, included with the plan kit, is designed to alert emergency workers that a memory-impaired person resides in the home. The symbol hangs on the front of the home’s refrigerator. The corresponding packet of forms, which contain important emergency contracts and care instructions provided by the caregiver, are located inside the refrigerator. Once a trained emergency worker sees the symbol, he or she will automatically know to search for an Alzheimer’s client in the house and using the information in the refrigerator, take appropriate measures to see that care for this person is provided.

The Dubin Alzheimer’s Resource Center staff works closely with local law enforcement and emergency workers throughout lee County to help train them on how the safety program can assist them when they respond to an emergency involving the caregiver of an individual with memory loss.

The safety program packet is provided at no charge, through grants from the Southwest Florida Community Foundation and the Cape Coral Community Foundation, to caregivers caring for a loved one at with memory loss in their homes in Lee County. Each packet contains all the items necessary to participate in the safety program. Instructions to put the emergency plan in place are included with each packet and assistance is available from the Dubin Alzheimer’s Resource Center. The safety program also stresses the importance of having an identification bracelet for individuals with memory loss to wear at all times. Identification bracelets help local law enforcement identify individuals who are separated from their caregivers and are unable to find their way home or even tell someone where they live due to memory impairment. Each bracelet (or necklace) is engraved with the person’s first name or “nickname”, a code number which matches their application number, the words “memory impaired”
and the phone number for the Lee County Sheriff's Office. Both the Dubin Center and the Sheriff's Office maintain records of the enrolled persons' application numbers and identifying information. Being able to look at a bracelet, make a phone call, and escort the lost person home reduces the time memory persons are away from their homes and saves law enforcement departments valuable effort. A brochure with an application to obtain a bracelet is included in each safety program packet. Bracelets are provided at no charge by Walgreen's.

**Caregivers interested in participating in the Safety Program for Lee County can call the Dubin Alzheimer's Resource Center at (239) 437-3007 to obtain a Safety Program packet. The Dubin Center will provide ID bracelet applications for memory impaired persons living in assisted living facilities or retirement communities in Lee County.** If you live outside of Lee County, the Dubin Center can help you find the Alzheimer's Resource Center or local chapter of the Alzheimer's Association in your community.
HOW WE CAN BEST DEAL WITH EMERGENCY SITUATIONS

Some common stories we hear from dementia families are:

“He took off in the car.”

“All of a sudden, she got so angry and ran toward me with fists.”

“He’s always found his way home before.”

“All of a sudden she doesn’t know where she is or who she is; she won’t stop crying or wringing her hands.”

IT’S GREAT TO HAVE A CONTINGENCY PLAN, BUT ALZHEIMER’S SITUATIONS ARE KNOWN FOR CHANGING INSTANTANEOUSLY, WHAT WE CALL “A CATASTROPHIC REACTION.” SOMETIMES WE HAVE TO REACT QUICKLY WITHOUT WARNING.

What should you do if your loved one’s needs exceed your ability to control or cope in a particular situation?

NEVER STAY IN A POTENTIALLY DANGEROUS SITUATION, LEAVE THE IMMEDIATE AREA.

If you need to “get away,” take your portable phone, go to a designated neighbor or public building/store and call for assistance. Most likely you will be able to keep an eye on your loved one from where you are. You or any well meaning citizen should not attempt to persuade your loved one if he/she is still extremely agitated.

A DEMENTIA FAMILY MUST NEVER HAVE FIREARMS ON THEIR PREMISE, EVEN IF THEY ARE UNLOADED. OUR ALZHEIMER’S PEOPLE CAN BE EXCELLENT AT HIDING ALL KINDS OF THINGS!

When you have time to use a contingency plan, some situations you may want to plan for are WANDERING and/or BEHAVIORAL DETERIORATION.

You can prepare a plan should your loved one wander off.

1. Have an I.D. bracelet for memory disorders and a registration number with the police.
2. Know and have your emergency phone numbers handy.
3. DO NOT LEAVE WHERE YOU ARE! Your loved one may return or authorities may need to contact you. Leave only if another individual is stationed there.
4. Always have medical history, current physicians phone numbers and directive papers accessible (house, glovebox, suitcase, etc.)
5. Have a recent picture of your loved one.
When a dementia person demonstrates a rapid change in mood or behavior, plan to have his/her medical situation assessed. It could be an easily correctable physical problem such as a urinary tract infection or virus. When you have eliminated a physical problem, plan to have a behavioral assessment done.

CONTACT YOUR NEUROLOGIST OR PRIMARY CARE PHYSICIAN TO REVIEW THE PRESENT SITUATION. IF YOU ARE NOT CURRENTLY UTILIZING THESE SPECIALISTS SOME OF YOUR OPTIONS ARE:

Ruth Cooper Institute where they have an outpatient clinic and a mobile crisis unit
(239) 275-3222

Riverside Behavioral Center a psychiatric hospital in Charlotte County – crisis team is also available. 1-(800) 722-5563

Lee Memory Care  Lee Memorial Hospital an outpatient clinic to assess and diagnose memory disorders. This is a non-emergency clinic for evaluation, diagnosis & treatment. (239) 334-5634  Monday- Friday 8:30a.m. to 4:30p.m. for appointments.

When setting up a contingency plan ask yourself:

1. “What would I do if ___________________________?”
2. Think of the action steps you need to solve your problem situations.

REMEMBER – YOU CANNOT BE ALL THINGS TO ALL PEOPLE AT ALL TIMES – PLAN TO ASK FOR HELP!

OUR LOCAL DUBIN ALZHEIMER’S RESOURCE CENTER HAS HELP IN PLANNING FOR AN EMERGENCY- PLEASE SEE PAGES 13 & 14 TO REVIEW INFORMATION ABOUT THE SAFETY PLAN.
RESPITE

RESPITE is defined as a period of rest or relief. For those who give constant care to an ill person, it can be a very welcome word. The need to relieve a primary caregiver is becoming more and more apparent, and programs to provide respite are being started in many places.

A few words about what a respite worker will prevent misunderstandings. Although respite workers in general have gone through training programs, they do not, for obvious reasons, administer medications. Their primary purpose is to relieve the caregiver. As part of that purpose, they do whatever is necessary to ensure the comfort and safety of the homebound person, such as feeding, seating, making comfortable, etc. They provide companionship and supervision.

Respite might also be provided in a setting such as an assisted living facility or a nursing home. Such respite would generally be for more than a few hours. Some ALFs and nursing homes will accept a person for as little as a day, and some will not. Several agencies can provide either short or long term respite and emergency respite.

Listed below are a few volunteer or minimal fee-for-service that can help provide short-term companions for social interaction, transportation or help with light homemaking/chores.

INTER-FAITH CAREGIVERS, INC.
San Carlos/Ester – (239) 992-6080
Fort Myers – (239) 936-4544
Cape Coral/N. Ft. Myers/Pine Island –(239) 573-8323

Provides volunteer respite to family caregivers, including home visits, phone support and transportation.

You may also check with other local churches for this type of assistance. Most assisted living facilities or skilled facilities can provide a fee-for-service respite stays of several days to months – information begins on page 27 for a compilation of these facilities. Please be aware that this information is ever changing as well. Please call the SW Florida Elder Helpline at 1 (866) 505-4888 for the most current information.

You may also call our local Dubin Alzheimer’s Resource Center for a list of respite services @ (239) 437-3007.
SW FLORIDA ELDER HELPLINE

Southwest Florida has many services available but determining the various eligibility requirements or seeking a service that seems unavailable can seem like an endless task. That’s where the Elder Helpline can help to reduce frustration and confusion by evaluating individual needs and then “linking” the caller with the right service agency. The Elder Helpline is designed to provide information and referral assistance to put the caller in touch with appropriate health or human services.

Anyone who wants to obtain services for a Lee County resident sixty or older can call Elder Helpline for help or information.

DR. PIPER CENTER FOR SOCIAL SERVICES (Call Elder Helpline) 1-866-505-4888
1771 Evans Ave., Ft. Myers, FL 33901

The services provided are:

Senior Companion Services – Senior Companions help ease loneliness and illness. They bolster self esteem, help clients solve problems and provide personal assistance. They do not serve as home health aids or drivers or social workers. They are companions…friends. They help people…what friends do for friends. They provide respite care.

Outreach Service – Outreach service attempts to identify needy elderly, evaluate their needs, discover resources to meet their needs and arrange for provision of services.

SENIOR FRIENDSHIP CENTERS, INC. (Call Elder Helpline) 1-866-505-4888
COMMUNITY CARE FOR THE ELDERLY PROJECT
3600 Evans Ave., Ft. Myers/9 Beth Stacey Rd., Lehigh Acres

The purpose of the Community Care for the Elderly Program is to allow the frail elderly to remain in their homes with dignity and comfort as long as possible. The services provided are those which have been deemed essential to prevent unnecessary or premature institutionalization. The services provided are:

Case Management-A case manager evaluates potential clients to determine eligibility and to develop a case plan designed to deliver the most effective set of services. Regular monitoring of the client’s condition and situation ensures that the client’s needs
are being met through changing circumstances. A case manager serves as an advocate for clients, calling on community, family, volunteer and governmental services for elderly persons. A case manager is also able to respond to immediate or emergency needs of clients.

**Adult Day Care**-Adult Day Care Centers in Fort Myers and Lehigh Acres operate Monday through Friday, providing socialization, companionship, field trips, stimulating and enjoyable activities, crafts, discussions, and good times for persons who might otherwise be alone, isolated and lonely. These activities take place in a protective environment with trained caregivers and a nurse. A hot, nutritionally balanced meal is served, and transportation is provided to and from the Center for those who need it.

**Personal Care**-Trained personal care workers assist clients on a regularly scheduled basis to maintain personal hygiene and comfort.

**Homemaking**-Assistance is provided on a regularly scheduled basis with light housekeeping services, such as vacuuming, dusting, mopping, laundry, dishes. Shopping may also be provided as a part of this service.

**Medical Transportation**-Transportation to and from appointments with doctors, dentists, etc. is provided for clients.

**Tele-Mate**-Is an emergency response system which allows frail elders living alone to signal for emergency assistance.

**Respite**-Routine respite care can be provided on a weekly basis to provide relief for a person caring for an ill elderly person who cannot be left alone. Requests can be made for emergency respite or for respite for longer periods of time.

**Home and Community Based Services Medicaid Waiver Program**-A community alternative to nursing home placement.

**STATE OF FLORIDA DEPARTMENT OF CHILDREN & FAMILIES**

**ADULT PROTECTIVE SERVICES HOTLINE – 1-800-96ABUSE (1-800-962-2873)**

A 24-hour hotline to report abuse (including self abuse and self neglect) to yourself or others. If case is accepted, an investigation will be made. Callers do not have to identify themselves.

**CARES – 278-7215**

Comprehensive assessment and review for long term services.

**CLIENT RELATIONS OR COMPLAINTS – 338-1431**
HOME CARE FOR THE ELDERLY PROGRAM – 338-1128

A program of financial assistance for person who must stay at home to care for an elderly person who lives in the home. Eligibility depends on the income of the elderly person who needs care. The program is designed to encourage care for the elderly in a family setting as an alternative to institutional care.

MEDICAID INSTITUTIONAL CARE PROGRAM (ask for adult payments) 936-5000

NURSING HOME COMPLAINTS – 338-1493
LONG TERM CARE OMBUDSMAN COUNCIL

OPTIONAL STATE SUPPLEMENTATION (ask for adult payments) 936-5000

Assistance in paying for adult congregate living facility care for eligible individuals.

MEALS ON WHEELS

MEALS ON WHEELS OF LEE COUNTY, INC.

Hot, nutritionally balanced meals delivered to homebound and handicapped persons during the lunch hour. Charge is made according to area. Food stamps are accepted.

GREATER FORT MYERS AND NORTH FORT MYERS – 337-1055
CAPE CORAL – 542-1552
LEHIGH ACRES – 369-2075 OR 369-5818
BONITA SPRINGS – 947-1755
ESTERO/SAN CARLOS – 992-6080
SANIBEL – 472-4096
Hope Hospice is a unique health care organization providing medical, emotional and spiritual care to patients and families facing a life-limiting illness.

Care is provided in homes and nursing facilities throughout Lee County and portions of Hendry and Glades counties.

Hospice care provides:

- Scheduled Nursing Visits
- Physician on Staff
- Personal Care & Homemaking
- Counseling for Patient & Family
- Chaplains
- 24-hour On Call Services
- Volunteer Assistance
- Inpatient Respite
- Bereavement Counseling
- Children’s Programs
- Hope Life Care – pre-hospice service
HOW CAN COUNSELING HELP YOU?

There are many feelings and emotional difficulties that can interfere with everyday living:
- Depression
- Anxiety
- Grief
- Sadness
- Guilt
- Loneliness
- Irritability
- Adjustment Problems

It is not unusual to experience difficulties arising from relocation, retirement, being a caregiver, or from a chronic health problem. Counselors will work with you to assist in the resolution of your emotional issues. We build on your strengths and help you develop skills that will enhance your ability to adjust and cope with life. We provide these services in the setting that is most comfortable for you:

- Our offices in Fort Myers and Cape Coral
- Home Visits
- Nursing Homes
- ACLF’s

Services Offered:
- Assessments
- Consultations
- Individual Therapy
- Family Therapy
- Group Therapy
- Marriage Counseling
- Information & Referrals
- Community Education
- ACLF Overlay

Ethics and Standards:

Counselors are bound by a code of ethics specific to the profession. Confidentiality is strictly maintained and information will not be given to others without informed consent or when required by law.

Costs:

Fees are based on a sliding scale. We are covered by Medicare, Medicaid and most health insurance plans. We will bill your plan for you. Fee will be discussed prior to your first appointment and we will be happy to answer any questions you may have.
TRANSPORTATION FOR SENIORS
MEDICAL AND NON-MEDICAL

AMERICAN CANCER SOCIETY – 936-1113
P.O. Box 6038, Ft. Myers, FL 33911

American Cancer Society will provide medical transportation for cancer patients only for treatments, doctor appointments, etc.

CAPE CORAL HOSPITAL CARE VAN – 574-2323, EXT 1741
636 Del Prado Blvd., Cape Coral, FL 33990

The Care Van provides free transportation to and from Cape Coral Hospital for day surgery, outpatients, and inpatients. Service is provided Monday through Friday from 8:30 a.m. to 4:30 p.m. Van is equipped with a wheelchair lift. No medical attention is provided.

CAPE CORAL PARKS & RECREATION – 574-0801
In conjunction with CAPE CORAL SENIOR CENTER (for senior citizens and handicapped)
LAKE KENNEDY – 574-0575
ROTINO – 574-0807
400 Santa Barbara Blvd., Cape Coral, FL 33904

Transportation to medical appointments and an area grocery store is available to Cape Coral residents who are frail, elderly or who have no other means of transportation. A van which is equipped with a lift for wheelchairs will pick up residents on scheduled days.

GOOD WHEELS - 768-2900

Transportation for medical appointments, grocery shopping, sliding scale fee. For the disadvantaged, disabled and general public.

LEE TRAN SPONSORED RIDES (ADA) 277-5012 X 2224

DR. PIPER CENTER (Call Elder Helpline) 1-866-505-4888
1771 Evans Ave., Ft. Myers, FL 33901

Medical transportation is provided for clients of DEPC.
ADULT DAY CARE

One of the options available to families caring for a memory impaired person is adult day care. It benefits the impaired person, providing him or her with socialization and stimulation frequently not available in the home; it also benefits the family by giving them a break from the never-ending demands that their responsibilities as caregivers entail. Some working children have found adult day care the way to provide needed supervision to a memory-impaired parent while still remaining in the work force.

Adult day care programs vary in size, structure, physical environment, staffing, cost and level of population served. Factors to be considered when choosing one include whether or not a nurse is on staff (important if medications need to be administered while at day care), whether or not ancillary services such as transportation are provided, the types of activities offered, and whether or not the center can accommodate incontinence or mobility restrictions.

Adult day care is not covered by Medicare or supplemental insurance. However, if a memory-impaired person carries long-term care insurance, his or her policy may cover this cost. Some day care centers will give sliding fee discounts and there is limited assistance available through state programs which are locally administered by Senior Friendship. For further information, contact the Elder Helpline 1 (866) 505-4888.

Adult day care is especially appropriate when the memory-impaired person can still benefit from stimulating activities and socialization in a protective environment. For persons with Alzheimer’s disease, the middle stage is the most appropriate time to begin day care. The earlier a person enters day care, the greater the benefits to both the person and his or her caregivers. If a family waits until they are totally exhausted, the impaired person is more easily agitated, frustrated, confused and disoriented, making the adjustment more difficult for both.

The security and peace of mind offered by day care benefits both the impaired person and the family. He or she returns home content, less frustrated and ready to be with family. Caregivers and family members benefit from having had time to themselves and are therefore able to be more responsive to the impaired person and consequently better able to continue. Additionally, many family members find themselves able to sleep better at night because, as a result of coming home tired from day care activities, the impaired person gets his or her rest during the night.
ADULT DAY CARE

ALMOST FAMILY
6324 Corporate Court
Ft. Myers, Fl  33919
(239) 482-4459

ARDEN COURT
15950 McGregor Blvd.
Ft. Myers, Fl  33908
(239) 454-1277

CHOICES in Living
3812 Skyline Blvd.
Cape Coral, Fl  33914
(239) 540-6813

FINE CARE CENTER
1929 Winkler Ave.
Ft. Myers, FL  33901
(239) 278-3463

MILLENNIUM HOUSE
8951 Bonita Beach Rd.
Suite 297
Bonita Springs, Fl  34135
(239) 992-5513

SANTA BARBARA COURT
1333 Santa Barbara Blvd.
Cape Coral, FL  33919
(239) 772-1333

SENIOR FRIENDSHIP CENTER
The Living Room
3600 Evans Ave.
Ft. Myers, FL  33901
(239) 275-1881

The Living Room
9 Beth Stacey Blvd., Suite 207
Lehigh Acres, FL  33936
(239) 275-1881
As the Alzheimer’s person becomes further impaired he/she will require constant supervision. Quite often, there is no spouse or family member able to take on this enormous responsibility. An Assisted Living Facility (ALF) may be an appropriate living situation for your loved one. An ALF provides a comfortable living arrangement in a home-like setting. ALF’s are not nursing homes but do provide room and board, twenty-four hour supervision, assistance with daily needs and personal care, limited medical supervision and companionship. This type of facility can be a residential home, a high rise building, a multi-unit dwelling or a specially designed retirement community. The monthly cost can range from $1,800 to $3,000 PLUS, and this cost is not covered by Medicare or Medicaid. However, if you meet specific financial criteria, you may be eligible for Optional State Supplementation. For more information, call (239) 936-5000 and ask for Adult Medicaid/Payments.

Many ALFs will take Alzheimer’s persons and some have a better track record with this population than others. It does take special care and training to understand and manage a person with “Alzheimer”. Generally, if your loved one is ambulatory, able to assist with their personal needs, has no serious behavior problems and is continent of both bladder and bowel, they will be acceptable for an ALF. When the person becomes further deteriorated, a more appropriate placement will need to be made. ALFs provide limited health care services and the person must be ambulatory.

Most ALFs are licensed and inspected regularly. The Department of Children and Families is responsible for this. You will want to visit the prospective ALF, meet the owner or administrator and ask questions. The following list of agencies are ALF’s, but please note that their are particular facilities that specialize in dementia care. They are noted as such.
ASSISTED LIVING FACILITIES (ALFs)

ARDEN COURT – 454-1277
15950 McGregor Blvd., Ft. Myers, FL 33908
Facility specializes in Alzheimer’s care

BARKLEY PLACE – 939-3553
36 Barkley Circle, Ft. Myers, FL 33901

CALUSA HARBOUR – 332-3333
2525 E. First Street, Ft. Myers, FL 33901

CANTEBURY HOUSE – 992-8599
10 Seventh St., Bonita Springs, FL 34134
Has dementia care

CAPE CHATEAU – 574-9494
804 S.E. 16th Pl., Cape Coral, FL 33990

CLARE BRIDGE OF FORT MYERS – 561-2463
13565 American Colony Blvd., Ft. Myers, FL
Specializes in dementia care

CLARE BRIDGE OF CAPE CORAL
Santa Barbara Blvd., Cape Coral, FL
Specializes in dementia care

THE COTTAGES – 656-0720
145 W. Mariana Way, N. Ft. Myers, FL 33903

CROSS KEY MANOR – 369-2194
1550 Lee Blvd., Lehigh Acres, FL 33936

CYPRRESS COVE
10200 Cypress Cove Dr (near Health Park) Ft. Myers, Fl 33908

CYPRRESS SQUARE – 278-0136
7205 Cypress Dr., S.W., Ft. Myers, FL 33907
ENCORE – 437-5511
9461 HealthPark Circle, Ft. Myers, FL 33908
Specializes in Alzheimer’s care

FAMILY HOME CARE, INC. – 334-1255
2580 1st Street Ft. Myers, Fl 33901

THE HARBOR (GULF COAST VILLAGE) – 772-1333
1333 Santa Barbara Blvd., Cape Coral, FL 33991
Specializes in Alzheimer’s care & has general ALF

HAWTHORN PLACE 368-6362
209 Punta Alta Ct., Ft. Myers, Fl 33936

HERON HOUSE 334-2500
9731 Commerce Center Ct.

IVY STEVEN HOME 368-8287
300 Edward Av, Lehigh, Fl 33972

KINGS CROWN (SHELL POINT VILLAGE) – 466-1111
15000 Shell Point Blvd., Ft. Myers, FL 33908

THE LAKES – 454-4100
7460 Lake Breeze Dr., Ft. Myers, FL 33907
Special Alzheimer’s Unit and general ALF

MILLBROOK HOMES of SW FLORIDA 415-1169
5812 Beechwood Trail, Ft. Myers 33919
2324 SE 5th Court, Cape Coral 33904
14556 Aries Way, Ft. Myers 33912

MILLIES’ CONVALESCENT CARE 458-0080
113 SW 28th Terrace, Cape Coral, Fl 33914

MILLIES’ CONVALESCENT CARE II 337-1099
2919 Nelson St., Ft. Myers, Fl 33901

THE PALMS – 275-7800
2674 Winkler Ave., Ft. Myers, FL 33901
THE PARK CLUB OF FORT MYERS – 939-5421
1896 Park Meadow Dr., Ft. Myers, FL 33907

PERIDOT PLACE – 549-5502
4610 Coronado Pkwy., Cape Coral, FL 33904

PERIDOT PLACE – THE WOODLANDS 574-8789
825 Santa Barbara Blvd, Cape Coral, Fl 33991

PERIDOT PLACE- DEL PRADO 574-9732
2728 SE 16th Place, Cape Coral 33904

THE PLAZA 948-2600
26850 S. Bay Drive, Bonita Springs, 34134

PLEASANT VIEW RETIREMENT CENTER – 772-5609
1318 Santa Barbara Blvd., Cape Coral, Fl 33991

RIVERSIDE VILLAGE RETIREMENT COMMUNITY – 332-3788
3331 E. Riverside Dr., Ft. Myers, FL 33905

SPRINGWOOD COURT – 278-0078
12780 Kenwood Lane, Ft. Myers, FL 33907

STERLING HOUSE OF FORT MYERS – 481-6666
14521 Lakewood Blvd., Ft. Myers, FL 33919
Can take early stage Alzheimer’s

STERLING HOUSE OF LEHIGH – 368-2500
1251 Business Way, Lehigh Acres, FL 33936
Can take early stage Alzheimer’s

STERLING HOUSE OF CAPE CORAL – 543-7777
1416 Country Club Blvd., Cape Coral, FL 33990
Can take early stage Alzheimer’s

VILLA PALMS – 433-5553
6722 Winkler Road, Ft. Myers, FL 33919

WEST BAY – 542-3121
4920 Viceroy Ct., Cape Coral, FL 33904
NURSING HOME PLACEMENT

Each year thousands of families make the decision to place a loved one in a long term care facility. This is usually an agonizing decision. Unfortunately, institutionalization is generally seen as a tragic defeat rather than a natural transition in providing the best possible care for a loved one. Families often experience grief, sadness and guilt after making this decision. Keep in mind that adjusting to the nursing home placement is a two-fold process requiring emotional changes for both the individual with Alzheimer’s and the family.

When choosing a nursing home, you will want to consider factors such as location, services provided, cost, atmosphere, recreation, and most important, the quality of care. You will want to make an appointment to visit the nursing home, meet the administrator and staff, and have all of your questions answered. It is also recommended that you make at least one additional “unannounced” visit to get a clearer idea of what the home is like. Remember, choosing a nursing home is often made during a crisis situation when time is short and minds are troubled. Try to use careful, clear-headed consideration and take the time you need to feel comfortable with your choice.

Paying for nursing home care can be a confusing issue. You will need to educate yourself as much as possible about this aspect of care. Charges vary among nursing homes with the average cost around $5,000 per month. Many people are mistaken in thinking that Medicare or other private insurance companies cover long-term placements.

This is not true. Medicare does not cover custodial care, nor do VA Hospitals admit on a diagnosis of Alzheimer’s. Medicare is a short-term federally aided program that can pay for some days of nursing home care. Supplemental insurance policies are very specific about what they WILL cover and most DO NOT cover long term care. Many people are in nursing homes paying for care out of their personal resources.

If you have no way of paying for nursing home costs you may be eligible for Medicaid, a government assisted program. This program has strict eligibility requirements. This program will supplement your own income to pay for nursing home care if you are low
income or have spent down your personal finances to a certain amount. To find out the specific requirements and to apply for this program you must contact your local Department of Children & Families Institutional Care Program Office (936-5000).

The Dept. of Children & Families worker will ask for various information and documents in order to process your application. If you are married and your spouse will be the one applying for Medicaid, you will be allowed to retain a fair amount of income and assets to care for yourself. Your residence and automobile is not considered an asset.

For specific information on appropriate nursing homes, Medicaid guidelines, placement procedures or other concerns, contact Dept. of Children & Families Medicaid Institutional Care Program at (239) 936-5000.
NURSING HOMES IN LEE COUNTY

CALUSA HARBOUR – 332-3333
2525 E. First Street, Ft. Myers, FL 33901

CAPE CORAL REHABILITATION – 574-4434
2629 Del Prado Blvd., Cape Coral, FL 33904

CORAL TRACE - 574-4434
2629 Del Prado Blvd., Cape Coral, Fl 33904

CROSS KEY MANOR - 369-2194
1550 Lee Blvd., Ft. Myers, Fl 33936

CYPRUS COMMUNITY CARE – 936-0203
7173 Cypress Blvd., Ft. Myers, FL 33907

CYPRUS COVE 415-5100
10200 Cypress Cove Drive, Ft. Myers, Fl 33908

EVANS HEALTH CARE - 277-3977
Has Alzheimer’s unit
3735 Evans Ave., Ft. Myers, Fl 33901

GULF COAST VILLAGE CARE CENTER – 772-1333
Has Alzheimer’s unit
1333 Santa Barbara Blvd., Cape Coral, FL 33991

HEARTLAND HEALTHCARE CENTER – 275-6067
Has Alzheimer’s unit
1600 Matthew Dr., Ft. Myers, FL 33907
HEALTHPARK CARE CENTER – 433-4647
16131 Roserush Court, Ft. Myers, FL 33908

IHS – 482-2848
13755 Golf Club Parkway, Ft. Myers, Fl 33907

LEE CONVALESCENT CENTER – 334-1091
2826 Cleveland Ave., Ft. Myers, FL 33901

MANOR CARE – 561-7700
Special unit for Alzheimer’s
13881 Eagle Ridge Dr., Ft. Myers, FL 33912

SHADY REST NURSING HOME – 277-5000
Special unit for Alzheimer’s
2300 N. Airport Road, Ft. Myers, FL 33907

SHELL POINTE NURSING PAVILION – 466-1111 unit for Alzheimer’s
15000 Shell Pointe Blvd., Ft. Myers, FL 33908

TANDEM HEALTH CARE CENTER – 995-8809
991 Pondella Rd., Ft. Myers, Fl 33903

WINKLER COURT – 939-4993
Special Unit for Alzheimer’s
3250 Winkler Ave. Ext., Ft. Myers, Fl 33916
STATE OF FLORIDA BRAIN BANK
RESEARCH PROGRAM

The Brain Bank is a program of the Alzheimer’s Disease Initiative, Department of Elder Affairs. Through the Alzheimer’s Disease Initiative, the State supports research, service and training in Alzheimer’s disease and related memory disorders.

The state recognizes the gravity of Alzheimer’s disease as a major medical, social economic and emotional problem to its increasing elderly population. Alzheimer’s disease is the leading cause of dementia and is the fourth leading cause of death among American adults.

The purpose of the Brain Bank is three-fold:

- To provide families with confirmed diagnosis
- To provide tissue for Alzheimer’s disease research
- To establish a diagnosis for use in clinical and pathological studies

For individuals meeting criteria for selection into the Brain Bank program there is a cost for the autopsy procedures and transportation from the site of death to the family’s selected funeral home. An autopsy report will be sent to the family and the person’s primary care physician within three months of the time of death.

Family members of persons with Alzheimer’s disease and other memory disorders who are interested in learning more about the State of Florida Brain Bank programs are encouraged to contact:

Mount Sinai Medical Center
4300 Alton Road
Miami Beach, FL 33140
305-674-2543
Contact: Mercy Luis
CREED FOR CAREGIVERS

By Barbara Nelson

I will strive to:

- Acknowledge that I am living in an abnormal situation of being responsible for the thinking of another person.
- Realize that I am not alone in this. Millions of others are doing the same thing, and help is available.
- Seek a good medical diagnosis for the confused person.
- Talk with other persons (support groups) or read information to learn all I can about dementia.
- Separate the disease process from the personality I have known as my loved one.
- “Let go” of any resentments, anger, guilt, anxiety, embarrassment. I am not to blame for this disease, nor is anyone else.
- Learn to “flow with the disease” and learn techniques of care and attitude to make life easier for me and more enjoyable for my loved one.
- Communicate with some Higher Power than myself, and with other persons regularly to maintain my strength and courage.
- Get legal and financial advice, and act on that. Educate and include family and friends in my “adventure.” It is an important part of my life, and should be part of theirs.
- Ask for and accept help to keep me in good physical, mental, emotional and spiritual health. This means regular respite care (time away from caregiving for me).
- Seek to give the AD victim a sense of dignity and worth and my respect and love, knowing that the disease process prevents them from returning much gratitude or affection to me.
- Enjoy them by building on their strengths, and accepting their limitations.
- Be proud of the job I am doing! It is a tedious and commendable act of sincere devotion.
- “Reach out” to give support to other caregivers.
- Anticipate and know when I have reached the limits of my responsibility as a sole caregiver.

Courtesy Boise/Treasure Valley Chapter
MEMORY AIDS

General

- Keep pen and white, undecorated paper for reminder notes in same place for easy location. (Use black felt tipped pen).
- Simplify activity schedule.
- Place easily read list of important numbers near the telephone, most used ones first.
- Keep doctor’s instructions for taking medication and other health care in visible, consistent place (e.g., post on wall or refrigerator door).
- Keep checklist near the usual exit door of things to be done before leaving the house (e.g., put keys in pocket, turn off stove, put out the cat, lock door).

Daily Activities

- Make a checklist of daily activities with times in large print. Keep in visible and consistent place.
- Set alarm clock or a timer as a reminder of specific things to be done. Place note by clock or timer reminding of what is to be done.
- Arrange to have a friend call at designated times to remind of an appointment.
- Establish consistent routines for important activities (e.g., put morning medication near pan used to cook morning cereal).

Location

- Remind person of where he or she is, or is going, and why.
- Place signs designating important locations such as the bathroom.
- Place pictures designating function on refrigerator, stove, bathroom door.
- Keep person’s familiar significant objects in consistent locations.
- Post list of major items in each cupboard and drawer.
- Arrange for a friend to become familiar with objects in the home to help if they are misplaced.
- Attach eyeglasses to a chain that the person can wear around the neck.
GENERAL GUIDELINES FOR COMMUNICATING WITH
THE MEMORY IMPAIRED PERSON

Communication occurs on both a verbal and a non-verbal level. The tone of your voice and facial expressions are just as important as the actual words. Alzheimer patients can be sensitive to non-verbal communications.

VERBAL

Speak slowly and simply. Use short sentences and words. Avoid complex conversations or instructions.

Use nouns and proper names frequently. Avoid using “he, she, it, those”, etc. Cue the person with necessary information.

Begin conversations (especially at night) by calling the person by name, touching them gently, and identifying yourself if needed.

Discuss only concrete actions and objects. The person cannot relate to concepts.

Don’t ask questions with multiple choices, this adds to confusion and stress. Try to ask questions that can be answered with a yes or no, or with a gesture.

Do not expect a quick response. Allow time for information to be processed. Wait silently for several minutes until they answer.

Use simple directions for tasks being done. Go one step at a time.

If you must repeat a question, repeat it exactly. Do not re-phrase the sentence or use different words.

Speak in a lower voice tone, do not express excitement in your voice.

Maintain eye contact, sit or kneel if necessary. Don’t tower over the person in bed or in a wheelchair.

Repeat the person’s last words to stimulate memory and assist them to continue their thoughts.
GENERAL CONSIDERATIONS

If possible, correct any visual or hearing problems the person may have.

Reduce environmental noise, activity and distraction.

Keep your face well lighted.

Use gestures or other clues to aid your communication. (Objects, pictures, smells, things to touch and feel).

Look for reminiscence in the person’s hallucinations, delusions, or fragmented conversations.

Do not argue with or contradict the impaired person. Respond to feeling rather than fact.

Do not assume the person lacks insight or does not understand. Do not speak in a negative manner in front of the person.

Praise and reassure! There is a great loss of dignity and confidence as the person’s knowledge and abilities deteriorate.

If you are unable to “get through”, try again later.

NON-VERBAL

Stand in front of the person, keep at eye level. Do not startle by approaching from behind.

Use exaggerated facial gestures to emphasize your point.

Walk with the person if he/she starts to walk away. Do not restrain – distract to a new activity.

Use touch to:

- gain attention and enhance listening behavior
- show you care and that they are worthy of care – touch can reinforce trust
- reduce feelings of isolation, rejection
- increase interaction
• let them know you are listening
• fulfill a need greater than the need to talk

Listen actively. If you don’t understand, say so. If the person becomes agitated, offer your best guess. If wrong, guess again.

Indicate you understand the person by nods, smile, or touch.

Be aware of the impaired person’s non-verbal responses. (Smiling, relaxed appearance vs. hand wringing, fidgeting).

GENERAL CONSIDERATIONS

There is an increased awareness of non-verbal clues as the disease progresses; the non-verbal level becomes more important.

The Alzheimer patient is extremely sensitive to the emotional climate of the environment.

If the person doesn’t understand he may avert the eyes, look down, or increase hand gestures.

Non listening behavior includes: lack of eye contact; lack of nodding or affirmation; lack of facial expression, turning body away.

Receptive behavior includes; nodding, relaxed appearance, smiling, touching.

Signs of anxiety may include: pacing, hand wringing, crossing and uncrossing legs, fidgeting.

Sources:


Quite frequently in the early stages of Alzheimer’s disease, the patient will have periods of lucidity. It is bewildering and sometimes comforting to a family which suspects, and is trying to deny, a problem with the memory or reasoning ability of a family member. During the lucid moments, the patient will seem to be entirely normal. Sometimes you have to overlook a few deviations from normality to deep it going but the patient seems to be able to think clearly and remember recent events as well as the old memories that early phase Alzheimer patients can usually recall. As the disease progresses, the lucid times become briefer and less frequent. In a severely impaired patient the lucid moments are usually for less than a minute and extremely rare.

Experienced caregivers tell us to accept the lucid moments as a gift which comes as a surprise and brings a kind of transient joy. Enjoy the moment when the patient seems to be his or her own self. However long or short it is, delight in it, but don’t assume it is a cure or permanent change. It can’t be predicted and, in fact, may never happen again. And if your patient never has a lucid moment, once you are aware of the diagnosis and the inevitable outcome, don’t push for one. A lucid moment is a gift from heaven and not anything that you can arrange to make happen no matter how much you crave one.

HELEN KELLER: We could never learn patience or to be brave if there was only joy in the world.
PROFANITY AND THE ALZHEIMER PATIENT

University of Alabama at Birmingham
Center for Aging Alzheimer Family Program

The most courtly of old gentlemen and sweetest of old ladies, when afflicted with Alzheimer’s disease, may use language you didn’t suspect they knew. Where did they learn it? Why do they recall it when they have forgotten so much?

It is possible they heard the words as children and suppressed childhood memories do last longest. They may overhear strangers use “ugly” language and pick it up. Profane and obscene exclamations are often invested with a great deal of emotion and the Alzheimer patient may recognize that they are words that carry a lot of emphasis. Or, the patient may hear new and strange words and want to try them out. The effect on the startled family may delight the patient. Most probably, the patient has been aware of socially prohibited words all along. Very few people reach a ripe old age totally oblivious of them. When Alzheimer’s disease strips the patient’s mind of social inhibitions, the patient vocalizes words which have heretofore been unutterable.

What do you do about it? There’s little chance of restoring the social inhibitions or training the patient to avoid words that offend you. Maybe there are grandchildren or great grandchildren who have been told that they should not use the words the patient now says. What do you tell the kids when they ask why they can’t use the language that an older (but impaired) relative uses?

One of the most experienced caregivers, whose mild-mannered mother now uses words “that would make a sailor’s parrot blush,” told her nieces and nephews that Granny was ill, as they knew, and one of the things her illness did was to keep her from being aware of what she was saying. This fitted with their experience of hearing the patient talk nonsense and they accepted it.

As for offending others, it is probably a poor idea to take a patient afflicted in the manner out in public. If the patient is in a long-term care facility, few of the other patients will take offense or even take in what is being said. Of the patient is in your home, you can try saying sharply, “Don’t curse!” or “Don’t talk ugly!” It might work. If it doesn’t, accept the fact that the patient is ill and may have no conscious control over the words or phrases that come out. Remember, this is a new and limited person and not a hidden side of a person you thought you knew.
REACTIONS TO “STRESSORS” AND CHANGE

Stress and change can be difficult for anyone, even those with normal cognitive abilities. But for those with memory impairments, “change” can be overwhelming. One of the most common calls we receive is when rapid decline or a dramatic increase in difficult behavior occurs. After questioning the caregiver further we generally discover that the person experienced some type of “Stress” before the behavior changes occurred.

For an Alzheimer victim a stressor may be anything from going on a trip, being hospitalized, moving to a new residence, falling, experiencing the death of a loved one, etc. People with memory impairments are very sensitive to the emotional climate and to disruptions in their daily routines. Something that we do not consider to be overly stressful may truly be so for an impaired person. It is very common and almost predictable, that behavior change will occur after a stressful event. Usually, the changes will be temporary and the patient’s behavior will level off in time. However, sometimes a new behavior will remain with the patient.

Points to remember:

• Anticipate change and potentially stressful events. Avoid them if possible. If events are unavoidable, realize that a decline or change in behavior is common.
• The patient may exhibit an increase in present behaviors (wandering, agitation, suspiciousness) or may develop a completely new behavior (incontinence, hallucinations, sleep problems, etc.)
• Sometimes, difficult behaviors can be relieved with medications.
• Remember that the situation is frightening and overwhelming to the patient. Remain calm and gentle, reassuring the patient that everything will be fine. As usual, do not scold or argue.
• The patient may level off and return to a prior level of functioning or he may settle in to a new level in his abilities.

NOTE: The patient often goes into a speedy decline following surgery. Consider only life threatening situations for surgical interventions. Consult the physician regarding elective surgery.
SUNDOWNER’S SYNDROME

People with dementing illness have more behavior problems in the evening. The frustrations and sensory stimulations build up throughout the day and, by “sundown”, they aren’t able to cope as well with the confusing environment around them. They may become increasingly confused agitated, and anxious and may pace the floor, begin to wander or show other nervous behaviors.

To help minimize Sundowner’s Syndrome, maintain a structured daily routine. This reduces the anxiety that decision-making can produce. Scheduled rest periods should be included in that routine. Try to keep the daily activities within the person’s coping ability. Surprises, challenges or lots of new information can be very upsetting. Special occasions, outings, family visits and other changes in routine should be explained in advance and approached gently. It is best to schedule these events after quiet days. Turn lights on inside the house well before dusk to lessen disorientation.

CATASTROPHIC REACTIONS

Catastrophic reactions occur when a situation overwhelms the thinking capacity of a person with a dementing illness. The behaviors that result may include:

- rapidly changing mood
- anger
- crying
- striking out
- paranoia
- agitation
- wandering
- blushing
- stubbornness
- pacing

“The best and most beautiful things in the world cannot be seen or touched but are felt in the heart.”
Helen Keller
CLINGING OR PERSISTENTLY FOLLOWING YOU AROUND

Families tell us that forgetful people sometimes follow them from room to room, becoming fretful if the caregiver disappears into the bathroom or basement, or that they constantly interrupt whenever the caregiver tries to rest or get a job done. This can be distressing. Few things can irritate more than being followed around all the time.

This behavior can be understood when we consider how strange the world must seem to a person who constantly forgets. The trusted caregiver becomes the only security in a world of confusion. When one cannot depend on himself to remember the necessary things in life, one form of security used is to stick close to someone who does know.

The memory impaired person cannot remember that if you go in the bathroom, you will be right back out. In his mind, with his confused sense of time, it may seem as if you have vanished. Child-proof door knobs on the bathroom door may help give you a few minutes of privacy. Sometimes setting a time and saying, “I will be back when the timer goes off”, will help. One husband got himself a set of headphones so he could listen to music while his wife continued to talk. (Then he got her a set because he discovered that she enjoyed the music.)

It is important that you try not to let annoying behaviors such as these wear you down. You must find other people who will help with the person so you can get away and do the things that relax you – go visiting or shopping, take a nap or enjoy an uninterrupted bath.

Find simple tasks that the person can do, even if they are things that you could do better or things that are repetitious. Winding a ball of yarn, dusting or stacking magazines may make a person feel useful and will keep him occupied while you do your work.

Mrs. Hunter’s mother-in-law, who has a dementing illness, followed Mrs. Hunter around the house never letting her out of her sight and always criticizing. Mrs. Hunter hit upon the idea of having her mother-in-law fold the wash. Since Mrs. Hunter has a large family, she has a lot of wash. The other woman, folds, unfolds, and refolds (not very neatly) and feels like a useful part of the household.

Is it being unkind to give a person made-up tasks to keep her occupied? Mrs. Hunter doesn’t think so. The confused woman needs to feel that she is contributing to the family and she needs to be active.
Angry or aggressive behavior from an Alzheimer’s patient can be very disturbing. This behavior may cause undue physical and emotional distress for the caregiver, leaving him/her with feelings of anger, guilt, or incompetence. Such feelings may lead to physical symptoms of distress, such as headaches, sleep problems, fatigue, tense muscles, breathing or eating problems. Fortunately, angry outbursts are generally short-lived and, in many cases, can be diffused or avoided if we know what to look for and how to respond. Most often it is not a personal attack at you but rather the result of a frustrating event or situation. The person may be fatigued, confused, or in pain and unable to express or describe what he is feeling. When the anger is directed toward you, it may be the result of a misunderstanding or a misperception of clues. An angry outburst may be the patient’s way of telling you that something is wrong. It helps if you remain calm. Your attitude and approach can calm the patient or add to his agitation.

SOME APPROACHES INCLUDE:

• Ignore the behavior, even when the outburst includes profane or inappropriate language.
• Remove the individual from the area if the situation or environment is overwhelming. If the angry outbursts are frequent, try making the environment clutter-free, noise-free, limited in number of activities or persons, and provide as much predictable routine and structure as possible.
• Simplify difficult tasks. Be sure your expectations and requests of the person are realistic. At the same time it is important to support your relative in using his full potential by allowing him to be as independent as he can be.
• Use distraction. This is a simple but effective strategy (change the subject, offer a treat or a favorite object, suggest another activity, etc.)

IF PATIENT IS NOT EASILY DISTRACTED AND VIOLENT BEHAVIOR ESCALATES TO CREATE DANGER:

• Call for assistance. Your first obligation is to protect yourself and your patient/family member.
• Remove any object which could be easily used as a “weapon.”
• Remove the person from the environment if it appears to be contributing to the angry outburst.
• Do not argue. Be sure your voice is calm and reassuring. Soothing music may also be helpful.
• Do not overwhelm the person with “why” questions or give too many instructions at a time.
• Do not startle the person by approaching unexpectedly, with raised hands, etc. or in any way which appears threatening.
• Provide ways of releasing tension, i.e. safe areas to pace, suitable physical activity, etc.
• If you observe a pattern to the violent episodes, try to determine the cause. Often a simple change in routine or environment can ease frustration or anxiety which may lead to or contribute to angry outbursts.
• Simply walk away.
• Medication may be necessary to control the behavior. Consult your family physician. Keep in mind, however, that adverse effects of the medication, i.e., drowsiness, incontinence, etc., may be more undesirable than the occasional outburst.

Caregivers find that they are more tolerant and capable of handling behavior problems, including angry, aggressive behavior, when they have taken care to attend to their own needs. It also helps to remember that this is a consequence of the disease process and not hostility toward you. Angry outbursts are often a response of feelings of fear, insecurity and frustration at one’s own limitations. The loss of normal inhibition causes people to lose control. If you can reassure the person and arm yourself with ideas to handle the behavior, this aspect of the disease may become more tolerable for you and the person you are caring for. It's worth a try.
DELUSIONS/HALLUCINATIONS/PHOBIAS IN ALZHEIMER’S

The delusion that people are stealing things:

Alzheimer’s patients are unable to recall the precise whereabouts of household objects. This probably is the psychological explanation for what is the most common delusion of patients of the disease, that someone is hiding or stealing objects. More severe manifestations of this delusion include the belief that persons are actually coming into the home to hide or steal objects and the patient’s actually speaking with or listening to the intruders.

The delusion that one’s living place is not one’s home:

Alzheimer’s patients, as a result of their cognitive deficits, may no longer recognize their homes. This appears to account, in part, for their common conviction that the place in which they are residing is not their home. Consequently, they commonly request that their caregiver take them home. They may also pack their bags for their return trip home. More disturbing to the caregiver, and of greater potential danger to the patient, are actual attempts to leave the house and go home. Occasionally the caregiver’s attempts to prevent the patient’s departure may cause the patient to become angry or even violent. Such violence is extremely upsetting to a spouse or caregiver.

The delusion that the spouse is an imposter:

With the evolution of cognitive deficits, patients with Alzheimer’s disease no longer recognize their caregivers as well as they did previously. Perhaps for this reason, a frequent delusion in Alzheimer’s patients is that persons are imposters. In some instances this conviction may make them angry or even violent.

The delusion of abandonment:

As intellectual deficits develop during the course of the disease, patients usually retain a degree of insight into their conditions. Although they are largely aware of their cognitive deficits, denial protects them from this awareness. Similarly, they may be aware of the burden they have become. These insights probably relate to the patients’ common delusion that they will be abandoned or that caregivers are conspiring or plotting to institutionalize them.

The delusion of infidelity:
The insecurities described in the preceding paragraph also relate to the patients’ occasional conviction that his or her caregiver, regardless of whether the caregiver is a spouse, is unfaithful, sexually or otherwise.

Hallucinations:

Hallucinations are also present with some Alzheimer’s patients. Commonly patients with Alzheimer’s disease see intruders or dead relatives at home or have similar hallucinatory experiences. Less common are when the patient smells odors such as fire.

Anxieties and phobias:

The fear of being left alone is the most common phobia among patients of Alzheimer’s disease. As in any other phobia, it is entirely out of proportion to any real danger. For example, anxiety may be manifested as soon as a spouse goes into another room.

Tearfulness:

Tearfulness is a manifestation that generally appears in brief episodes. If queried about why they are crying, patients might say “because of the person I once was”, or “I forgot the reason.” Like other illness, a depressive syndrome may co-exist with Alzheimer’s disease.
One of the most difficult challenges for caregivers is how to handle some of the disturbing behaviors that Alzheimer’s can cause. Symptoms such as delusions, hallucinations, angry outbursts, suspiciousness, failure to recognize familiar people and places are often the most upsetting behaviors for families. The following points may help in responding to disturbing symptoms.

• **First**, try to understand if there is a precipitating factor causing the behavior. Were there household changes, too much noise or activity, was the daily routine upset? Time of day can affect behavior (Sundowning). Being aware of these factors can help to better plan activities or anticipate problems.

• **Suspiciousness** – The confused person lives in a world where each moment is a new beginning. Often, there is no recollection of prior events or explanations. Things that are misplaced are thought to be “stolen”, unfamiliar people are frightening and may be there to cause harm. Sometimes, suspiciousness can be an expression of the overwhelming sense of loss and confusion a person may feel. Generally, it makes things worse to argue or confront the person with facts. Understand that the behavior is due to the brain disease and is uncontrollable. Try to reassure the person that everything is fine and that you will take care of them. Offer to help find the missing item. If accused of stealing personal finance, assure the person that their money “is safe in the bank and all their bills are paid.” Try to distract the person to more meaningful activity.

• **Wandering and Pacing** – Wandering occurs for a variety of reasons. Some people wander when any type of “change” occurs, others wander as an expression of boredom or restlessness, others wander as a way of saying, “I’m lost, I need to find the person I once was”, still others wander for no apparent reason. An agitated, determined pacing can sometimes be relieved with medication. Try to get the person engaged in an activity such as sweeping, folding towels, sorting coins, drawing with crayons or chalk, or winding a ball of yarn. Sometimes, periods of restlessness are unavoidable. It is essential that a mobile person wear a visible identification bracelet or necklace that states the person is memory impaired and gives the information for contacting the caregiver. If wandering behavior becomes unmanageable or unsafe, you will need to realistically consider alternative living arrangements.
• **Repetitive Questions/Behaviors and “Clinging”** – Sometimes it is the little things that unnerves people the most. People with dementia tend to get stuck on one question or behavior and often cling to the caregiver, not letting them out of sight. Instead of answering the question over and over it may help to offer reassurance that you will take care of everything and not to worry. Often, the person will be worried about something unrelated and be unable to express it. Regarding repetitive actions it may help to touch the person while giving instructions for movement. Try to distract the person by giving them something to do. “Here, hold this”, “Help me over here.” Helping may enable the person to stop the repetitious behavior. “Clinging” can be understood when we look at the world of a confused person. The trusted caregiver is the only source of security a person may have. Again, tasks given to occupy and distract the person may help.

• **Inappropriate Sexual Behavior** – People with dementia may demand or express sexual activity at frequent or inappropriate times. Self exposure, masturbation, or touching other people may occur. The best way to respond to this is not to over react or scold the person. Remain calm and matter-of-fact. Realize the behavior is due to the brain impairment and not the underlying personality of the person. The person has forgotten social manners and is only doing what feels good to them. Try using more difficult clothing to get off such as shirts that button in the back, pants that pull on and have no fly, etc. If masturbation occurs, gently lead the person to a private area, try distracting them with other activities.

• **Delusions and Hallucinations** – Delusions are untrue beliefs that are generally unshakable. Hallucinations are sensory experiences that are very real to the person with dementia. Often, medication can help alleviate some of the symptoms. However, when they do occur react calmly. You must be in control for the person. Avoid denying the person’s experience or arguing the facts, this will only further upset him. You do not need to play along with the experience, or agree or disagree. Just listen and give non-committal answers such as, “I don’t hear what you’re hearing, but it must be frightening” or “You talked with your mother? Oh, what did she say?” You could reminisce about ‘mother’ and the ‘good times’. Try to distract the person if possible and be reassuring. Also, let your doctor know these symptoms are occurring.

• **Agnosia** – (Failure to recognize familiar people or things). People with dementia frequently lose the ability to recognize familiar things due to the fact that the brain is unable to process information properly, this is called agnosia. The person may not recognize his own home or spouse. Reassure the person, “I am your wife”, but avoid arguing. Help the person to focus on familiar details, “This is your chair, here is your room.” Again, distract if possible.

• **Angry, agitated behavior** – Quite often these behaviors are symptoms of the dementia and the abnormal brain changes and are not deliberate responses on the
part of the patient. A person may become agitated because they are overloaded with too much noise, activity, clutter, etc. They may be fatigued, feeling insecure, inadequate or overwhelmed with a task. They may also be responding to the difficult feeling of losing control of their lives. The approach that a caregiver takes with patient is critical to avoiding outbursts. As difficult as it is, try not to scold, contradict, reason or rationalize with the person. This will usually lead to further frustration and anger. A gentle, supportive manner will get the best results. Acknowledge their feelings; “I know you’re upset”, “I want to help you”, “I will take care of everything, don’t worry”. As usual, try to distract the person to a new activity or setting. When the outburst is over, avoid bringing it up for discussion. The person will usually forget about it rather quickly.

- **Wanting to go home/Wanting Mommy or Daddy** – This yearning is very common for people with dementia. A home that has been the primary residence for years will no longer be recognized as such. The person will insist he wants “to go home” or will complain they are being kept away from their “real” home. As the brain changes, the person can no longer remember the present and the home they may be remembering is the home they lived in 50 years ago with their parents. Instead of trying to convince them that this is their home, respond to the feeling they may be projecting. “Are you feeling lonely?” “Are you scared?” “I’ll take care of you.” Try going out for a walk or drive. During the outing the person may relax and may recognize the home when he returns. Calling out for long deceased parents or relatives is also very common. Remember, the past is what the person remembers most vividly and in the past his parents were there for him. The person may feel abandoned, wondering why his parents never come to see him, or may insist his mother is coming soon. Again, remember the feeling behind their responses. They may need nurturing, may miss long deceased family, may need to know they are loved and will be safe. Avoid arguing the facts that the relatives have long since died. This will only further confuse them and they may even feel you are lying to them. Help the person to reminisce about their relatives, look at pictures, etc. There is no harm in this. Often, a “white lie” is helpful – “Your mother is coming soon”, “She loves you so much”, “Remember when your mother did such and such…” Redirect their attention if possible. From the perspective that the person’s world no longer makes sense to him and he is in a state of confusion most of the time, it makes perfect sense that he or she would yearn for mother to be there to provide comfort.
AD CHECKLIST

The following checklist will assist the caregiver in initiating the necessary steps when a loved one is diagnosed with Alzheimer’s Disease.

MEDICAL:

_____ Obtain a complete medical examination from a Physician
_____ Proper diagnosis – possible second opinion
_____ Consultation with the physician about what to expect
_____ Evaluation in terms of level of functioning
_____ Identify medication currently taking and full medical history
_____ Evaluate when a Do Not Resuscitate Order will be needed.

LEGAL:

_____ Contact an Attorney for advice regarding:
  • Durable Power of Attorney
  • Will
  • Living Will
  • Guardianship
  • Health Care Surrogate
  • Living Trust
  • Ownership or real/personal property

FINANCIAL:

_____ Determine if the person can manage his/her own financial matters – if not someone should take responsibility of:
  • Checking Account (Bill Payments)
  • Savings Account
  • Other Accounts (Money Markets, etc.)
  • Real Estate or other property owned
_____ Locate and review all insurance policies (Medical, Life, Disability, VA, Car, House, etc.)
_____ Locate Safety Deposit Keys and signature authorizations (also personal safe combinations)
_____ Check for Waiver of Premium Clause on Insurance Policies
_____ Identify Monthly Income Sources (Social Security, Direct Deposits, Pension, etc.)
_____ Regarding Social Security – Do you want to be made Representative Payee? Has Social Security been applied for?
INSURANCE:

Know policy schedule, location and agent.  **CHECK WAIVERS!!!**

- House  - Life Insurance  - Medical
- Car  - Veterans medical  - Medicare
- Theft   - Disability  - Medicaid

CAREGIVING:

- Contact the local Dubin Alzheimer’s Resource Center for pertinent information
- Obtain knowledge of community resources by contacting Helplines
- Develop a plan for care – include several alternatives
- Utilize available programs such as Adult Day Care, Respite, Volunteers, etc.
- Perform a safety sweep throughout the home
- Have a plan should you become ill and need to be hospitalized*

OTHER:

- Driving (You must judge when the person can no longer operate a motor vehicle safely)
- I.D. bracelet for the person in case of wandering
- Alcohol and weapons

FUNERAL/BURIAL ARRANGEMENTS:

- Does this person prefer burial or cremation?
- Have previous arrangements been made regarding purchase of burial lot, caskets, funeral etc.?
- Autopsy arrangements

*Do you have pertinent information (the routine meds, etc.) about your loved one in a designated place so that a neighbor or family member can “fill your shoes” while you are away.

**CREATING A SAFE AND MANAGEABLE ENVIRONMENT**

Four words summarize what an individual with Alzheimer’s needs from the environment: SIMPLICITY, CONSISTENCY, SAFETY, AND REMINDERS.  You will need to adapt your home as the person’s abilities decline.  Walk through your home and try to
determine areas that may be unsafe, confusing or overwhelming to your patient. Things around the home are often used inappropriately, unrecognized or misplaced from time to time. Do not take for granted that he/she will know where rooms are or where things belong. **However, do try to maximize independence whenever possible.**

- Remove, hide or disguise potentially hazardous items (medicines, cleaning fluids, poisons, matches, knives, power tools, firearms, throw rugs, etc.)
- Use night lights throughout your home to reduce confusion when it is dark. Turn lights on before it gets dark at night to help reduce Sundowning (this is an unexplainable increase in confusion/agitation that occurs just as evening approaches).
- Secure doors with a chain lock placed high on the door. The patient will usually not look for a lock above them. Or use a dead bolt lock that needs a key to open.
- Remove knobs from the stove or use burner covers to disguise the stove. The patient will usually not think to look under something.
- Orient the person with an easy to read wall clock – a digital clock may be better to understand. Post a simple daily schedule. Post a sign telling the month, date, day of week, etc. This helps to lessen the great amount of uncertainty that goes along with this disease.
- Use a child’s safety gate on the top of stairways to prevent falls.
- Place colorful decals on glass doors, windows or mirrors if they present any spatial problems.
- “Clue” the person by posting large signs such as “BATHROOM”, “TOM’S ROOM”, “FRIDGE”, etc. Label cabinets and drawers such as “PLATES”, “SILVERWARE”, “SOCKS”, “UNDERWEAR”. Use signs that say “STOP!” or “NO!” to keep the patient out of potentially dangerous areas. Using reflective tape to show the way to various rooms can also help. If they have problems comprehending words, try pictures instead.
- Hang reminders such as “CHANGE YOUR CLOTHES”, “BRUSH YOUR TEETH”, “LUNCH IN THE FRIDGE”, etc.
- Remove seldom worn clothes from the closet to reduce confusing choices. You may need to choose the person’s clothing.