



What Now?

Caregiver's Quick Guide and Resource Manual

alzheimer's  association

• *San Luis Obispo County & Santa Barbara County Edition* •



www.centralcoastalz.org

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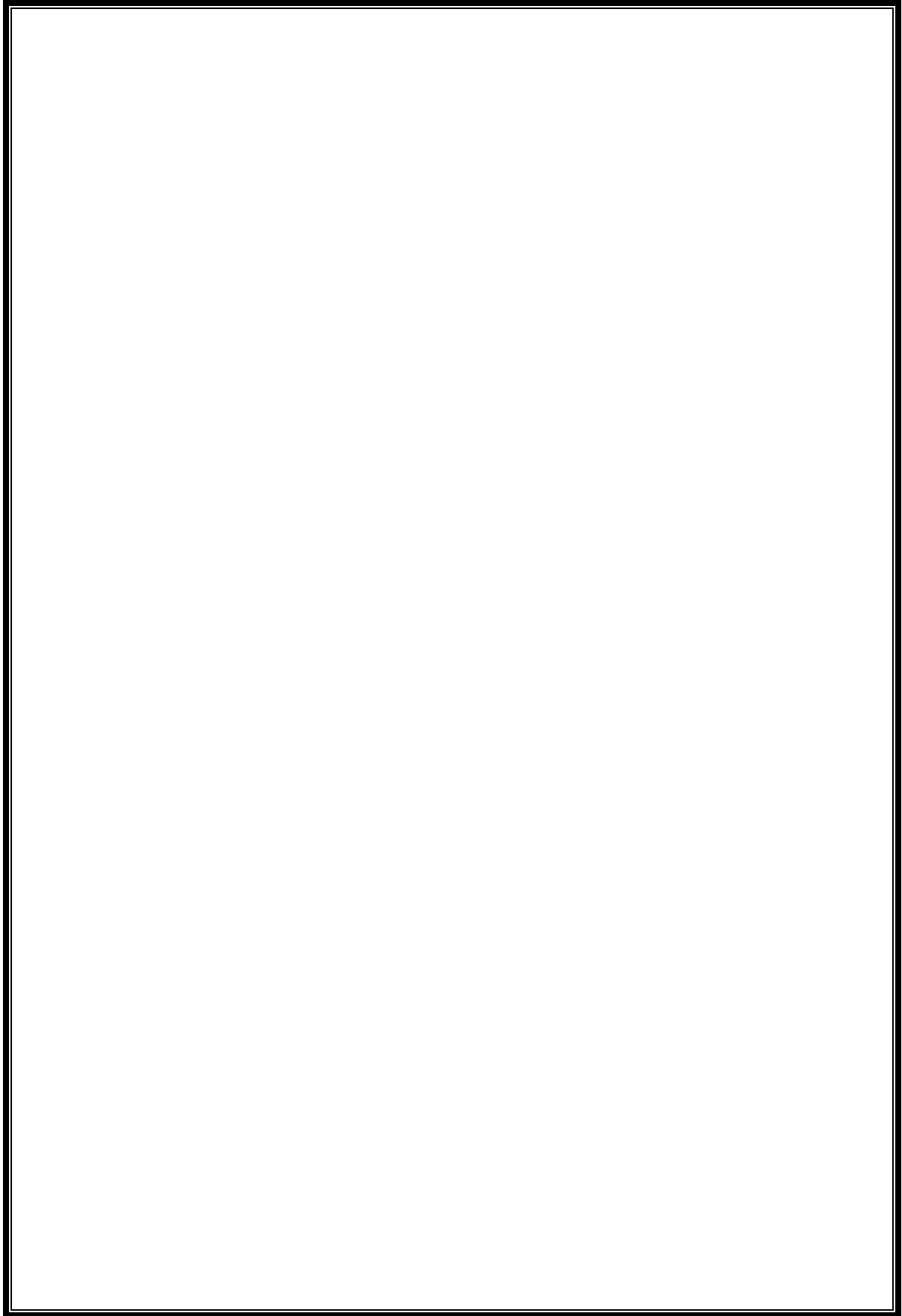
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Introduction

Alzheimer's disease can strike people under the age of 50, but most commonly occurs with those over the age of 65. The effects of this disease can have an enormous impact on the families and friends of the diagnosed people, as well as on the community at large. As more people move through the aging process in the United States, the incidence of this disease is expected to triple over the next 30 to 40 years. The pressing need for education and services for families dealing with the disease has prompted the development of this manual.

While there are excellent books on the subject, we have found that many family caregivers simply do not have the time to read them while struggling with the day-to-day caregiving demands. With this in mind, this manual has been written as an easy-to-use reference for busy caregivers and family members.

Topics include:

- A comprehensive guide to understanding the specifics of the disease
- How to begin with the medical, legal and financial issues
- How to approach some of the more challenging care situations that arise
- Introductions to homecare planning and management
- Relationships with family and friends
- Where one can go for most of the related government, non-profit and private enterprise services in the California Central Coast area

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SECTION 1

EDUCATE YOURSELF ABOUT THE DISEASE

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What Is Alzheimer's Disease?

Alzheimer's Disease Is:

- The most common irreversible dementia.
- A progressive, dementing, fatal disease of the brain where brain cells are being destroyed and not replaced
- The cause of 100,000 deaths in the U.S.A. each year
- An emotional challenge for victims and families
- An enormous financial burden for families
- A growing economic challenge for the U.S.A.
- A disease that cuts across culture, social class, race and education

What Causes It?

The cause has not been determined. Extensive research is being done to learn the cause of Alzheimer's disease. Investigations involve neurology and brain chemistry; the possibility of genetic linkages; environmental and dietary factors; and a complex array of interrelated studies.

Is There A Cure?

Not yet, but research advances are coming at a fast pace.

Are There Pharmaceutical Treatments?

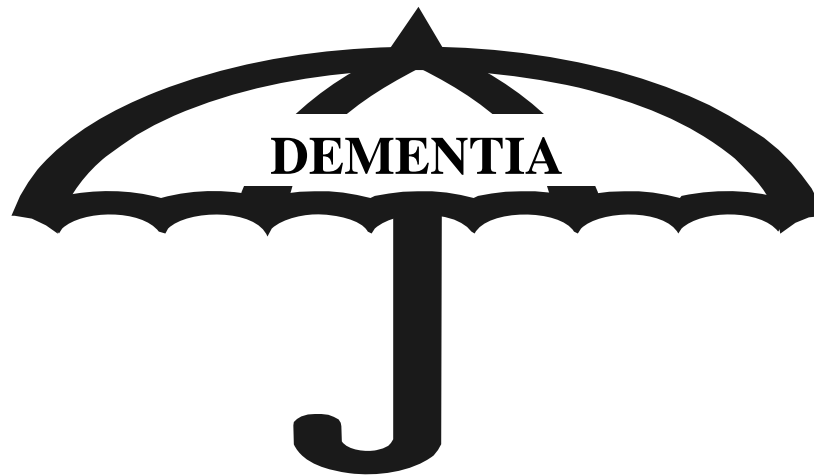
There are a number of medications currently being used to treat some aspects of the disease. They are not cures, and not everyone responds effectively to them. These include:

- Aricept™ • Exelon® • Razadyne® • Namenda®
- Other drugs are in various stages of testing

Call the Alzheimer's Association office to ask for the drug fact sheets. Talk to a physician who specializes in dementia diagnosis and treatment. . (Referrals to physicians are available)

The Dementia Umbrella

Dementia is a global term (an umbrella), that is applied when an individual presents with memory loss, confusion, declining problem-solving and judgment skills, and language deficits. Under the umbrella are examples of the irreversible and reversible causes of dementia.



Irreversible, Treatable

Alzheimer's disease
Creutzfeldt-Jacob
disease
Multi-infarct dementia
Frontotemporal Dementia
Parkinson's disease
Lewy body disease
Huntington's disease

Reversible

Depression
Medication Interactions
Normal-pressure
Hydrocephalus
Vitamin B12 Deficiency
Infections
Hormonal / Thyroid
Malnutrition

Head Injury

Medical & Scientific Basics

Selected Irreversible Dementias

Alzheimer's disease (AD)

Discovered in 1907 by a German doctor for which the disease is named, AD is a progressive, degenerative disease of the brain that gradually causes declines in intellectual ability, including memory, problem solving, and judgment. Eventually the disease leaves persons unable to care for themselves. Medications are available and under development that may improve thinking or slow the advance of the disease, but no cure is yet available.

Creutzfeldt-Jakob disease (CJD) (often referred to as Mad Cow disease)

CJD is a rare, fatal brain disease caused by infection. Symptoms are failing memory, changes in behavior and lack of muscular coordination. CJD progresses rapidly, usually causing death within a year. No treatment is currently available.

Multi-Infarct dementia (MID)

Also known as vascular dementia, MID results from brain damage caused by multiple strokes (infarcts) within the brain. Symptoms can include disorientation, confusion, and behavioral changes. MID is neither reversible nor curable, but treatment of underlying conditions (e.g., high blood pressure) may halt progression.

Frontotemporal dementia

FTD (formerly Pick's disease) is a rare brain disease that closely resembles AD, with personality changes and disorientation that may precede memory loss. Diagnosis is difficult and can be confirmed only by autopsy.

Parkinson's disease (PD)

PD is a disease affecting control of muscle activity, resulting in tremors, stiffness, and speech impediment. In late stages, dementia can occur, including AD. Antiparkinsonian drugs can improve steadiness and control, but they have no effect on mental deterioration.

Lewy body disease

Recognized only since the 1980s, this is a disease in which the symptoms are a combination of AD and PD. Usually dementia symptoms are initially present followed by the abnormal movements associated with PD. Other symptoms include hallucinations and delusions, falls, and varying consciousness. People with Lewy body disease also can be very sensitive to psychotropic medications. There is no treatment currently available.

Huntington's disease

Huntington's disease is a hereditary disorder characterized by irregular movements of the limbs and facial muscles, a decline in thinking ability, and personality changes. It can be positively diagnosed and symptoms controlled with drugs. The progressive nature of the disease, however, cannot be stopped.

Selected Reversible Dementias

Depression

Depression is a psychiatric condition marked by sadness, inactivity, difficulty with thinking and concentration, feelings of hopelessness, and, in some case, suicidal tendencies. Many severely depressed people also display symptoms of memory loss. Often, depression can be reversed with medical treatment and counseling.

Medication Interactions

Many older people take a variety of prescription and nonprescription “over-the-counter” medications. Misuse of these medications or use of medications that are not compatible can cause symptoms of dementia.

Normal-pressure Hydrocephalus (NPH)

NPH is a rare disease caused by an obstruction in the flow of spinal fluid. Symptoms include difficulty in walking, memory loss, and incontinence. NPH may be related to a history of meningitis, encephalitis, or brain injury and is often correctable with surgery.

Vitamin B12 Deficiency

Low levels of vitamin B12 and folic acid can cause symptoms of dementia. Treatment can often improve or reverse the dementia.

Infections

Left unchecked, infections can cause symptoms of dementia. Fortunately, this problem usually responds to medical attention.

Hormonal

Very low or very high levels of thyroid hormone can cause symptoms of dementia. Correcting the problem will usually reverse these symptoms.

Malnutrition

When someone does not eat well, he or she can actually become malnourished. This is particularly a problem when an individual lives alone. At its worst, malnutrition can contribute to dementia.

Selected Irreversible Dementias and Selected Reversible Dementias

(Adapted from Alzheimer’s Association. [1997]. An overview of Alzheimer’s disease and related dementias [Publication ED205Z]. Chicago: Author.)

*How do I get
him/her to a
doctor?*

Mary took her mother, in her best dress, “out to lunch” and drove to the doctor’s office on the way home. It had been pre-arranged that they use a side door and the doctor “visited” with both of them in his study rather than an intimidating examination room.



Hazel took her husband along to “her” appointment. The alerted physician pretended to examine her, too.



Linda told her husband that their doctor’s office had called to remind them it was time for their annual physicals. “I made appointments and we are going next week.”

Get a Complete Diagnosis

Other health problems can often mimic Alzheimer's:

Stroke Metabolic changes Depression
Head Injury Hypothyroidism Medication interactions

A good diagnostic work-up is essential for developing an appropriate treatment plan.

Prepare thoroughly for the doctor's visit:

- Take time to write a list of the symptoms, when they began, and how frequently they occur
- Bring all medications, over-the-counter and prescription, to the visit
- Bring a list of past and current medical problems. Have other family members had illnesses that caused memory problems?
- Ask the doctor to explain the tests and how long it will take to get a diagnosis

*Make copies of the charts in the back of this book
and use them with the doctors!*

A complete medical evaluation for memory loss should include:

- A medical and psychiatric history
- A neurological and physical exam, which may include brain imaging techniques, such as CT Scan, MRI, or PET Scan
- Lab tests (blood and urine)
- An evaluation of the patient's ability to perform common daily activities, such as balancing a checkbook or taking medications
- A 'mental status exam' to measure the patient's thinking and memory
- A family caregiver interview regarding history of, and present day symptoms
- A cataloguing of all medications being used

Questions to Ask About Treatment

- What medications are available for memory loss?
For behavior changes?
- What are the risks and benefits?
- What are the side effects?
- How long will the patient take this medicine?
- Should we consider participating in a clinical trial?
- What are the risks and benefits of a clinical trial?
- Are there any treatments that do not involve medications?

Monitoring and Reporting on the Treatment

Your doctor may prescribe medication or other treatments for the patient. It is your job to keep track of how things are working (or not working) and report them to the doctor(s).

- Are the prescribed treatments working?
 - What has improved?
 - What has gotten worse?
- Have you noticed any side effects of the medications?
Are they causing problems?
- Have you noticed any new problems that may need treatment?

Keep a list of the patient's medications, prescription and over-the-counter. Bring the list to every visit with each doctor.

Other Concerns

- Will the physician report the diagnosis to the DMV?
- Should the patient continue to drive?
- How often should the physician see the patient?
- Under what circumstances should we contact the doctor's office?

Communication Tips for Follow-Up Visits

- Be prepared! Make a list of the types of issues you want to discuss with your doctor.
 - Changes in symptoms
 - General health of diagnosed person
 - Caregiver health
- Ask questions!
- If you do not understand something, ask questions until you do
- Do not be afraid to speak up, share your point of view!
- Get information
- Take notes during the visit
- Make time to write notes afterward, or even bring a tape recorder

***Watch those
multiple
medications!***

Sarah had been asked to leave one nursing home after another due to her disruptive behavior. A wise medical director discovered she was on multiple medications for many conditions, none of which were life threatening. He gradually withdrew all medications.

Within a matter of time, after the drugs were flushed from her body, Sarah no longer exhibited disruptive behavior. She began to form friendships with other residents in the community.

Is It Alzheimer's Disease, Or . . .

Is it something that mimics the disease?

COMMON MEDICATIONS FOR

High blood pressure,
Heart medications

Depression

Sleeping Problems

Arthritis

Diabetes

Ulcers

Pain

Multiple medications . . .

CAN CAUSE

Confusion, memory loss,
depression, fatigue, disorientation,
nervousness, hallucinations

Short-term memory problems,
impaired attention span, confusion,
agitation, delirium, anxiety,
insomnia, sleepiness,
disorientation, irritability

Confusion, depression, dis-
inhibition, decreased coordination

Depression, psychosis, paranoia

Acute mental changes

Short term memory loss, anxiety,
disorientation, depression

Agitation, hallucinations,
depression

Can add to any of the above!

- *Ask your pharmacist about possible medication side effects.*
- *Borrow a book about medications from the library.*
- *Talk to your doctor.*

Are All Persons with Alzheimer's Disease Alike?

“As the saying goes, *when you've met one person with Alzheimer's disease, you've met just one person with Alzheimer's disease.* There can be tremendous variations in the manifestation of dementia; the impact on visual/spatial abilities, judgment, and even short and long-term memory can vary. Also, symptoms and behaviors can change over time. This is a good news/bad news situation for caregivers. The good news is that problems that seem daunting sometimes diminish or end. The bad news is that care would be easier if the future could be predicted.”

The Best Friends Approach to Alzheimer's Care
Virginia Bell & David Troxel
Health Professions Press, Inc. (1997)

ALZHEIMER'S DISEASE IS

Real
A disease (or diseases)
A disease that has an impact on a person's memory, judgment, language, problem-solving ability, initiative, and personality
A disease that attacks selected areas of the brain
One form of dementia
Progressive
Irreversible
Age related
Worldwide
The fourth leading cause of death among adults in the U.S.

ALZHEIMER'S DISEASE IS NOT

Normal Aging
Inevitable
Faked symptoms, stubbornness
A disease of only older persons
Senility
Sudden
The same as dementia caused by stroke, Parkinson's disease, depression, etc.
A disease of any one culture, socio-economic group, or gender
Imagined
A mental illness

What Can I Expect From My Loved One?

Not every person goes through all of the behavioral changes in the following list. Please refer to the following pages on *Symptoms* and “*Stages.*”

On the Bright Side	Challenging Symptoms and Behaviors
<p><i>A person with AD may become:</i></p> <ul style="list-style-type: none"> • Free of worry • More focused in the present moment, with little attention on the past or future • More delighted with simple things in daily life • More spontaneously honest • More inclined to be playful • More emotionally intuitive • More deeply appreciative and grateful • More humorous <p><i>AD provides us with opportunities to learn:</i></p> <ul style="list-style-type: none"> • Compassion & Patience Tolerance & Kindliness • How to communicate with the language of emotion—because people with Alzheimer’s may slip away from reason and logic, but always need to feel safe and cared for. • Sometimes he or she will demonstrate “a peculiar wisdom.” 	<ul style="list-style-type: none"> • Short term memory loss • Long term memory loss • Combativeness • Depression • Irritability • Paranoia • Unreasonable anger • Fear of bathing • Pacing • Repeating questions, gestures, and stories • Hoarding • Unable to learn new things • Delusions • Hallucinations • Bizarre or inappropriate behavior • Insomnia, or sleeping days and awake nights • Wandering, running away, getting lost • Loss of bowel and/or bladder control (incontinence) • Loss of speech • Loss of ability to walk or sit up • Loss of ability to swallow • Eventual total physical deterioration and death

Early-Onset Alzheimer's Disease

Early-onset Alzheimer's is the name for the disease when it affects people under the age of 65. It can occur in people in their 40s and 50s. Early-onset accounts for up to 10 percent of Alzheimer's cases – reminding us that Alzheimer's is not just a disease of old age.

The diagnosis of early-onset Alzheimer's is a shock to the families as well as to the professionals involved. It does not follow the order of life as we expect it to unfold. And, it is difficult to understand how, and why, this is someone's path in life...



Lena's husband lost his job as an architect at the age of 48. His symptoms included an inability to track and organize his work. After a year and a half of dealing with the challenges that his diagnosis presented to them, Lena and Hal arranged their finances so that they could do some traveling and take art classes together. They decided to move their future plans into the present, not knowing what tomorrow would allow them.

If you have early-onset Alzheimer's disease, it is important to understand that your life is not over.

However, living with early-onset Alzheimer's means dealing with some life transitions sooner than you had anticipated.

It is important to know that:

- The disease affects each person differently and symptoms will vary.
- New medications may reduce the severity of symptoms and improve the quality of daily life for extended periods of time. More and more research is suggesting that the sooner the treatment begins, the greater the benefits.
- Genetic research has found connections between a number of genes and Alzheimer's disease in a small percentage of families with Alzheimer's. Currently, there are at least three genes that have been associated with early-onset familial Alzheimer's.
- You are not alone. There are people who understand what you are going through and can help you and your family in many ways.

*Contact the Alzheimer's Association
to learn about Early-Onset support groups in your area.*

What I can do now to take care of myself and my family . . .

Career, family finances, medical and legal concerns will require careful planning and adjustments *(see Section 2)*

- Take the time to understand and plan for the costs involved with the caregiving and medical expenses that you will incur.
- Learn about government assistance programs such as Social Security, Medicare and Medicaid, and Social Security Disability.
- Explore and plan for how your family will address the needs for the spouse and children, education costs, housing and healthcare, and all the other normal family income/expense needs as the disease progresses.
- Pay particular attention to creating all the necessary legal instruments that will provide family members with the tools to make appropriate decisions for your care.

Take an active role in designing how you will be cared for as the needs develop *(see Section 8)*

- Join an early-onset support group and have your spouse join a caregiver support group.
- Talk openly with your children about the changes you and they are experiencing.
- Allow your children to express their fears and hurt.
- Record your thoughts and feelings for yourself and for your family.
- Keep open communication with your spouse and seek counseling as needed.

AN IMPORTANT REMINDER ABOUT THE *SYMPTOMS* AND “*STAGES*” DURING THE COURSE OF THE DISEASE

It is important to keep in mind that Alzheimer’s disease affects each individual in different ways. We are not able to accurately predict how, or when, a particular individual will appear to move through these general descriptions of stages.

Some people seem to skip a stage completely, while others might appear to move back and forth a bit, having good days and challenging days.

A person may seem to be in stage one, but then act out as though he is in stage two.


One person might progress through the stages more rapidly or slowly than someone else.

Susan may become very hostile and paranoid for some months, but then become more docile and cooperative. We can sometimes “wait-out” difficult behaviors.

The stages do not always begin and end according to any predictable schedule or time frame.

One person may move through the disease, and into the final stage in a few short years – while another might progress more slowly over a decade or more.

Keep a close eye on your *expectations*. Alzheimer’s disease requires that we learn to remain *flexible* and willing to *accept* what is going on at the present time.



*As the disease
progresses,
expect changes*

Henrietta still knows her own name, but does not recognize her children. She can still feed herself, but must be led to the dining room. She still recognizes the need to urinate, but must be reminded to sit down to use the toilet.



Lydia had been unable to speak for several years. One day she started talking. Her caregivers were stunned and delighted. She didn't stop until bedtime. She has not uttered a word since.



Howard had fetched his own cup of coffee for years. Suddenly one day, he no longer knew how to get a cup from the cupboard.

The Three Stages of Alzheimer's

STAGE 1: THE EARLY STAGE

A person can be in this stage for two-to-four years, or longer.

- He/she has problems remembering recent events
 - Forgets location of keys, papers, coat, hat, purse, garden tools, etc.—or puts them in weird places, i.e., the watch in the sugar bowl
 - Forgets what he/she was just told
- He begins to have trouble concentrating
 - Takes longer with routine chores
- She has trouble performing familiar tasks
 - Paying bills, sewing, following instructions or a recipe
- He becomes disoriented
 - Gets lost while driving the car, going for walks in the neighborhood
- She has trouble thinking of the right word to use for common items, i.e., the phone
- Lacks initiative to begin activities by herself; needs instructions to perform familiar tasks
- He begins to exhibit new behaviors
 - Less energy; less patient; more often frustrated, angry or withdrawn
- She has difficulty learning new activities—needs to be guided through them patiently, one step at a time

HOW YOU CAN HELP – Stage 1

- Pay close attention to the frustration and anger
 - Remind yourself that it is a sign of confusion and fear
- Offer support and help in a calm, non-critical manner
- Carefully organize and simplify daily routines
 - Do them one step at a time
- Be patient
- Make the home safe (*see **Making the House Alzheimer's Safe in Section 3** of this manual*)

STAGE 2: THE MIDDLE STAGE

A person can be in this stage for approximately two-to-twelve years (*professional opinion varies*).

At this stage, it is unrealistic to expect that your loved one can learn how to cope with the effects of the disease. What he needs now is more constant companionship with people who help him through the **activities of daily living**. The world he lives in has become very immediate, in the moment. The greatest challenges come in the form of frustration, anxiety and the need for emotional comfort—a sense of safety in the moment.

- Short term memory-loss becomes more severe
 - He forgets more quickly than in **Stage 1**
 - She cannot remember visits right after the visitor has left
- Trouble with thinking clearly
 - He cannot understand, concentrate, or make plans
 - She may have trouble reading, writing, doing simple math
- Confusion about time and place
 - She cannot remember where she is
 - He confuses day and night, or gets up at night thinking it is morning
- May wander outside and get lost very quickly
- Poor judgment
 - He cannot judge safe conditions
 - She forgets to wear a coat when it is cold outside
 - He forgets to turn off the stove, the lawn sprinkler, or flush the toilet

- Problems with speaking the language
 - She cannot put words together in a complete sentence
 - He cannot remember the names of common objects (coffee cup, television, toothbrush, driveway)
- May not recognize family and friends, or even herself in the mirror
- Greater need for help with **Activities of Daily Living (ADL's)** like bathing, dressing, eating, etc.
(It is probably time for a constant companion)
- May begin to wet and soil clothing (incontinence)
- Behavior problems (lack of inhibition)
 - She may forget the proper place to dress and undress
 - He may say inappropriate things or act out sexually
- Frequent restlessness
 - She becomes restless, especially in the late afternoon (*Sundowning* condition), or at night
- May have problems judging distances and heights
 - He has a difficult time getting into a chair, sitting on the toilet, climbing stairs or getting in and out of a car
- May imagine hearing or seeing things that are not really there (hallucinations, delusions)
- May have thoughts or ideas that are not true (including paranoia)
 - He may think that someone is stealing from him
 - She may think that her husband is in the Mafia
- May become irritable, teary, or silly for no apparent reason

HOW YOU CAN HELP – Stage 2

- Be calm and patient
 - Remind yourself that poor judgment, behavior problems, restlessness, etc., are signs of confusion and fear
- Give simple, one-step directions with the immediate activity
 - “Put this towel in your hand.”*
 - “Now, dry your hands with the towel.”*
 - (Do not use words like “and,” “but,” “or,” “maybe,” “which one?”)
- Limit choices.
 - Do the same things the same way each time
 - Do them one step at a time
- Remind and repeat – gently
- Celebrate success (but don’t overdo it)
 - “You ate all your ice cream, Mom. Very good.”*
 - “You did a good job brushing your teeth, John.”*
- Accept that he/she will not talk to you at times
- Reduce noise and activity that may confuse, frighten or agitate
 - Run the dishwasher and garbage disposal, vacuum the floors, etc., when he/she is asleep, out of earshot, or away from the house
- Speak in a normal voice. A person with Alzheimer's is not necessarily hearing impaired
- Do not argue or expect them to *think rationally*

STAGE 3: THE LATE STAGE

A person can be in this stage for one or more years.

The conditions listed below are likely to be effects of disease related brain deterioration in the late stage. For instance, one may have perfectly healthy legs, but be unable to walk because of deterioration in the part of the brain that controls the walking activity (motor skills).

- The ability to speak clearly and make verbal sense is gone; may be completely unable to talk
- Direct care is needed all the time, 24 hours a day
 - She is unable to feed herself, and has trouble chewing and swallowing
 - He may be unable to walk without assistance
 - She may have total incontinence, requiring adult diapers, plastic bed mattress covers and absorbent pads on top of the sheets (*a critical time to check regularly for bed sores*)
 - He needs someone to bathe, dress, feed him
 - She needs to be assisted with all bathroom activities
- He may put things into his mouth and want to touch everything.
- She may groan, yell, or make grunting sounds.
- The condition eventuates in death generally brought about by an “opportunistic illness” such as pneumonia, heart attack or stroke.

HOW YOU CAN HELP – STAGE 3

- Make and use memory aids
 - Put a large picture of the toilet on the bathroom door.
 - Take the door off the clothes closet.
- Approach the person slowly
 - Avoid touching them from behind.
- Lead them through tasks one step at a time
 - Always tell them what you are doing.
“I am going to wipe your hands with this warm washcloth now.”
“Now, dry your hands with this towel.”
- Pay close attention to their reactions and feelings
 - Do not expect them to be able to communicate effectively with words.
- Touch the person, as well as using words, to communicate.
- Compliment them for being a good person and doing a task well.

*Please contact the Alzheimer’s Association
for further reading materials on Late Stage care.
See the educational brochure, book and video listings
in Section 8 of this manual.*

SECTION 2

PUTTING LEGAL & FINANCIAL AFFAIRS IN ORDER

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Starting the Process with Legal Needs

Caring for family members with Alzheimer's Disease brings up some important legal concerns.

As you care for your loved one, you will need to have the legal papers in order so that you can make decisions and take responsibility for his/her care.

Many people have produced end-of-life instruments such as Wills, Family Trusts, Life Insurance, etc. However, it is also very important to plan ahead for the possibility of becoming *disabled and/or incapacitated while continuing to live*. Without appropriate planning, one can lose control over who will make decisions on their behalf and how those decisions will be made.

When a person becomes disabled and eventually incapacitated with Alzheimer's disease, the laws require that the persons caring for them are appropriately authorized to make decisions on their behalf. These include:

- Health care decisions
- End of life decisions
- Financial and property decisions

If we plan well and have our legal instruments in order, then the appropriate people can take charge, and manage our care and personal resources accordingly.

- Advance Health Care Directive
- Durable Power of Attorney for Property Management (finances)
- Living Trust
- Declaration of Homestead
- Public Benefits Planning: Medi-Cal

However, if we fail to plan appropriately, then other legal steps will have to be taken through the courts in order to assign authority to people to manage our care and personal resources.

- Conservatorship of the Person
- Conservatorship of the Estate

Some of the legal documents/instruments you will want to learn about are:

✓ Advance Health Care Directive

(This replaces its predecessor, the Durable Power of Attorney for Health Care. Such documents executed on or before January 1, 1992, have expired.)

This document gives another person legal authority to make medical decisions on one's behalf. It can specify how he or she wants these decisions to be made. *A person must be legally competent when filling out these documents.*

This form is available for free at the Alzheimer's office.

✓ Durable Power of Attorney for Property Management

This provides for *management of financial affairs*. A person must be legally competent when filling out these documents.

This instrument allows a person to choose who will manage their assets and how they will be used. It is an alternative to trusts or Conservatorship.

✓ Public Benefits Planning: Medi-Cal

Standard health insurance policies are not written to cover custodial care and extended long-term care. A separate Long Term Care Insurance policy serves this purpose. Without this insurance, one may find themselves turning to Medi-Cal: California's state and federal subsidized program for limited nursing home care assistance. The rules for Medi-Cal are complex, and you may want to consult with a specialized attorney in order to learn how to use this benefit.

✓ **Conservatorship of the Person**

“But my husband has been diagnosed with Alzheimer’s already.”

The Conservatorship of the Person is a public legal process for assuming control over an incapacitated individual’s personal affairs, health care and medical decisions. This requires costly legal expenses and a court hearing. It is usually the last alternative considered and can be avoided if the person has current and well drafted Advance Health Care Directive and Durable Powers, which must have been executed when the person was competent.

✓ **Conservatorship of the Estate**

This is similar to the Conservatorship of the Person (see above). It allows for the management of one’s money and other property. This instrument is not required if one already has a Durable Power of Attorney for Property.

Some Optional Approaches when Using Professionals

- You may want an attorney with experience in Elder Law.
- You may want to use a legal document service.

Call the Alzheimer’s office to ask for referrals for local, elder care attorneys.

*For legal document services, see listings in **Section 8** of this manual.*

When consulting with professionals, ask what papers to bring to your first appointment.

It is advisable to have the following collected together and stored in a safe place:

Legal

- House and car titles
- Military Veterans records
- Pre-paid or pre-planned funeral documents
- Death certificates
- Marriage licenses
- Keys to desks, file cabinets, safety deposit boxes
- Wills and trusts

Financial *(See the following pages on Financial Planning)*

- Bank account records
- Loan payment and mortgage records
- Investment portfolio records for stocks, bonds, retirement plans
- Investment broker and accountants' names
- Insurance policies and Social Security records
- Tax returns
- Inventory of personal and household valuables

*But, I'm just not a
numbers person . . .*

Think of the *Income/Expense Report* as the “diary” of your monthly life.

However, it is written in numbers instead of words, and it takes the form of a list instead of paragraphs.

Indeed, the numbers tell stories. Once you get the hang of it you will probably find it to be fascinating.

Taking Stock of the Financial Situation

Welcome to Your New Role of Homecare Manager!

Caring for a loved one at home can be like taking on a new career. For many people, this includes learning new ways to keep track of family financial matters. It does not have to be terribly complicated or difficult, even though it may seem that way at first. It is very helpful to look at family finances with a fresh perspective. The costs of caregiving can be significant, and need to be planned for and monitored carefully.

Financial Planning and Cash Flow Management

Here are some steps you can take in order to get a clear picture of your current financial conditions. This will help you when talking about your financial affairs with attorneys, bankers, professional estate planners, tax accountants, financial planners, elder care professionals, doctors, and family members.

You will need to gather up all of your financial information and organize it on paper. If this is new to you, it may seem a bit challenging at first. This is natural, and your confidence will grow as you move through these steps. Approach it as an interesting new learning process.

You may want to take an Adult Education class in personal financial management, or ask a friend or family member to help you get going with the process. The important thing is that you begin this project now.

STEP ONE • Gather together the following:

- Bank account records
- Loan payment and mortgage records (if there is money still owed)
- Investment portfolio records and retirement plans
- Insurance policies and Social Security records
- Inventory of personal and household valuables

STEP TWO • Make a list of the numbers on a sheet of paper

What you are doing here is creating a snapshot of your current financial condition.

It is very helpful to do this even if you think “*I have it all in my head,*” or “*I never was very good with numbers.*” This will provide an important collection of information that will help in many ways throughout the Homecare process.

This exercise will give you two very important pieces of information that describe your financial situation:

- 1) **Your Net Worth:** This tells you how much money and family assets you have compared with debt. This will help you understand what you can afford to spend to care for the Alzheimer's caregiving.
- 2) **Your current monthly/annual income and cost of living:** This shows how much money you have coming in each month (or year), how much you are spending, and how much you have left over (if any).

You will always be grateful to have this financial information at your fingertips. It will look something like the next page.

FINANCIAL ASSETS (*where our money is*)

Checking accounts _____
Savings accounts _____
Bank CD accounts _____
Investment Portfolio _____
 Cash account _____
 Investments _____
 Retirement fund _____
Life Insurance cash value _____
Mortgage Equity _____
Other Assets _____

TOTAL ASSETS \$ _____

FINANCIAL LIABILITIES (*money we owe*)

Personal Loans _____
Credit card balances _____
Mortgage Principal _____
Auto Loans _____
Other Debt _____

TOTAL LIABILITIES \$ _____

Now, to complete this picture: Subtract the *Liabilities* from the *Assets* and arrive at your *Net Worth*.

TOTAL ASSETS _____
minus **TOTAL LIABILITIES** - _____

NET WORTH \$ _____ (*amount we have left over*)

STEP THREE • Make an Income and Expense sheet

There are three elements to this process are:

1) *Income*; 2) *Expense*; 3) *What's Left Over (Net Gain/Loss)*

1) INCOME (*monthly or yearly*)

Salary/wages	_____	
Retirement plan	_____	
Social Security	_____	
Interest	_____	
Dividends	_____	
Other	_____	
TOTAL INCOME	\$ _____	

2) EXPENSE (*monthly or yearly*)

Alzheimer's Homecare		
Caregiver wages	_____	
Employment taxes (withholding, SSI, Workers' Comp, etc.)	_____	
Supplies (personal care items, special needs accessories, etc.)	_____	
Agency fees, daycare facility fees, etc.	_____	
Total Alzheimer's Homecare	_____	
Auto (gas, repairs, payments, license fees, traffic/parking tickets, etc.)	_____	
Banking & Financial (bank fees, credit card fees, brokerage fees, etc.)	_____	
Household (groceries, supplies, repairs, gardener, pool service, subscriptions, etc.)	_____	
Interest (loan & credit card interest)	_____	
Insurance (auto, home, life, health, caregiver liability, etc.)	_____	
Medical (doctors, chiropractors, medications, lab costs, supplies, etc.)	_____	
Mortgage/Rent/Property Taxes	_____	
Professional Services (lawyer, accountant, financial planner, etc.)	_____	
Personal (clothing, restaurants, entertainment, toiletries, haircuts, video rental, gym, church tithing, memberships, donations, books, gifts given, etc.)	_____	
Taxes (property, State & Federal Income Tax)	_____	
Travel (train, plane, motels, dining, etc.)	_____	
Utilities (water, electric, gas, trash service, home alarm, cable TV & internet, etc.)	_____	
Other (loan principal payments, etc.)	_____	
TOTAL EXPENSE	\$ _____	

The final step: Subtract *Expense* from *Income* to get:

3) WHAT'S LEFT OVER (*each month or end of year*) \$ _____

The Valuable Benefits of Doing This Are . . .

You will create a tool that is necessary to help with planning and making decisions regarding your Alzheimer's Homecare.

Many elder care expenses may qualify as tax deductible and/or as a Caregiver Tax Credit. Review this with a tax accountant.

You will use these tools when talking with:

- Elder care agencies
- Residential facilities
- Financial planners
- Attorneys
- Insurance agents
- Family members

Having these collections of numbers at your fingertips will help you and others understand the situation clearly. This will help you make intelligent choices and informed decisions.

Think of these financial review sheets as helpful gauges, and instruments – like the gas gauge and the speedometer on your car's dashboard. You look at them, and ask:

“How far have we gone since this trip began?” How long have we lived with the Alzheimer's disease, and what is the projected duration ahead?

“How many miles per gallon are we burning; how much fuel do we have left; how much further can we go?” What is our spending rate, and how much longer can we spend like this – given our financial reserves at this time?

It has been said that life is a journey. Learning how to create and use these financial tools will provide you with the information you need to make well-informed decisions along the way.

Public Benefits: Services You Can Use!

Applying for these programs can prove to be a challenge to your self-esteem. However, please remember that your taxes are paying for these services.

Supplemental Security Income (SSI)

Administered by Social Security. This program provides income for persons without a substantial work history. You must be over 65 or have a disability. For more information, call (800) 772-1213.

Social Security Disability Income (SSDI)

Another program of the Social Security Administration. Provides income for persons under the age of 65 who cannot work because of a disability. For more information or to apply, call (800) 772-1213.

Medi-Cal

California's healthcare plan for persons with disabilities and the elderly. Funding and administration shared by the state and federal government.

Major Medi-Cal programs of interest to caregivers:

Medi-Cal "at-home"

Medi-Cal for persons living at home pays for doctor visits, therapy, testing, hospitalization and prescription drugs. Persons receiving SSI or In-Home Support Service can receive Medi-Cal for free. Others may have a share of cost. Asset and income limitations apply.

Long-term care Medi-Cal

If your spouse must enter a skilled nursing facility, different asset and income limitations apply. For the year 2005, the spouse living at home may:

- Own their own home
- Own their own car
- Keep at least \$95,100 of the couple's assets (2005 rate)
- Keep \$2,378 of their income per month (2005 rate)

For both programs, please call (805) 681-4528 in Santa Barbara County.

In-Home Support Services (IHSS)

This County program provides low-income persons with disabilities help with activities of daily living (ADLs). It provides caregivers, home health aides and attendant care. Services must be needed to help persons remain safely at home. If you receive SSI or Medi-Cal, you may be eligible without a share of cost.

Multi-Service Senior Program (MSSP)

This program provides social and health care management services for persons who are over the age of 65 and receiving Medi-Cal. Services include home health care, personal care, transportation, home repair and other services.

SECTION 3

LEARNING TO MANAGE CHALLENGING BEHAVIORS

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What are Challenging Behaviors?

People with Alzheimer's disease can sometimes do and say things that you do not like. This can be an occasional or frequent occurrence.

Sometimes he/she will behave in challenging ways with familiar caregivers, but suddenly behave very differently (polite, respectful, well-composed) with others – such as medical professionals, visitors and other family members. This can be confusing and frustrating for you.

All of us can become frustrated with a temporary inability to function normally resulting from a head cold, injury, surgery, etc.. Imagine how it is with Alzheimer's. The frequent frustration may quickly develop into impatience, fear, embarrassment, shame, and all the resulting emotional conditions that are difficult to cope with.

When your loved one is becoming confused, upset, and distressed with momentary emotional upheaval – it is important that you make a clear decision to pause and calm yourself. This will help you work with the emotional situation more effectively.

The following pages offer insights and suggestions on how you can use strategies, and different methods to help yourself, and your loved one shift gears, move out of the emotional upheaval and into a more comfortable condition.

This requires a **moment-to-moment coping process**. There is no one-size-fits-all method for success. Use your own creative abilities. Most of all: *Do not expect him/her to **understand reason and logic**. They live in a world of **feeling and emotion**. They lose control of their will and their mind. Remember always that the disease is causing this behavior.*

Common Causes of Difficult or Challenging Behavior

1. Health Problems

Poor eyesight or hearing	Depression
Fatigue from poor sleep patterns	Constipation
Illness such as urinary tract infection	Medications

2. Environment

- Over-stimulating noise and/or physical activity of other people in the room or public place
- Lack of structured time, boredom, inactivity
- Lack of orientation or cues (which way to the bathroom?, poor lighting)
- Environment is too large (or too small) and confusing
- Too much visual and/or physical clutter
- And other things

3. Task Related

- Difficulty in learning new tasks and remembering the steps involved in repeating familiar tasks
- Task is too complicated, too many steps, unfamiliar
- Caregiver may be trying to move a person with AD through the steps of a task too quickly

4. Communication

- Unable to find or pronounce words
- Does not know how to answer the question
- Frustrated when not able to communicate what they want

5. Perception of Reality

- What the person with dementia sees (hallucination) or thinks (delusion) may not be reality, but seems real to them.

*“Becoming a caregiver with knack:
The art of doing difficult things with ease.”*

*The Best Friends Approach to Alzheimer’s Care
Virginia Bell & David Troxel
Health Professions Press, Inc.; 1997.*

Use the **“Four Handy Helpers”**

Do not argue

*If she thinks her husband is still alive, that is her reality.
Arguing with her will encourage frustration, confusion,
fear, anger and a difficult time for both of you.*

This is not about “being correct.”

This is about helping a person with a serious disability.

Use finesse, and do not be afraid to fudge the truth

*Finesse: To be delicate, subtle, skillful and strategic, when
handling a difficult situation.*

*Card players use finesse to bluff their opponents in a
game.*

*When he is upset, apologize to diffuse the situation, even
though you are not at fault.*

Make up a story to help them relax

“Wait till the store brings the part this afternoon.”


*“I’ve already called a repairman. He’ll be here on
Saturday.”*

“Oh, Dad went on a business trip this week.”

Re-direct (change the subject and/or activity)

“OK, but first we need to eat some lunch.”

*“Let’s wait and call your sister after we’ve had a nap,
Mom. She is probably taking a nap now, too.”*



***“Take me home!
I want to go home!”***

Whenever Sylvia looked plaintively at John, and said she wanted to go home, he gently explained to her that she was home, right there in the house they had lived in together for 25 years.

Then, in his support group, he learned that this is a common expression to hear from people with Alzheimer’s. A woman shared her notion that what the person might really be saying is, “I want to be normal again, to be the person I used to be.” A man theorized that this may be an effect of his mother’s connection with long term memories of her childhood home. She would say she was going upstairs to bed, when she had not lived in a two story home since her childhood.

This made sense to John. From then on, instead of trying to reason with Sylvia when she asked to be taken home, he put his arms around her, calmed her, and then got her involved in an activity – to change the subject. Or, sometimes he would say, “Tell me about home.” Other times, he would get out an old photo album and enjoy reminiscing with her about her childhood days.



Jean cried a lot and seemed always on the brink of tears. Weeks went by before her caregiver discovered why. Jean missed her church. Short visits to services were made. At times, just seeing the building was enough. The pastor visited their home. Members of the prayer group took turns visiting and prayed with her. She doesn’t cry as much now.



Freda learned that her husband, Arnold, could be calmed by cuddling with him on their bed.

Crying and calling-out. . .

Crying can be a result of sadness, frustration, anger or physical pain.

Calling-out can be occasional or repetitive:

“I want to go home!”

“Mother! I want my mother!”

“Help! Police! Help!”

Try to find out why:

Pain in the body?

Depression, confusion, loneliness?

Frustration?

Hunger or thirst?

Constipation?

If you can rule out all of the above, TRY:

Gentle physical contact, touch, embrace

A dish of ice cream

A drive in the car to change the subject

A nap

Talk about a funny episode from earlier times

A project they can “help” you with

Sometimes, you can’t help them to stop crying or calling-out.

It may be therapy for them, a release

It is a common behavior of the disease

Discuss this with the doctor

Remember: This phase will most likely come, go and pass.

Sleeping difficulties at night . . .

Your loved one may have trouble sleeping at night for a variety of reasons. Here are some of the many possible causes:

- Too warm or cold; hunger and thirst
- Her brain is no longer able to regulate the “body clock”
- Incontinence and/or bed wetting
- Troubling dreams
- Not enough exercise during the day
- Too much napping or inactivity during the day
- Confusing night with day
- He thinks it is time to get up and dress for work
- She thinks it is time to get up and prepare to take a trip

*As a result, you — the caregiver —
experience sleep deprivation, too!*

Here are some steps to take, depending upon the cause:

- If you sleep in a different room, use a room monitor (like those used for infants) so that you are alerted to any situation
- If he is confused upon awakening, talk to him, help him to orient with his surroundings
- Monitor room temperature, blankets, and bathroom lighting
- Limit alcohol and caffeine
- Limit daytime naps to short catnaps
- Initiate plenty of daily exercise
- Wake him earlier in the morning rather than letting him sleep late
- Discuss this with the doctor/neurologist. It may be time to introduce a specialized medication that regulates the brain’s “body clock” function.
- Utilize a Day Center so that your loved one will have more activities and be tired at night

Having delusions or hallucinations . . .

Delusion: A fixed, false idea

Hallucination: Seeing something that is not there

A person may become frightened, annoyed, or amused by the delusions or hallucinations they are having.

Never tell them that they are crazy, stupid, or imagining things.

Use the “*Four Handy Helpers*”

- *Do not argue*
- *Use finesse and do not be afraid to fudge the truth*
- *Make up a story to help them relax*
- *Re-direct (change the subject and/or activity)*

- You may need to enlist a friend to play the role of an authority figure (repairman, detective, etc.) to whom the person with Alzheimer’s will listen
- Sometimes, a pretend phone call to “the authorities” works
- Your doctor can be consulted if the episodes are overwhelming

Margaret was afraid of the red-haired woman who kept looking in the windows. Her husband calmed her by saying that the woman had been hired to block-watch and protect the neighborhood.



Virginia was angry about the squirrels in the living room and the nuts they left on the carpet. Sally opened the door to let out the squirrels. She cheerfully used the broom and dustpan to sweep up the nuts as Virginia “helped” her find them.



Lillian loved the imagined little blond-haired girl who frequently sat on her bed and talked. For Lillian, it was the best time of day.

Repetitive behavior . . . Pacing, Rummaging, etc.

The person with Alzheimer's may pace around the room; or rummage through drawers, closets, kitchen shelves, etc., for long periods of time without seeming to get tired.

Do not try to stop them if doing so causes them to become frightened, angry or confused.

If pacing:

- Make sure their footwear is comfortable
- Check for blisters on their feet
- Make the pacing area safe

If rummaging:

- Try giving them laundry to fold (they may fold a stack of towels over and over again for an hour or more)
- Give them a box of beads to sort, a jar of screws, a box of silverware
- Inform their doctor – they may want to adjust a medication

This, too, will most likely pass

Phyllis used clothesline to rope off a safe pacing path for her husband that went all around the apartment. He never tried to untie, go over, or go under it. After many hours of carefully observing him, she went to bed, knowing he would be safe and that she really needed to sleep. Phyllis had no one to help her.

If you find yourself in this type of situation, it may be an important time for you to call a friend, family member, or hired help – to keep an eye on things while you are absent.

Wandering . . .

The person leaves the building and wanders down the street.

They may be looking for something

Are they looking for . . .

Childhood home?

Workplace, jobsite?

Mom, Dad, or children?

Favorite fishing hole?

Sometimes they think they need to run away from something or someone.

Could it be . . .

An ex-mate?

The enemy soldiers?

Angry parents?

A frightening noise?

DO THIS:

Use the “*Four Handy Helpers*”

- *Do not argue*
- *Use finesse and do not be afraid to fudge the truth*
- *Make up a story to help them relax*
- *Re-direct (change the subject and/or activity)*

- Double-check the house/yard security
- Alert the neighbors
- Enroll in the **Safe Return** program (*see next page*)
- Take them for walks – they may enjoy fresh air and sunshine
- Take them for a drive – they may have cabin fever

THE SAFE RETURN PROGRAM

Safe Return is a program of the Alzheimer's Association, to assist in finding, and returning home safely, people who wander and become lost.

Because the person with Alzheimer's frequently cannot communicate clearly, including their name and address, **Safe Return** is an invaluable assurance to the caregiver. People in any stage of Alzheimer's can benefit. Several disoriented drivers have been found hundreds of miles from home.

Call the Alzheimer's office and ask for the **Safe Return brochure**. It contains everything you need for entry into the program.

- Safe Return maintains a 24 hour hotline for calls about a lost registrant.
- Participants wear an identification bracelet, or necklace, with the Safe Return 800 number. They also receive clothing labels and wallet cards.
- A similar bracelet, or necklace, is available to caregivers. It alerts others to look after the patient if the caregiver becomes incapacitated.
- Participants' photos, and emergency contact numbers, are entered into a national database. A photo, and information about the missing person, can be sent anywhere via a fax alert system.

There are three ways to register a loved one in the Alzheimer's Association Safe Return Program:

- 1. On the Web at <http://www.alz.org>**
- 2. Telephone Safe Return at 888-572-8566**
- 3. Call your local chapter of the Alzheimer's Association and ask for a registration brochure to be mailed to you; or go to their office for registration assistance**

Wanting to drive the car . . .

IT'S THE LAW: If a diagnosis of dementia has been made, California law requires the physician to report it to the Department of Motor Vehicles (DMV).

The DMV will then notify the person with the diagnosis that they are required to come in for appropriate testing. (*The DMV does not automatically revoke or suspend the drivers license prior to the appropriate testing.*)

This can be particularly helpful because you can let the State “*be the bad guy*” who takes their driving privilege away—not you.

You can further prevent them from driving in a variety of ways:

- Hide the car keys
- Have the ignition re-keyed
- Have the ignition put on a hidden switch
(shop around, prices vary greatly)
- Remove the distributor cap or battery connection
- Remove or sell the car

One of the more emotionally challenging losses to the person with Alzheimer’s is not being able to drive anymore. This is an issue that is often addressed in support groups.

Call the Alzheimer’s Association office. Ask for the free booklet, “*At the Crossroads: A guide to Alzheimer’s Disease, Dementia & Driving.*”



*Should we let Dad keep driving?
It means so much to him...*

The diagnosed person needs to have their driving evaluated by the Department of Motor Vehicles (DMV).

As difficult as it may be, the family also needs to take responsibility and evaluate the safety of the diagnosed driver.

This is one of the disabling conditions that, **at some point**, requires a *designated driver or other modes of transportation*.

Some things to consider:

- Does your auto insurance cover a driver with Alzheimer's?
- Have you evaluated his driving recently by being in the car as a passenger?
- Do you let her drive the grandkids around?
- If your answer is "no" . . .
- Worse case scenario: someone is injured or killed.

Embarrassing me or others . . .

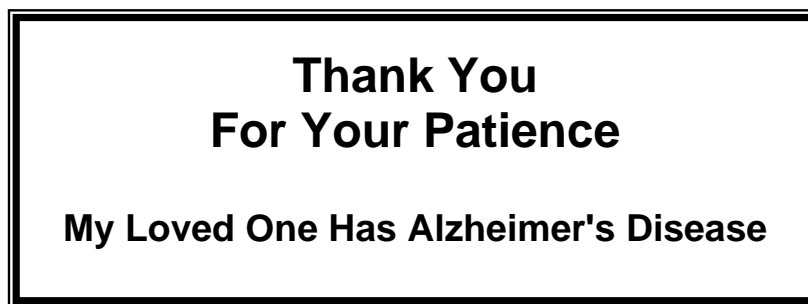
There may be public episodes of:

- Inappropriate sexuality
- Cussing/swearing, making off-color or rude remarks
- Spitting
- Accusing people of theft, abuse, infidelity, neglect
- Other disturbing behavior

Remember that the disease is causing this behavior.

- Chances are that if you criticize the afflicted person for misbehaving, they will grow more confused and disturbed.
- Use finesse to guide, distract and redirect.

Small “business card” handouts are available to you at the Alzheimer’s office. You may want to keep some with you to hand out.



Using the cards can bring different responses . . .

- You may get puzzled looks sometimes, but that is OK.
- Most readers of the card will smile, and tell you that they understand, and perhaps that they also know someone who has Alzheimer’s disease.
- Most of the time the card helps.

Wanting to fix things . . .

(even when they are not broken)

Use the “*Four Handy Helpers*”

- *Do not argue*
- *Use finesse and do not be afraid to fudge the truth*
- *Make up a story to help them relax*
- *Re-direct (change the subject and/or activity)*

If necessary, hide the tools.

Direct his attention to tinker with non-electrical things.

Dorothy usually told her husband that their son was coming soon, and whatever needed to be fixed should be saved until the son arrived. It would “give the son something to do.”



Joe had been an appliance repairman. Every time he wanted to “fix” the TV, VCR or stereo equipment, Mary would tell him that she looked forward to having that done, but first they needed to eat lunch or have a look at the problem with the kitchen faucet. Being distracted by the change in subject, he would forget about wanting to fix the electrical equipment that was never broken in the first place.



Rita enlisted a neighbor to wander over and “chew the fat” with her husband every time he went to the garage to “work on the car.” This was after she discovered that John had removed all the spark plugs and was not able to put them back in properly.

Sundowning

Sundowning refers to agitation, and behavior problems, that can escalate as the sun begins to set.

The behavior can begin any time, from mid-afternoon to sunset, and can continue into the evening.

No one knows the exact cause:

- It may be one's biological clock.
- It may be the change in lighting as the sun moves in the western sky.
- It may be a metabolism phenomena, such as getting tired, low blood sugar, etc.

What does Sundowning look like:

- The person with Alzheimer's may begin to get nervous, irritable, depressed, sad or angry, begin pacing around the room or house.

Try this:

- A hearty snack as soon as sundowning starts
- A walk, if you suspect excess energy
- A nap, if you think he may be overly tired
- Turning on lights to hide the fact that the sun is setting
- Offering their favorite activity if you suspect boredom
- A calming herbal tea
- Asking the doctor for suggestions and guidance

Refusing to bathe . . .

It may be caused by a variety of issues:

- Forgetting how to feel safe with water
- Loss of visual/spatial perception (*Where is the bottom of the tub?*)
- Being in a small room and feeling trapped
- Being cold, confused, and uncomfortable with not being able to control the temperature of the shower spray
- Feeling ashamed of being naked in front of someone else, regardless of who you are
- Afraid of slipping
- Not being agile, and able to move comfortably through the process of washing and drying themselves
- Forgetting the sequence of the bathing process: disrobe, turn water on, check water temperature, etc.

Some things to try, steps to take:

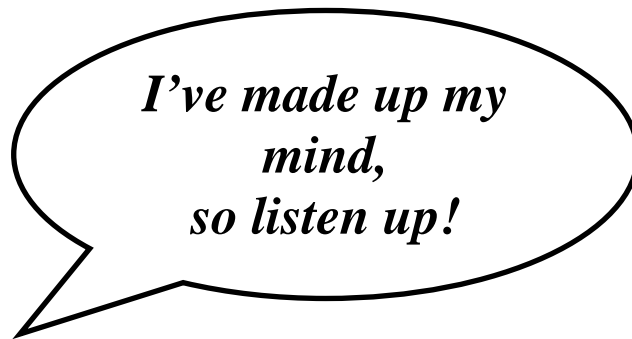
- Make sure the bathroom is warm and well lit.
- Make sure the room is safe (remove throw rugs, slippery floor conditions, electric hair dryers and razors, etc.).
- Do not announce bath plans until it is time—and then take him to the bathroom.
- Have everything ready before you bring her into the bathroom.
- If the shower is frightening, try a bath.
- If the bath is frightening, try a shower.
 - Try using a hand-held shower head.
 - Try using a stool for him to sit on in bath or shower.
- Carefully monitor the temperature of the water.
- Try joining her in the tub or shower.
- Is he too modest to be seen naked?
 - Let him stay wrapped in a towel or wear a swimsuit.

- If she is combative:
 - Ask her to hold a washcloth, empty plastic shampoo bottle, yellow rubber duck, sponge, etc.
 - Do not force her to bathe—this can cause increasing emotional challenge. Wait and try later.
- A daily bath/shower may be unnecessary.
- Between baths, a daily ‘sponge bath’ at the sink works fine.
 - Try the bath kits now available (pre-treated, non-rinse, disposable wash cloths).
- If you have access to a Jacuzzi or spa tub, she might find that to be more appealing than an conventional bath or shower.
- A back-rub with lotion may convince him that a bath is not all that bad.
- Try: *“The doctor says you must bathe every Tuesday. Today is Tuesday.”*

Above all, do your best to maintain the person’s dignity. You may need a home health aide to help with the bathing. When the time comes, the Alzheimer’s Association has a list of home health agencies.

***Call the Alzheimer’s Association office.
Ask for the handout, “Bathing”.***

Hillary coaxed her husband into the tub, but when she tried to wash his genitals, he took a swing at her. She gave him a washcloth to hold. He got it sappy-wet and tossed it toward the stool. She retrieved it. He again tossed it. This time when she retrieved it, she caught a devilish twinkle in his eye. They both laughed and finished the bath.



Dee announced one day that she would drink coffee, which she loved, and that she “was never going to eat again.” The caregiver fixed her many cups of decaffeinated coffee a day: with 75% chocolate flavored drink, 25% coffee. After five days, Dee started eating solid food again as if nothing had happened.

Will not eat . . .

- Check their mouth, gums, teeth and dentures.
- Watch for signs of irregular bowels and constipation.
- Try a complete, balanced nutrition/protein drink. If he/she does not like it, try a different brand, type (rice, soy, egg, whey, etc.) and/or flavor. Try mixing it in a milkshake with ice cream or fruit juice. (*Read the labels carefully and compare different products. Some have significantly more nutritional value than others.*)
- Puree cooked vegetables, and grains, in the blender or food processor.
- Offer finger foods—such as raw vegetables, crackers and cheese, dried and fresh fruit, toast and jam.
- Keep offering fluids—such as water, fruit and vegetable juices.
- Use wine glasses and make a toast!
- They may want extra attention—which not eating can accomplish.

In the case where an eating problem persists:

- There may be an underlying medical problem.
- Discuss this with their physician.

Angry, combative behavior . . .

As the disease progresses, momentary frustration can quickly develop into anxiety and fear. When this happens, it is natural for your loved one to feel threatened. This can trigger physical aggression as an irrational attempt to protect themselves or gain some control of the situation.

Types of behavior that can occur:

- Hair-pulling
- Spitting
- Kicking
- Pushing, hitting and pounding
- Fierce arguing and shouting

Use the “*Four Handy Helpers*”

- *Do not argue*
- *Use finesse and do not be afraid to fudge the truth*
- *Make up a story to help them relax*
- *Re-direct (change the subject and/or activity)*

Tune in on yourself and the situation . . .

- Stop what you are doing, step back and take a deep breath.
- Remind yourself that this is caused by the disease.
- Do not get angry with him.
- Think about what she is feeling.
- Reflect on your behavior: *Was I pushing to get something done? Am I being impatient? Did I present him with too many choices?*

Steps to take with your angry friend . . .

- Check to see if he is physically uncomfortable (wet pants, too cold, startled by a loud noise or something).
- Make eye contact, speak in a gentle voice.
- Talk to him in ways that are positive and reassuring.
- Help her feel safe.
- Walk away for a few minutes – this often works wonders!

Take threats of your own physical safety seriously!

It is important to take care of your own safety in any threatening situation. If you feel physically threatened, it is important to first remove yourself from the immediate, threatening situation (walk away to let things cool down; lock yourself in a bedroom; dial 911; or leave home and get help before reentering). You cannot help the person with dementia until your own personal safety is assured.

- Remove all weapons (guns, hunting knives, etc.) from the house – this *should be done whether or not there is threatening behavior*.
- Have a **plan** for how you will deal with emergency episodes.
 - Is there a neighbor, friend, or relative you can call who can come on a moment's notice?
 - If you ever have to leave the house in a hurry without a key, do you have one hidden somewhere so you can get back in?
 - Do not hesitate to call 911, and explain when they arrive that your family member has dementia.

Making Errors in Perception . . .

**Perception errors are the result of the disease.
They can be visual, spatial and/or auditory.**

The person with Alzheimer’s disease may:

- Walk into walls
- Have difficulty maneuvering into chairs
- Refuse to walk on dark or light floors—perhaps seeing them as holes
- Think the TV program is real
- Not realize the car is moving—and open the door
(Please lock the doors for safety)
- Become frightened at their own image in a mirror
(Cover or remove mirrors if that occurs)
- Become confused by shadows or glare
- Think radio voices are strangers in the house
- See windows as doorways

Some adjustments can be made to the environment:

- Cover mirrors.
- Select “benign” TV programs.
- Place furniture in front of windows.
- Provide good lighting, etc.

The physician should be consulted if extreme agitation occurs.

When I Lose My Patience

There may be periods when he/she presents a behavior, story, or question REPEATEDLY.

Your patience may wear very thin . . .

Understand that . . .

- It is the disease causing him/her to do this.
- It is a malfunction in the brain.
- The annoying behavior can be temporary or long term.
- Sometimes the “*Four Handy Helpers*” just don’t work.
- You may not be able to change his/her behavior.
- However, you CAN change *your* thoughts and feelings *about* his/her behavior using the “**Do this...**” guidelines.

Do this . . .

- Take a break.
- Experiment with different kinds of music to sooth the person and reduce the anxiety that may be driving the behavior.
- Get your broad-view perspective refreshed.
- Read **Section 4** in this manual on taking care of yourself and take action on the suggestions.
- Limited financial help for **Respite** may be provided by the Alzheimer’s Association so that you can get a break.
- Learn about your local **Adult Day Care** facility.
- Contact the Alzheimer’s **Helpline**.
- Attend a **Support Group**.

The action you take can restore your:

Patience	Equilibrium
Compassion	Sense of humor
Tolerance	

Whoops . . .

George is 74, but Alzheimer's makes him behave like a six year old. At age six, his family had no indoor plumbing. He now sees his closet door as the door of the old out-house.

His daughter put a slide bolt on the closet door, near the floor. She also painted the door knob to match the door, thus making it invisible to George.

Then she purchased a baby monitor in order to hear him get up at night and get to his room in time to guide him to the bathroom.



Roland mistakenly put his hearing aid batteries in his ears. They made a midnight trip to the hospital Emergency to have them removed. It would have been good to hide the batteries.



Janet tried to eat wax fruit from a decorative display bowl.



Minnie thought the vitamin pills were candy.

Making the house “Alzheimer's Safe”

- Act as if you are child-proofing your home.
- Use plenty of night lights.
- Keep an eye on stove knobs or remove them.
- Hide weapons, knives, scissors, tools, or anything that could be dangerous—and use an electric razor to eliminate razor blades.
- Lock up anything poisonous.
- Put slide bolts on doors (top or bottom) and windows.
- Buy electrical outlet cover plugs.
- Hide lighters, matches, car keys, etc.
- Supervise smoking.
- Gradually pack away valuable items, heirlooms, jewelry, etc.
- Have grab bars installed in the bathroom.
- Buy a fire extinguisher.
- Turn the water heater down to 120 degrees.
- Remove throw rugs and put railings on stairways.

Begin to develop a keen eye for anything, or any situation, around the house that may become a hazard. You do not need to do all this the day after a diagnosis has been determined.

Call the Alzheimer's Association office for more tips.

*Work at finding
something he/she enjoys*

Emily spends hours every day taking her clothes out of the closet and folding them neatly on her bed. It keeps her busy and happy. Her daughter re-hangs them every evening.



Bradley enjoyed working the New York Times crossword puzzle most of his adult life. He can no longer write, or understand the alphabet, but he is content for hours to fill in all the squares.



Howard was a building inspector. His wife bought him a clipboard with pad and pencil. He spends a part of each day “inspecting.”



Heather enjoyed old Shirley Temple movies on tape. Paul loved animals, and any animal/nature video gave him many pleasurable hours. Their caregivers then had time to do chores or just be by themselves.

Some Activity Tips

Depending upon the person's history and ability:

- Do simple household chores together (folding laundry, dusting, sweeping). Even though the person may not be able to do the task correctly, that is OK. Your purpose is to involve them in an activity. You can always go back later and fold the laundry properly.
- Go to the beauty salon or barbershop.
- Go for walks.
- Make scrapbooks, photo albums.
- Work in the garden, rake the leaves.
- Go fishing and picnicking.
- Ride a stationary exercise bike.
- Watch Respite Tapes on TV.
Video Respite® tapes may be available at your library or call 800-249-5600 for a catalog. The videos are expensive, but wonderful, and your loved one may enjoy the same one 500 times.
- Listen and dance to favorite music.
- Toss soft balls into a laundry basket.
- Do exercises while sitting in a chair.

Tips for Successful Activity

- He/she needs to be permitted to do as much for themselves as they can.
- Praise them for whatever they accomplish.
- Note: Watching TV may become frightening. Flawed perception may cause them to think TV events are in the room. They may enjoy Wheel of Fortune and Jeopardy long after they can no longer enjoy more dramatic shows with stories in them.

Plans for the Day

This includes both *ADL's (Activities for Daily Living)* and *Recreational Activities*

IMPORTANT

- A *set routine* helps you AND the person with Alzheimer's disease.
- The familiarity of doing the same thing, at the same time, every day, helps the person feel comfortable and safe.

Your Daily Activity Schedule will look something like this:

- Get up at the same time every morning.
- Grooming and dressing may take an hour or more.
- Breakfast: "dining activities" can include reading the morning paper and discussing current events.
- Morning Activity: a walk, grocery shopping, a haircut.
- Lunch: "dining activities" can include listening to music, reading a story out loud, looking at pictures, etc.
- Afternoon Activities: a drive, tending the garden and a nap.
- Dinner: "dining activities" can be similar to lunch time.
- Evening Activities: reading, stretching exercise, television.
- Go to bed at the same time every evening.
- Getting ready for bed activities may take an hour or more.

BE PATIENT—DO NOT RUSH

BE F L E X I B L E

There will often be days, or parts of days, when your set routine is disrupted.

A key to Alzheimer's caregiving is:

Expectations are challenged, and change is frequent.

He/She Lives a Long Distance from Me

You are realizing that he/she should no longer be living alone.

After having assessed the situation (in person if possible), you have several options:

- Arrange for an agency in his area to provide for in-home care.
- Arrange for her to move into a residential facility in her home area.
- Bring him to live in your home.
- Bring her to live in a residential facility near your home.

Some typical problems:

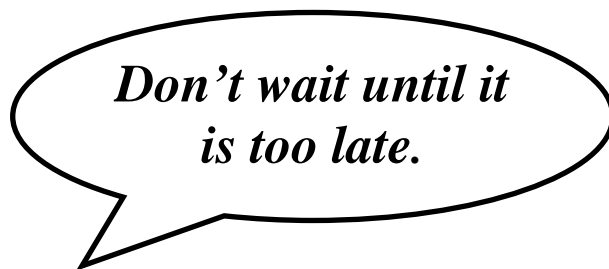
- She will not accept help and you cannot force her to.
- He does not want to come live with you.
- You cannot move to her home or area.
- You cannot afford to keep flying back and forth to check on him.
- You do not have guardianship or any legal means to help her.

Explore the options, be ready for change:

(These are often very complex issues)

- It is up to each family to creatively produce solutions to these challenges along the way.
- Sometimes a solution that looked like it would take care of him/her for the duration of the disease turns out to be only a temporary success.
- Sometimes taking up residence in a relative's home can become unworkable over time.

Please contact the Alzheimer's Association for further information and resources on long distance caregiving.



Sandra's Story

At her support group, everyone urged Sandra to find a home for her father who lived in another state. It was obvious to the group members, but not to her, that more secure living arrangements needed to be made. Then, one night, her father left the house and went wandering. He became completely lost. Fortunately, he was picked up by an attentive police officer who happened to notice him.

Sandra had not inspected a single extended care home facility, nor had she made any other arrangements. Now, something had to be done immediately—as he was clearly not safe by himself.

Expensive, around-the-clock care was recommended by the local Adult Protective Agency until Sandra arranged for long term care.

Facing and Surviving the Challenges

“No man is an island; no man stands alone. Each of us are a piece of the continent, a part of the main . . .”

John Donne

The words of John Dunne, the nineteenth century poet, ring true today:

They are especially true for caregivers of persons with Alzheimer’s disease.

Every caregiver needs and deserves the support of family, friends, community agencies, and physicians—just to name a few of the sources of support.

So . . .

- Ask for help.
- Do not try to do it alone.
- Share the experience with others.
- Use respite resources; take a break.
- Take time to care for your own emotional and physical health.

Please Remember

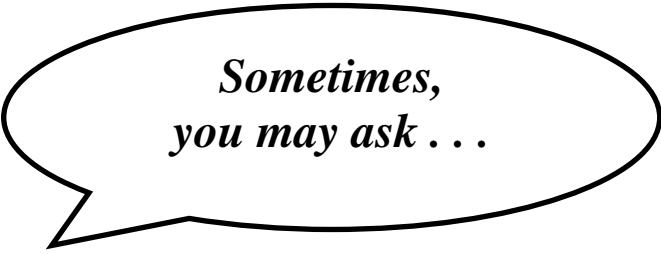
In order to give to others, and nurture them, we have to be nurturing ourselves along the way. It is necessary to replenish our own reserves in order to be at our best as a caregiver.

SECTION 4

TAKING CARE OF YOURSELF

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*Sometimes,
you may ask . . .*

*Why me, God?
How can this be happening to me/us?
What will become of all my plans for the future?
How can I get out of this?*

And have thoughts like . . .

*I wanted to ask for help earlier,
but I hoped it wasn't really Alzheimer's.
This isn't fair.
I don't want to face this.*

Be aware that . . .

The shock wears off.
Not every question has answers.
You discover courage and bravery you didn't know
you had.
Every life has challenges – the trick is to work with them.
You can do this.
It is time to shift gears, make plans, get some help.
The Alzheimer's Association is here to stand by you.

***“Remember that facing Alzheimer's disease
is preparing for a marathon, not a sprint.”***

Debra Cherry, Assistant Executive Director
Alzheimer's Association, Los Angeles Chapter

The Caregiver's Goals

Adopt these goals for yourself as a caregiver:

- *I will give the best possible care to my loved one*
- *I will give the best possible care to myself*

Both goals are equally important!

Both goals require:

- Commitment – to yourself and to your loved one with the disease
- Patience – with yourself and with your loved one
- Understanding – of yourself, of your loved one and of the disease
- Compassion – for yourself and your loved one
- Respect – for both of you

This may be one of the most challenging and demanding jobs you've ever had. It can also be one of the most rewarding.

Learn to ask for help rather than trying to do it alone.

The “*I can do this myself*” attitude is like a team player refusing to pass the ball. It is exhausting, and it ignores the richness that other people can bring in to the situation.

Caregiving is too large a job for any ONE person alone.

Even professional caregivers take turns with their duties.

Use the resources listed in **Section 8** of this manual.

- Many agencies are State and Federally funded – your tax dollars working for you!
- Others, like the Alzheimer's Association, are privately funded and depend upon donations.

Keep in mind that there are volunteers who have been where you are now. They have learned a lot and want to share in your time of need.



***Troublesome
thinking . . .***

Husband thinks . . .

*I can do this by myself!
Be a man! Be strong! I've been through
the Great Depression and WWII. I can do this.
Be independent!
Feelings are a weakness and a waste of time.*

Wife thinks . . .

*Mothers and wives come last.
Take care of everyone else first.
Don't ask for help (this is a private affair).
Our wedding vows said...
I owe it to him.
We've been together all these years.*

Baby Boomer female thinks . . .

*I am superwoman! I can do all this—job, kids,
husband (or single mom), caregiver for parent.*

Daughter thinks . . .

*I'm the only daughter and can't expect my
brothers to take on these caregiving duties.*

Siblings think . . .

*Mom always got along best with you, so you're the
right one to be with her now.
I live in town near Mom & Dad. All my siblings live
far away. Of course, I'm the one to do this caregiving.*

Avoid Caregiver Burn-Out

You are #1 Priority • Put yourself First

You still have a life with your loved one, but now you must start building a life of your own. One of the great challenges to the caregiver is thinking, “*I cannot take the time to care for myself.*”

Continue to do the activities that you enjoy such as golfing, gardening, playing bridge, painting, sewing, hiking, volunteering, etc.

Do not withdraw from:

Friends

Relatives

Church

Civic organizations

Weekly hobby or activity groups

Keep your sense of humor!

There are humorous moments and situations with the disease. Use these to laugh. Your humor will help you to cope better.

Take care of your physical self:

- Grooming
- Exercising
- Eating healthily
- Regular medical check-ups

Give yourself private time and space.

Give yourself permission to take a break – day off – vacation. Learn how to deal effectively with feelings of guilt when you do something for yourself.

Let your doctor know you are under a new stress.

Join a **Support Group**.

Line up helpers now. Consider:

- Adult Day Care
- Respite Care

What Is Respite?

Pronounced *res'pit*—it means “*a time of rest and relief.*”

To you, it means:

Placing your loved one in the care of someone else, for a time, so that you can give yourself some “time out.”

The respite care may be with a:

Friend

Relative

Volunteer

Companion sitter

Adult Day Care Center

Respite Care Home

Professional Caregiver

Along the way, many of us have learned that our loved ones often fair quite well with strangers. Strangers are not as emotionally involved as we are and can offer a fresh experience for him/her.

Even though it may be challenging to leave your loved one for this purpose, it is in their best interest that you give yourself an opportunity to refresh. Respite can help you strengthen your mind, emotions and physical health.

Rather than waiting until you near the breaking point, discipline yourself to schedule such breaks on a regular basis.

How to Use Adult Day Care

What is Adult Day Care?

Adult Day Care is a day program of socialization, activities, and meals in a safe, supportive environment.

Who attends Day Care?

- Someone with Alzheimer’s disease or other dementia
- Someone who needs supervision during the day
- Someone with physical or mental limitations
- Someone who may be socially isolated, or lonely, and feels more comfortable in a supervised setting

Reasons for using Adult Day Care:

- Provides respite for the Caregiver! Adult Day Care allows the caregiver an invaluable source of respite.
- Socialization and activities for the person with the diagnosis.
- Day Care provides a safe, non-judgmental place, for folks to feel at home, active, social, and independent.

NOTE: Cost, hours of operation, and some services (such as transportation) vary between day care centers.

*Call the Alzheimer’s office to find the adult day center nearest you.
(see list in **Section 8**)*

“My husband just sat in front of the TV all day and didn’t want to get up in the morning. He’s never been a joiner, so I didn’t think I could get him to attend day care. However, this last year at the day care program, he has been happier than I’ve seen him in years. He has a reason to get up every morning—because the bus is waiting for him, and he’s looking forward to seeing his friends and the staff.”

About Support Groups

What is a Caregiver Support Group?

Support groups are designed to provide opportunities for you to learn from other participants how to deal more effectively with the challenges of caregiving. There may be anywhere from three to fifteen people in a group at any given session. They generally last for an hour and a half.

Sometimes a group will have guest speakers to address specific topics of care management. Other times, they are an open discussion format where participants present specific questions and situations. They will often receive feedback from others who may have similar experiences, and offer insight and helpful tips. Some participants attend every session, for years. Others will come occasionally when they have a specific need.

Our support groups have a code of ethics:

- Confidentiality – what is said there, stays there.
- Politics are not discussed.
- Religion is not discussed.
- No product endorsements are made.
- No fees are charged.
- No advice is given—just sharing.
- Participants learn how to listen and respect each other's situation.

Our support groups can be a good source for:

- Tips on how to ...
- Techniques that have helped others
- Information on doctors and other resources you will need
- Emotional support

Our support groups can:

- Be a place to find new friends.
- Help you get through some of the worst of times.
- Save you wasted time, effort and frustration.
- Allow you to participate as a listener.
- Provide humor – which has many benefits.
- Be alert for signs of stress that you fail to notice.

*Find a support group listed in **Section 8** of this manual or by calling the Alzheimer's Association office.*

*Support Groups are for those
Touch/Feely people...
I don't have time for that.*

Bernie was struggling with learning how to deal with everything, as his wife moved deeper into the challenges of Alzheimer's disease. Thinking that the Alzheimer's Association Support Group was some sort of "emotional release workshop," he gave little thought to attending.

Then he started hiring caregivers, and realized that he needed some help learning how to select, train and manage them. He called the Alzheimer's office to find out if there were any classes on the topic. The Helpline person told Bernie that the Caregiver's Support Group devoted a lot of attention to that matter. He decided to give it a try and went to a meeting.

Bernie has since become a strong supporter, and recruiter, for Alzheimer's Support Groups. He learned that the people attending his group were able to give him ideas, information, coaching, and encouragement over the years that followed. Looking back, Bernie wonders how he ever would have been able to manage his wife's care without the Support Group.

Some Advice On Stress Management

Stress is not always bad; it is a normal part of our lives.

Stress is a dynamic tension that produces a force capable of accomplishing a movement, a task. When a *stress* becomes a constant in our daily lives, it transforms into *distress*. You want to *manage* the physical and emotional stress in your daily life – so that it does not become *distress* – so that YOU do not become *distressed*.

Do not ignore signs of *distress* within yourself. Some signs are:

- Anxiety, worry, short temper, irritability
- Headaches, backaches, tense muscles
- High blood pressure, digestive disorders
- Restless sleep

Letting the *stress* develop into *distress* compounds the challenges, both for you and for the person you are caring for.

Give yourself the gift of learning how to respond to *stress* in healthy, productive ways – before it becomes *distress*.

Let's be realistic: Physical and emotional *stress* can become constant (*distress*) when caring for a person with Alzheimer's disease. It is essential that you experiment with different *stress* management techniques – in order to discover what will work best for you at any given time.

Stress Management Techniques

- Pause frequently throughout the day, take some deep breaths, allow your body's muscles to relax.
- When others are napping, or otherwise not requiring your attention, give yourself 20 minutes for:
 - Prayer, meditation, devotional practices
 - Exercise, walking, yoga
 - Reading, reflective writing
 - Learn relaxation techniques
- Join a Support Group and ask how others cope with and manage their stress.
- The person you are caring for cannot change their condition. However, you can decide how you react to the daily situations that arise.
- Get some help with household chores, yard work, shopping, and with the caring for your loved one.
- Eat nutritious meals.
- Treat yourself to a massage.
- Step outside and notice the weather, look at the sky, connect with nature.
- Get enough sleep and rest.
- Talk with a good friend who can listen, and provide useful and productive feedback.

What Can I Expect with Myself?

Some common thoughts, feelings & symptoms of possible caregiver depression:

Anger	Sleep problems
Fear	Denial
Grief	Guilt
Fatigue	Sense of Hopelessness
Withdrawal	Irritability
Headaches	Diarrhea
Upset stomach	Weight gain/loss

What can I do about this?

- Understand that your emotions are normal and understandably present.
- Learn stress management methods.
- Talk with:
 - A trusted friend and/or family member
 - A Support Group
 - Your minister
 - Alzheimer's Helpline
 - Your doctor

The following will happen:

- You will make mistakes.
- You will get discouraged at times.
- You will learn many new skills.
- You will make many new friends.
- You will grow in wisdom.
- You will learn that there *IS* life after Alzheimer's.

Spirituality in Our Lives with Alzheimer's Disease

It is not uncommon for a family member to say with great sadness that they have lost their loved one to Alzheimer's:

"My father doesn't even know who I am any more."

"That is not the woman I married – she's gone."

"This terrible disease has taken away my brother."

The thoughts and feelings of being disconnected from how we used to experience our loved one can be challenging to say the least. Let us pause for a moment and imagine how this experience of disconnection affects the person with Alzheimer's. They feel disconnected:

from the people they knew,

from the previous normalcy of their daily lives,

from the clock and calendar,

from being able to make sense of even "familiar" surroundings,

from their memories,

from their religion,

and indeed, from their ability to make their thoughts, speech,
and bodies do what they want them to do.

If *we* feel disconnected from them – imagine how *they* must feel.

It is important to understand that the person with Alzheimer's may have lost their memory; their ability to select words and speak them in the right order; their ability to perform even the simplest of tasks – *but they have not lost their spirit*. No matter how disassociated and distant they may seem to be, there dwells within them the enduring spirit of a human being who is alive and participating as best they can in the moments of daily life.

With this in mind, we can begin to understand that each person needs to be respected and appreciated for who they are: *A human being with just as much need for affection, companionship and connection as you and I.*

We often confuse the notion of spirituality with the idea of religion. In their extensive essay on the topic of spirituality and dementia*, Virginia Bell and David Troxel define religion as “*a personal set or institutionalized system of attitudes, beliefs, and practices relating to God or a higher power.*” They further define spirituality as that which “*encompasses a person’s broader values and beliefs. A religious person is a person with a spirit, but not every spiritual person embraces formal religious beliefs and practices.*” Indeed, our spirit is that which provides us all with a sense of being human, of identifying ourselves with the experience of being a person in the moments of our daily lives.

Each of us has this sense of presence with our spiritual self. It is this presence that we share whenever we interact with each other. It is how we define ourselves, seek out meaning, purpose, and fulfillment in our lives. I have it, you have it, and our loved ones living with the challenges of Alzheimer’s disease have it – no matter how much they may seem to be detached from their environment, physical body, or social communication.

We all have needs associated with our spiritual being-ness. It is with this in mind that Virginia Bell and David Troxel have identified a series of Spiritual Needs. As caregivers, the more we pay attention to addressing these Spiritual Needs, both with ourselves and with our loved ones, the more we can find ways to bring moments of quality, delight, and comfort into our daily lives together.

Spiritual Needs*

- 1. The need to be connected to others, to community and to one's faith or beliefs.**
- 2. The need to be respected as a valuable person apart from memory and appreciated for one's life achievement.**
- 3. The need to be loved and to love another.**
- 4. The need to be known, understood, and accepted.**
- 5. The need to be compassionate, caring, and helpful.**
- 6. The need to be productive and successful.**
- 7. The need to still become, still be in the flow of life, to teach and learn.**
- 8. The need to be hopeful.**

What can I do to bring the spiritual dynamic into the moments of our daily lives together?

Focus on the moment at hand.

Life takes place in the immediate present. It is easy for a caregiver to become distracted with her own immediate goals and become impatient, distracted and frustrated. Stop, look and listen. Ask the question: *What is most important here? I want Mom to decide what shoes to wear. Mom says she wants to wear her slippers.*

Erggggg...! Perhaps it is time to let Mom wear her slippers. Her spirit may be trying to express a momentary sense of identity, personal will, and the ability to make a choice—to be heard. Let her wear her favorite slippers and mention that you think they are cute. Then, after she has finished breakfast, bring her shoes with an invitation to go for a walk together.

Let your husband know that you respect and value him.

Always make eye contact and speak directly to the person with Alzheimer's. This lets him know that you respect and care about him. It creates an invitation for him to behave the same way toward you – at least to the degree that he is able. Take care not to diminish his self-respect by talking about him with another person while in his presence.

Help your sister continue to feel connected with her religion.

A person who has had a long history with a religious connection in their lifetime will often gain great comfort with being reminded of their faith, their belief in being connected with a Higher Power. Find ways to give them an ongoing experience with their rituals, religious writings, and familiar symbols. If you share that particular religious orientation with them, it can bring both of you significant connection with the spirit of life that you share.

Enjoy the simple wonders of life and Nature together.

Alzheimer's disease can greatly diminish and remove many of the "normal adult attentions" from our loved ones daily lives. However, the ability to catch the joy of watching a bird splash in the birdbath, step outside to smell the rain, and revel in the brilliance of a sunset are always with us. Even though a person with Alzheimer's may not be able to say so, the pause to notice the simple pleasures together touches the spirit.

"I want to go home. Please take me home."

Virginia Bell and David Troxel* suggest that *"this is much more than a literal statement of place. Instead it is a cry for spiritual connectedness. Home represents a place safe from the present, safe from dementia, a happier time."* They encourage us to endeavor to *"create a spiritual space or spiritual moment for them. In effect it is to allow them to go home – spiritually if not physically."*

“The search for meaning and acceptance surrounds us throughout our lifetime.”

Carly Hellen, a dementia care specialist in private practice

***The spirituality of
comfort and joy . . .***

A visiting nun was talking with a gentleman beset with dementia and confined to his bed in a nursing home. When she asked him what he longed for the most, he replied that he missed going to church. She asked him what he missed the most about going to church and he replied, “I miss the sound of the mission bells!”

The following Sunday, the nun went to the mission church and tape recorded the ringing of the bells. She then took the tape recorder to the gentleman’s bedside and instructed his caregivers to play the tape of the mission’s bells several times every day.

Everyone was deeply moved by the tremendous comfort and joy that sound always provided for the gentleman.

*“*Spirituality and the Person with Dementia: A View from the Field.*”
Virginia Bell and David Troxel. *Alzheimer’s Care Quarterly* 2001
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SECTION 5

HIRING & MANAGING IN-HOME CAREGIVERS

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Welcome to your new role as “HOMECARE MANAGER”

If you think you have seen this subtitle before, you are correct. It starts off *Section 2: Putting Financial and Legal Affairs in Order*. It is the subtitle for this section, as well, because hiring and managing caregivers for Homecare can be a challenging “new job” for many people. Working effectively with people entering your home to care for a loved one may require you to learn some new skills which we will address in this section.

*Will others know
what to do?*

BE CERTAIN to leave information, lists, and instructions for all caregivers. Things like:

- *Daily schedule*
- *Doctor’s name and number*
- *Closest relative’s/friend’s name and number*
- *Activities your loved one enjoys doing*
- *Things that upset your loved one*
- *Meal menus and snacks – what and when*
- *Medications – what and when*

Where Do I Find Good Caregivers?

*Should I pay an agency to provide professional caregivers?
Or, should I find and hire them by myself?*

- These are very important questions and require careful consideration.
- Everyone has their own story of what works best for them.
- There are potential benefits, and challenges, with both options.
- There can be financial differences.

The Caregiving Profession

- Some professional caregivers work only through an agency.
- Others prefer to work independently as private employees with families.
- Some caregivers work a variety of shifts, both as agency and as private employees.

NOTE: Professional caregiver training, experience, and skill levels, can vary significantly from one caregiver to another:

- Some professional caregivers are trained very well.
- Some have limited training.
- Others are not trained at all.
- A compassionate caregiver may have the best of intentions. However, without sufficient training and skill development, they may be unable to perform the tasks and responsibilities required of them.

Regardless of how well trained, or experienced they may be, coming into your home is a new challenge for them – and for you.

Working Relationships

The key to having good results with people working in your home is in the *relationship* you develop with each person. This is true, whether they are agency or independent hires.

With each professional caregiver who comes into your home there are two, or more, relationships involved:

- 1) The relationship between **you** and the professional caregiver
- 2) The relationship between **the person being cared for** and the professional caregiver
- 3) If there are **other people** living in your home, or who are directly involved in the affairs of your home – the professional caregiver may be interrelating with them, as well.

Whether you use an agency, or hire privately, you will need to take on the responsibility for helping both the Care Manager and the professional caregivers learn how to work effectively with your situation. Every home presents a unique situation for the people hired to help.

A good place to get help with learning these management and relationship skills is in an *Alzheimer's Caregiver Support Group*. Swapping notes with others, who are living through a similar experience, can help you with suggestions and insights that can be enormously helpful.

Working with an Agency

If you work with an agency, they will send over a **Care Manager** to conduct an assessment interview with you and with the person who will receive the care. They will assess different aspects of the situation:

- The condition of the person with Alzheimer's; what degree and manner of care they need; and a variety of other particulars
- The condition of the home and the ways in which it can be adapted to Alzheimer's care needs
- The other residents of the home; their health and related needs; their relationship with the person with Alzheimer's; etc.

This meeting with the Care Manager provides a good opportunity for you to learn about the agency and how they go about the business of managing the care they provide.

Ask questions!

- How long has your agency been in business?
- How many employees do you have working in private homes?
- Who will manage and train our caregiver(s)?
- How will your agency help me learn how to manage my relationship with the caregivers?
- Will the employees you send over be fluent in our language?
- How do you select the caregivers who come to work in our home? What qualifications do you require of them?
- Under what circumstances, and how often, will you send us substitute caregivers instead of our permanent ones?
- Who do we call when we have questions or challenges with our caregivers? What will be done about it?

- What sort of person do you think will work best for us?
- Man or woman / age / skill and experience level / physical strength / personality / etc.
- What do the caregiver labels mean: Nurse, personal care, companion care, RN, LVN, BSN, LCT, CNA, etc.?
- What hourly rate will I pay you, and how much do you pay the caregiver?
- What other costs/fees will I be expected to pay your agency?
- What kind of insurance do I need to have – in case the caregiver is injured on the job?
- How often do you come over to reassess the situation and monitor how well the caregivers are doing their jobs?

Who is Their Boss?

Me, or a person at the agency that sent them over?

If you contract caregivers through an agency, it is very important to discuss this (probably more than once) with the Care Manager from the agency.

Professional caregivers can become confused when family members have expectations that are different from those communicated by the agency Care Manager.

Likewise, caregivers can be challenged when a family member gives instructions that conflict with their training.

Think of the agency Care Manager as your partner (and perhaps your coach). Communicate with them often and openly.

Hiring Professional Caregivers by Myself

Professional caregivers can be found through some agencies. They send potential employees over for you to interview and hire privately on your own. (*See Agencies in Section 8*)

Some people find professional caregivers through newspaper ads, through word-of-mouth in church circles, through friends or co-workers, through their bank trust departments and through other professional caregivers. This can be a challenging undertaking. You will need to develop skills as an interviewer, and use your intuitive sense.

- Ask for previous employer references and contact them.
- Ask for documentation of legal residency status for non-citizens.
- Obtain Social Security numbers, and have them fill out W2 forms.
- Always hire people on a TWO WEEK TRIAL BASIS – so that in case things do not work out well, letting them go is relatively uncomplicated.
- Find out if they are skilled in (and physically capable of) lifting people from falls, in and out of chairs, bed, toilet, and bathing situations, etc.
- Ask how they deal with challenging behaviors.
- Find out if they have other jobs; how stable their schedule is; if they will be able to add hours if your needs increase.
- Learn what types of work and services they are willing to perform and are experienced with: cooking, laundry, house cleaning, feeding, bathing, toilet, recreational activities, outings, grocery shopping, etc.
- Observe them, and note their manner; loudness and rate of speech; and physical movements. Think about how such personal mannerisms will affect the person who will be cared for. Also, how will this affect you?

The Life Story

One of the more helpful things you can provide a professional caregiver with is a written *Life Story* of the person they will be caring for.

This can be a simple list of things that give a snapshot of their life and an easy reference guide about your loved one:

- Age
- Names of parents, brothers and sisters, mates, children, etc.
- Where they grew up
- Whether or not they went to college and where
- Their business or profession(s)
- Favorite places they have lived or traveled to
- Military service
- Happy events (marriage, birth of grandchildren, etc.)
- Tragic events (loss of family members, injuries, illness, etc.)
- Favorite color
- Preferences with music, reading, TV and video, etc.
- Favorite foods
- Hobbies, artistic talents and avocations
- Religious and spiritual orientation
- Names of friends and neighbors
- And anything else you can think of that you would like to know about them – if you were the stranger who was arriving to help them move comfortably through the moments of their days

This will help the professional caregiver be creative and effective in developing their relationship, conversations and activities with your loved one in innumerable ways.

Do I Have to Train Caregivers?

Don't they already know what to do?

Professional caregivers need your instructions and coaching.

A professional caregiver will, hopefully, be trained (perhaps certified in Alzheimer's care), but you will still need to train them about how things work in your home and with the person they will care for:

- What kinds of foods your loved one eats, and how to prepare them
- What kinds of activities to do; how and when to carry them out
- What manner of voice and language to use when speaking to the person they will care for
- How to appropriately occupy themselves when your loved one is sleeping or wants to be left alone for a while
- Whether or not it is OK to listen to music, watch TV, help themselves to food, read a magazine or use the telephone
- Under what circumstances it may be permissible to bring a family member to the job with them (*"Can I bring my 5 year old daughter over tomorrow? The baby sitter has to go be with her sister in the hospital."*)
- Is it permissible for one caregiver to call another and change schedules with each other or substitute for a shift?
- If there is an emergency, whom do they call? (A family member, the doctor, the police, etc.)

Write a Job Description

It can be very helpful to write up a job description for the caregiver, so that both of you understand what is expected. It can be a good tool for discussion and clarification of expectations.

Keep a Daily Log

Agencies will (hopefully) have caregivers fill out a log, or shift diary, of what took place during a given work period. If you do not use an agency, it is good to create your own daily log. Record:

- Sequence of daily activities
- Food consumption
- Bowel habits
- Personal care
- Health conditions
- Challenging behaviors
- Effects of medications
- Etc.

Keep a **separate page** for listing questions you have for doctors and care professionals.

Create **charts** for tracking things like medication schedules, bathing, bowel movements (constipation can be a very challenging condition for people with dementia), body weight, etc. **They can become valuable reference tools for caregivers and medical professionals.**

See the logs we have provided in the back of this book. They are especially useful for doctors and other health care professionals to review.

Management is an Ongoing Activity

The challenges of living with, and caring for, someone who has Alzheimer's are complex and demanding. Everyone involved with their care will benefit from talking about the developments and changes on a daily basis. Learning how to become an effective Homecare Manager requires continual improvement with interpersonal relationship and communication skills.

Me, the Payroll Administrator!

How much should I pay?

Pay rates will vary according to these and other factors:

- The qualifications, skills, licensing and education of the caregiver
- The current going-rates in a given geographical community
- Whether a caregiver is paid by the hour or for a block of time such as a 24-hour shift

What is involved with professional caregiver wages?

- Contrary to what you may be told, professional caregivers are **employees**. *They are not independent contractors.* **Caution: If a caregiver files a workers' compensation claim against your homeowners insurance policy, the government will look carefully at your payroll filings, and you may have serious liabilities if you have not been following proper payroll procedures.**
- ***Never pay a caregiver in cash:*** This is illegal, and can cost you fines, penalties and other unnecessary grief.
- As an employer, you are **responsible for:**
 - A. Having workers' compensation insurance** through a private insurance company such as homeowners or tenants.
 - B. Filing reports and making payroll deposits at different times throughout the year,** to government agencies like the IRS and the State government (employee and employer Social Security taxes, State and Federal Income taxes, etc.). You need to obey strict payroll reporting laws, regulations and employment codes—which can change.

Professional payroll service companies can do the job for you and at reasonable prices – such as, *Paychex, Inc.*, or *Payroll People, Inc.*, among others. Check the *Yellow Pages* or ask an accountant.

DEALING WITH CONCERNS ABOUT HOUSEHOLD VALUABLES

- Most professional caregivers are honest and trustworthy
- Agency employees are often bonded by insurance policies in case of theft
- Check with your household insurance company to learn to what extent your valuables are covered for theft
- Learn how to document your valuables for loss recovery purposes
- Use a bank safe deposit box for both small valuables and documentation records
- People with Alzheimer's disease can be inclined to hide, sell, and give away valuables
- If something is missing, discovering who may be responsible can be very challenging: the person with AD, a relative, an employee, a family friend, etc.
- *Keep it simple: Remove Temptation*

SECTION 6

WHEN IS IT TIME TO MOVE OUR LOVED ONE INTO A RESIDENTIAL FACILITY?

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Key Issues To Consider In Advance

Hard Choices: People with Alzheimer's *will* get to a point where they require 24 hr care, 365 days a year. This requires that they:

- A. Live in a Residential Care Facility for the Elderly (RCFE), or
- B. Live in a private home with appropriate, well managed care, or
- C. Live in a Skilled Nursing Facility

Think about this: Begin planning well in advance for how you will arrange for this type of intensive care. Learn about the different facilities in the area: the comparative costs (they can vary greatly); the quality of services; how to arrange for financing (long term care insurance, Medi-Cal, private resources, etc.) and all the rest. Learning this takes time. Start early and go at it slowly.

*Call the Alzheimer's office (800) 272-3900.
Ask for a list of licensed homes.
Take advantage of our placement counseling.*

It is time to make the move into an RCFE:

- When he/she requires more care than you can give
- Before your own health (emotional, physical, mental) becomes compromised
- Before skilled nursing placement is appropriate

Yes, but . . .

It is common for people to have mixed feelings about moving a loved one out of their home and into an unfamiliar place. You may feel:

Guilty – as though you are letting him/her down

Like a failure – as though you should have done better

Sadness – that your lives are going through this experience

Relief – for yourself and for your loved one

Fearful – with thoughts of the empty hours ahead for you

These feelings are normal . . .

This is a process of change that can feel distressing. It is a good time to be conscientious about the need for self-care. Set aside time for attending an Alzheimer's Support Group. Get together with a trusted counselor, church person, friend, or family member who has good listening and feedback skills. Let others share in the process with you.

Keep in mind that . . .

After the settling-in and adjusting, many residents in well managed RCFE's surprise us by actually being happier in their new environment. They enjoy being in a group situation with new friends and activities. They can also experience relief from no longer having to struggle with trying to "be normal" or recognize surroundings that should be familiar but no longer are.

How much does an RCFE cost?

This is a very important question and must be carefully examined.

- The fees and costs can vary greatly from one facility to another. *The Ombudsman office and the Alzheimer's Association have lists that include fees and contact numbers.*
- Be sure to study all the particulars of the contracts. You will want to clearly understand what the monthly fees pay for and *what is not included*. For instance, do not expect personal care supplies (such as sanitary undergarments for incontinency) to necessarily be part of the monthly fees. These costs can be significant.
- Some facilities are not able to provide the degree of companion care that you may want for your loved one. You may be obliged to hire additional caregivers for this purpose.

There is a great deal to learn on this topic, so begin now!

Types of Licensed Homes

Residential Care Facility for the Elderly (RCFE)

RCFE's can be referred to as *Board and Care Homes* or *Assisted Living Facilities*. These homes are for persons who are not able to live safely on their own, but who do not require Skilled Nursing. Many RCFE's have a *dementia waiver* authorizing them to specialize in dementia care. A growing number have a *hospice waiver* and provide end-of-life care. Most of the time, these are private pay.

Skilled Nursing Facility (SNF)

SNF's are often referred to as *Nursing Homes*, *Convalescent Hospitals* and *Rest Homes*. They provide continuous, around-the-clock nursing care. The patient must be admitted by a physician. The cost is covered by:

- Medicare for the first 30 days
- Private pay (personal funds and/or insurance)
- Many SNF's accept Medi-Cal, often for a limited number of persons, and for only those who qualify for Medi-Cal.

Special Care Units

Special Care Units are usually the wing of a SNF that specializes in Alzheimer's disease and related dementias. For persons with progressive dementia who are too mobile for the regular SNF, these units can provide more appropriate care. They are able to accept Medi-Cal, though not all do.

Psychiatric Locked Facilities

These facilities provide services for persons whose symptoms include challenging behaviors such as persistent wandering, and violent, disruptive behavior. They are distinguished from SNF's by having doors that lock from the inside and secured walking areas.

Some Things to Look For

When evaluating a facility, consider these sorts of things:

- Is it too far to visit?
- Is it licensed?
- Is there a waiting list?
- Is there enough staff? Do they appear to enjoy their work?
- Is the staff specifically trained in Alzheimer's care?
- Does the facility appear clean and well maintained?
- Do the residents look well taken care of?
- Evaluate the activities and functions.
(Often, larger homes offer more structured activities, while smaller homes may have more staff per patient.)
- How much are the monthly fees, and how do they change with evolving care conditions? Do they accept Medi-Cal?
- Can your loved one remain there for the duration of their life, or will you have to move them at some stage of the illness?
- What services, supplies and special needs are included in the monthly fees? What is NOT included in the monthly fees?
- Inspect the kitchen and eat a meal there. How is the food, the between-meal snacks and fluids?
- Good care can be provided in simple surroundings, and poor care can be found in beautiful new buildings. Look beyond the environment

Also . . .

- Take someone with you. Compare notes afterwards
- Visit and compare as many facilities as you can
- Go more than once to each facility – to see how conditions may vary from day-to-day and from morning-to-night

Call the Alzheimer's Association office to get a current list of homes to check out and compare, as well as placement counseling.

SECTION 7

EXTENDED FAMILY AND FRIENDS

*Facing the challenges as a family,
and the impact on friends*

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Everyone in The Family is Affected

In the Alzheimer's Association education programs we train professional caregivers to learn how to become aware of the impact on the whole family.

Likewise, it is important for you to understand how different members of your family may react, and respond to the complex issues that move through families living with Alzheimer's disease.

The effects of living with this disease reach into every area of the lives of family members and friends:

- Social
- Financial
- Spiritual
- Physical
- Emotional

Alzheimer's disease can develop in people as young as thirty years old. It can occur in grandparents, parents, spouses and partners, siblings and even one's own adult children.

This disease will present challenges that many families have never experienced before.

Each family will experience its own story.

Family Relationship Issues Can Stir Up

Many families experience varying degrees of interpersonal struggle. Old patterns of parent/child, and sibling relationship challenges can rise up and complicate the Alzheimer's care needs.

Indeed, one of the more frequent subjects that arise in support groups is about "*difficult family issues.*"

Siblings may begin to argue with each other over how a parent is cared for, how family finances are used, or whether or not a parent should be moved out of their home and into a residential care facility.

An adult child who feels rejected by Dad might refuse to become involved with his care.

An unmarried daughter may find herself overwhelmed with parent care responsibilities while her siblings appear to be too busy with their own families to offer help.

A son, taking care of his parents, may get little help from his siblings other than periodic phone calls accusing him of spending too much money.

A wife, caring for her husband, may get insensitive phone calls from in-laws who know little about the disease, or are unwilling to accept that their brother is suffering from anything other than "*a little problem with his memory.*"

Individuals React Differently

Family relationships are complicated.

Alzheimer's disease will most likely increase the stress and strain on family relationships, but may also bring family and friends closer to each other.

We may often misunderstand each other's intent, especially if there is poor communication.

Many of us have spent decades avoiding conflict and pretending to get along with each other.

Some of us require more time than others to adjust to the shocking news that our family member has been diagnosed with Alzheimer's disease.

Some family members have developed better coping skills and "rally to the cause" more easily than others.

While Alzheimer's disease may bring some family members together, others may "keep an arm's length" or retreat to a distance.

Disease, disability, and the dying process will challenge each person in new and profound ways.

Our family relationship challenges and issues are more normal and common than most of us realize.

On the Bright Side

Each member of the family has the opportunity to respond to the challenges in their own particular way. For some families, there is an overall theme of support and earnest collaboration. Each person finds ways to help and contribute to the well-being of everyone involved. For instance:

- A family member who is familiar with managing finances may offer to take on the job of putting all the records together, and create a projection of costs so that everyone can become aware of the reality of the family's changing financial condition. They may pay the bills and balance the checkbook.
- Another relative may have organization skills that they will use to schedule caregiving employees, develop job descriptions, create forms for tracking care activities and make the house "Alzheimer's safe."
- Still another relative might dedicate a regular amount of weekly time to do the grocery shopping, clean the house and give the primary family caregiver some time off.
- A son or daughter, who lives too far away to help with local activities and responsibilities, may contribute money to help with the expenses. Or, they may simply phone on a regular basis to provide emotional support and encouragement.

Keep Everyone Informed

Why is it important to keep everyone informed?

- Alzheimer's disease is a challenge for friends and family members, and often requires a slow, incremental learning process.
- People will want to know – so that they can learn how to respond to you and your loved one appropriately.
- Others may be going through a similar process with a loved one, and will want to learn with you and offer support.
- Others might offer to help in ways that you may never have expected.
- Being able to help makes people feel good!

What are some ways to make the information available?

- Write a periodic note and send copies to selected people.
- Arrange for a family member to write the note and/or make periodic phone calls to selected people.
- Invite family members and friends to attend a support group, an information workshop or class, the annual *Alzheimer's Association Conference* or *Memory Walk* function.

Be aware of your expectations of other people.

- Do other people have a clear understanding of what you expect of them?
- Expecting others to “rally to the cause” and behave like “mature adults” may not be realistic at any given time.
- Are your expectations of *yourself* clear, well thought out, understood, and realistic at any given time? Are other people aware of the expectations you place upon yourself? Do they think they are realistic?

When thinking about the need to keep everyone informed, picture how a child does it.

“I want a sandwich.”

“My stomach hurts.”

“I’m tired.”

“I want to go play with my friend, now.”

“I need a hug.”

“Thank you for helping me find my doll!”

This is how we keep each other informed of what is going on with our loved one and with ourselves.

We tell them.

We ask for help.

We thank them.

. . . plain and simple!

This is actually something that people with Alzheimer’s disease often get pretty good at doing: They say it like it is. They *“speak their truth.”*

Perhaps this is just another one of the things they have to teach us. They re-learn to speak like children.

*Keep everyone informed.
Be candid and share the news.
You may be surprised with all the support you get.*

Everyone involved needs to “be on the same page.”

It is very important that all family members, who have contact with the person with Alzheimer’s disease, learn how to behave appropriately and effectively with their loved one.

Whether one is frequently involved, or an occasional visitor, he/she may not understand how to behave in ways that are consistent with what has become “normal and appropriate” for the diagnosed person.

For this reason, it can be particularly valuable for all family members to:

- Study this manual
- See *Section 8* for help with the following:
 - ✓ Read books on the subject; study the educational brochures available at the Alzheimer's office; read the Alzheimer's Association newsletters
 - ✓ Attend a family support group
 - ✓ Attend Community Education Events and Caregiver Education Programs produced by the Alzheimer's chapter
 - ✓ Attend the annual Alzheimer's chapter conferences
 - ✓ Attend the annual Alzheimer's Memory Walk

Most important of all, it can be helpful for all family members to talk with the primary caregiver and learn what is appropriate with the current care conditions. This applies also to family friends and relatives – anyone who is interacting with the diagnosed person and the direct caregivers.

Friends & Neighbors Need to Know

This can be stated very simply:

Do you appreciate knowing when your friends, and neighbors, are experiencing significant challenges in their lives?

If you did not know that your neighbor had Alzheimer's disease – and you noticed her walking alone down the street – you may think nothing of it. The next day, however, you might learn that she wandered half the night until the police found her.

“If I would have known, I could have prevented that...”

Friends and neighbors need to know.



Howard hesitated to ask ...

Howard and Emily had lived next door to the Cartwrights for ten years and hadn't seen Ben out in the yard for many months. Howard suspected that there might be something going on with Ben's health, but didn't want to appear to be prying. After talking it over with his wife, he decided to knock on the door to see if everything was alright. Cynthia Cartwright stepped outside to talk with Howard for a few minutes. She told him that Ben had been struggling with Alzheimer's disease for over a year, and that she was very grateful for Howard's concern.

Over the next few years, Howard and Emily enthusiastically became active with helping Cynthia do the shopping, taking care of the yard, and other caregiving chores. They also learned how to maintain a friendship with Ben through his progressing symptoms.

SECTION 8

COMMUNITY RESOURCES

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The Alzheimer's Association

The Alzheimer's Association is a national, non-profit organization with headquarters in Chicago. With chapters across the United States, The Association relies on volunteers, grants, and private donations to provide many educational and service programs.

California Central Coast Chapter offices:

San Luis Obispo (805) 547-3830

Santa Maria (805) 636-6432

Santa Barbara (805) 892-4259

Camarillo (805) 485-5597

Web site: www.centralcoastalz.org

**To reach the Alzheimer's office nearest you,
call (800) 272-3900.**

THE ASSOCIATION IS DEDICATED TO:

- Funding research to find a cause and cure for Alzheimer's disease
- Supporting and helping families learn how to take care of their loved ones who live with Alzheimer's disease
- Education and training for communities, families, professional health workers and caregivers

THE ASSOCIATION IS AVAILABLE TO:

You

Health Professionals

Law Enforcement

Clergy

Families

Everyone

*Please call the office and learn how to become involved.
We provide newsletters, conferences, events, trainings,
support groups, family education services,
and many other valuable services.*

Patient and Family Services Department

The **Patient and Family Services Department** provides support, services, and the latest information in treatment and medical research, to the families, and to persons with a diagnosis who are met with the challenge of Alzheimer's disease and related disorders.

1. Support Groups

- **For Family Members and Caregivers**

Participants have the opportunity to share information, develop caregiving skills and provide mutual support.

- **For Persons diagnosed with Early Stage Alzheimer's**

Participants benefit from a supportive environment guided by a professional facilitator.

(See list of Support Groups on following pages)

2. Helpline

Our family care consultants are available during office hours to provide support, information, referrals, and guidance to community resources.

3. Contact Center

After business hours, on weekends and holidays, call 1-800-272-3900 for 24 hour help from trained care consultants through our Contact Center. The local office receives notification of all calls and provides follow-up with families.

4. Patient and Family Consults

Office consults, and home visits, are available in order to provide assessment, long-term care planning, and information, for both family members and the person with a diagnosis. Services are provided free of charge.

5. In-Home Care Consultation

Education, home safety assessment and family consults can be arranged in your home whenever appropriate or to meet the needs of the homebound..

6. Caregiver University: Coaching for Caregivers

One-on-One Meetings for Support and Education

Caregiver coaching guides you to provide the best possible care for your loved one, and the best possible care for yourself. When you need direction, planning, and/or resource information, please call to schedule an appointment in our office, in your home, or the location of your choice.

7. The Caregiver's Guide and Resource Manual

What Now? Caregiver's Quick Guide and Resource Manual

This easy-to-use handbook was produced by the Patient and Family Services Department to respond to the needs of family caregivers. While there are many books available on caregiving, we designed this manual to assist people who are short on time and need to learn about the disease, who want information on various aspects of the challenges that arise, and who need convenient access to many of the local resources that serve the caregivers' needs.

8. Safe Return

Our nation-wide Safe Return program aids in the prevention of wandering and becoming lost. Registrants are entered into a national database, and receive an identification bracelet, along with additional program materials.

There are three methods of registering:

- (1) Register in person at any of our offices or registration sites located throughout the three counties (*call your local Alzheimer's office for site information*).
- (2) Telephone: (800) 272-3900 (direct line to Safe Return)
- (3) Sign on the Web at **<http://www.alz.org>**.

9. Respite Grants

Respite funds are available for caregivers who are caring for a family member with Alzheimer's disease, or a related disorder, who have the financial need and who meet the fund guidelines.

10. Services in Spanish

All family services are offered in Spanish including Spanish brochures, books, and videos in our library.

Dear Alzheimer's Association,

I had the most wonderful vacation. I didn't realize how much it was needed and how it helped me to face all that is happening at home. When "burn out" catches up with you, you are the last person to see what it's doing and how it distorts the coping mechanisms that get us through hard times. My husband, Gary, is well into the middle phase now and is slipping downhill quite rapidly. For him, I think it is a blessing – but so hard for me to watch it happening. God bless you all. Your kindness and generosity is most sincerely appreciated.

Karen D.

Caregiver and Family Support Groups

Support Groups provide participants with a place to share information, discuss common problems, lend each other emotional support and, sometimes, to hear guest speakers present on specific topics.

WE OFFER A VARIETY OF SUPPORT GROUPS

Spouse Caregiver

Adult Child and Family Caregiver

Recent Diagnosis in family

Post-placement

Bereavement

General Interest group (open to all)

Early-Stage

For information on support groups, meeting times, days and location – please call (800) 272-3900 or the Alzheimer’s Association office nearest you:

San Luis Obispo County

(805) 547-3830

Santa Maria

(805) 636-6432

Santa Barbara

(805) 892-4259

Ventura County (Camarillo)

(805) 485-5597

*Also, you will find the support group listings, with all related information, in the **Family Resource** section of our quarterly newsletter, and on our website: www.centralcoastalz.org.*

Education Department

The Education Department offers a wide variety of conferences, workshops, and educational materials for family caregivers, people with dementia and professionals and the community.

1. Annual Conferences

We hold annual conferences throughout our service area: San Luis Obispo, Santa Barbara, and Ventura Counties. These conferences feature a variety of nationally known, and local, experts discussing recent advances in research and care.

Unless otherwise noted, conferences are day-long and include lunch. A variety of *continuing education credit* is available and pre-registration is required. Please call the Association office for dates, locations and registration information.

2. Community Education Events

Community Education events are offered on a variety of topics related to dementia. These events are offered free of charge throughout the service area.

3. Caregiver Education Programs

These programs are designed to support family caregivers in providing quality care for their loved ones. They feature practical caregiving tips and resources.

4. Training Programs for Professionals

The Association is committed to enhancing the quality of care for people with dementia by providing ongoing training opportunities. We are approved providers of the following categories of continuing education credit: R.N./L.V.N., M.F.T./L.C.S.W., C.N.A./H.H.A., R.C.F.E. and Nursing Home Administrators.

Ongoing programs for professionals include:

A. Achievement Certificate in Alzheimer's Care

This is a comprehensive, 16-hour program of classes in an interactive workshop format. It provides an overview of Alzheimer's disease and related disorders; its effects on the person with the disease as well as family members; specific training for caregivers on communication, creating activities; working with challenging situations; relating with family members and one's care team on the job.

B. Care Training

This eight-hour class provides a broad introductory understanding of normal aging, dementia, Alzheimer's disease and related disorders; strategies for caregiving, communication and activities.

C. Understanding Dementia

This is a three-hour train-the-trainer class that satisfies DHS requirements for staff dementia training regulations (AB13747). The three sections are divided into an introduction to Alzheimer's disease; techniques to enhance communication and interaction; and adult learning techniques and strategies.

D. Caring for People with Advanced Dementia

This eight-hour class covers care issues unique to people in the later stages of the disease. The program also explores issues related to death and loss.

5. Library

The Association maintains a large lending library with books, journals and videos on dementia care issues and activity kits. An interlibrary loan program makes it possible to borrow materials throughout our service area.

6. Free Literature

We have a large variety of informative booklets and brochures available. The first copy of any brochure is free. Please call us for prices on multiple copies. *(See list on following pages)*

7. Books and Videos for Sale

8. **Quarterly Newsletter**

Our quarterly newsletter is available free of charge.

It contains the latest information on dementia care and resources, current research on Alzheimer's disease, relevant public policy issues, and upcoming events of interest and association news. Please call us if you would like to receive the newsletter.

9. **Congregational Education and Outreach**

The Association provides a variety of supportive services and educational materials to support local congregations. Please call us if you would like someone to speak to your congregation, or to learn more about special training opportunities.

10. **Speaker's Bureau**

The Association has a **Speakers Bureau** consisting of volunteers from a variety of backgrounds including: nurses, family caregivers, attorneys and facility administrators. Speakers are available, free of charge, to address your staff, service club, church, business organization or school.

11. **Caregiver University Programs for Family Caregivers**

All Caregiver University workshops and coaching sessions are paid for by a grant from the Area Agency on Aging. We have many workshops, so call for a current list of offerings.

What Now? – A Class for Caregivers

A two-hour introductory workshop in a small, Interactive setting. Participants receive a complimentary Resource Manual. This program is offered in both English and Spanish.

Coaching for Caregivers (see Patient & Family Services Department)

One-on-One Meetings for Support and Education

Caregiver coaching guides you to provide the best possible care for your loved one, and the best possible care for yourself.

When you need direction, planning, and/or resource information, please call to schedule an appointment in our office, in your home, or the location of your choice.

Powerful Tools for Caregivers: Taking Care of You

Six weekly workshops in a small, interactive setting.

Complimentary Powerful Tools workbook provided. In this workshop, you will break through one of the toughest issues for caregivers: self-care.

Library Books, Booklets and Video Tapes

The Library Service at the Alzheimer's Association office

We offer a large assortment of library materials that can be checked out on loan. Here is a list of the categories of *publications* and *videos* within our library. Call the Alzheimer's office nearest you to learn how to use the library.

- **Caregiving for others with Alzheimer's disease**
- **Caregiving for oneself while being a caregiver for others**
- **General Aging**
- **Long Term Care**
- **Multicultural Resources**
- **Personal Accounts**
- **Research**
- **Resource Guides**
- **Training Materials**
- **Resources for Young People**
- **Dealing with Grief and Loss**

Educational Brochures

Available at the Alzheimer's Association office

About the Disease and Diagnosis

- An Overview of Alzheimer's disease and Related Dementias
- Is it Alzheimer's? Warning Signs You Should Know
- Steps to Getting a Diagnosis: Finding Out if it's Alzheimer's disease
- Partnering With Your Doctor: A Guide for Persons with Memory Problems and Their Care Partners
- If You Have Alzheimer's disease: What you should know, what you should do
- Living with Early-Onset Alzheimer's disease
- Steps to Caring for a Person with Late-Stage Alzheimer's disease: Responding to the individual's increasing needs
- Steps to Late-Stage Care: Making End-of-Life Decisions
- Autopsy: A lasting gift for your family

The Personal Care, Activities and Safety Series

- Steps to Assisting with Personal Care: Overcoming challenges and adapting to the needs of persons with Alzheimer's disease
- Steps to Planning Activities: Structuring the day at home
- Steps to Enhancing Your Home: Modifying the environment
- Steps to Ensuring Safety: Preventing wandering and getting lost
- Safe Return – For safety and peace of mind
- Steps to Understanding Challenging Behaviors: Responding to persons with Alzheimer's disease
- Steps to Enhancing Communication: Interacting with persons with Alzheimer's disease
- Steps to Facing Late Stage Care
- Steps to Caring for a Person with Late Stage Alzheimer's disease

The "Caregiver" Series

- Especially for the Alzheimer Caregiver
- Steps to Understanding Financial Issues: Resources for caregivers
- Steps to Understanding Legal Issues: Planning for the Future

The “Caregiver” Series (continued)

- Hiring In-Home Help: A practical Guide for Seniors and their Families
- How to be a Long-Distance Caregiver
- Caregiver Stress: Signs to watch for... Steps to take
- You Can Make a Difference: 10 ways to help an Alzheimer Family
- Helping Children and Teens Understand Alzheimer’s disease: A Guide for Parents

Folletos en Español

- Centros Para El Diagnostico Y El Tratamiento De La Enfermedad De Alzheimer
- Qué hacer cuando sospecha problemas de memoria
- Retorno Seguro: Para la seguridad y tranquilidad mental
- Qué le pasa al abuelito? (La familia cuida al enfermo de Alzheimer)
- Unidas en la lucha! (La familia cuida al enfermo de Alzheimer)
- Diez Señales que Pueden Indicar la Enfermedad de Alzheimer
- Platicando Con El Paciente, La Familia y Los Amigos
- Cómo cuidar a Alguien con Perdida de Memoria y Confusión

The Memory Walks

The *Memory Walks* are local events that bring together families, friends, medical and care professionals, and business supporters.

The events serve to:

- Raise funds for the Alzheimer's Association
- Increase public awareness of the challenges with Alzheimer's disease
- Provide recreation, celebration and camaraderie for everyone

The funds raised at the *Memory Walks* go to support the local programs and services, and to promote research sponsored by our national headquarters in Chicago.

The *Memory Walks* allow the community to join together and raise awareness of the need to support families who are meeting the challenges of the disease. They also highlight the importance of supporting the research, as scientists work to develop:

- Preventive measures and medicines
- Treatments and medicines to improve the quality of life for those living with the disease and their caregivers
- And one day, to provide a cure

Everyone is welcome to participate and enjoy the fun of the *Memory Walks*. We now offer six walks each year in San Luis Obispo, Santa Barbara and Ventura counties.

*To find out how you may become involved,
call the Alzheimer's office.*

Non-Profit Service Agencies

Area Agency on Aging

Santa Barbara County (800) 510-2020

San Luis Obispo County (805) 541-0384

Services

“AAA provides a wide variety of supportive, nutrition and health promotion services through funding from the Older Americans and Older Californians Act.”

“Santa Barbara County Senior Resource Directory”

This 100+ page booklet is produced by the Area Agency on Aging. It is available, at no charge, and updated every year. It provides a comprehensive listing of local resources. Available at the **Alzheimer’s Association** offices, **Area Agency on Aging** office, and many other government and public service organizations.

Coast Caregiver Resource Center of the Rehabilitation Institute at Santa Barbara

For San Luis Obispo, Santa Barbara and Ventura Counties
1528 Chapala Street, Suite 302, Santa Barbara, CA 93101
(805) 962-3600 • (800) 443-1236

Services

“Part of a statewide network of Regional Resource Centers serving families and caregivers of adults with brain impairment.”

- Information and referral
- Support Groups
- Long-term-care planning and problem-solving consultations
- Respite in-the-home and out-of-the-home
- Legal consultation and advocacy
- Training and conferences for caregivers

NOTE: Fees for services when applicable.

Community Partners in Caring

Santa Maria Valley, 608 East Main Street, Santa Maria, CA 93454
(805) 925-8000

Services

Volunteers in the *Lifelinks* program provide wide variety of services for the elderly in the Santa Maria Valley. Services include respite care, meal preparation and shopping, transportation, minor home repair and chores and much more.

Health Insurance Counseling and Advocacy Program

(HICAP) 528 South Broadway, Santa Maria, CA 93458
(805) 928-5663

All other areas of Santa Barbara and San Luis Obispo counties call:
(800) 434-0222

Services

HICAP provides a variety of services (free of charge) that help you make decisions required to get the most from your Health Benefit dollars, including: Medi-Cal and Medicare assistance; Medigap and HMO benefits; and long term care insurance policies.

Independent Living Resource Center

423 West Victoria Street, Santa Barbara, CA 93101
Josephine Black, Executive Director
Santa Barbara (805) 963-0595 • Fax: (805) 963-1350
Santa Maria (805) 925-0015
Ventura (805) 650-9278

Services

“This agency provides a variety of non-medical rehabilitative services to persons with disabilities.”

This includes personal assistant referral services.

Senior Connection (see Area Agency on Aging)

Santa Barbara County (800) 510-2020 or (805) 928-2552
San Luis Obispo County (805) 541-0384

Services

“A specialized senior information and assistance service of the Area Agency on Aging. This service will assist with information, referral, follow up, and education.”

Long Term Care Ombudsman

Santa Barbara County • 5638 Hollister, Suite 130, Goleta 93117
(805) 967-0499

San Luis Obispo • (805) 772-3059, (800) 231-4024 (24 hour emergency)

Services

This agency is responsible for investigating complaints about **residential care** and **skilled nursing facilities**. This includes allegations of abuse in such facilities; abuse issues include physical, financial, emotional and neglect. You may use the Ombudsman office as a resource to learn about the different facilities when you are exploring placement options.

LTCO does not get involved with caregiver complaint situations in one's private home. See Adult Protective Services—in Santa Barbara County listings.

Visiting Nurse and Hospice Care of Santa Barbara

222 East Canon Perdido Street, Santa Barbara, CA 93101
(805) 963-6794

Services

This is a non-profit organization, which provides a variety of direct, skilled care services on an intermittent basis. They accept Medicare, Medi-Cal, private insurance, and private pay.

VNHCSB provides the ***Loan Closet*** service, where all manner of care equipment and supplies are available on a loan basis for home use. This is an invaluable resource for things like wheel chairs.

VNHCSB manages the ***Leigh Block House***, which provides residential care for, terminally ill people.

Hospice Services

Hospice of Santa Barbara, Inc.

520 West Junipero Street, Santa Barbara, CA 93105-4212
(805) 563-8820

Services

Hospice of Santa Barbara provides emotional, social and spiritual support to people living with a life threatening illness, to people facing death, to people anticipating the death of a loved one or to people healing their grief after the death of a loved one. Volunteers provide respite care and companionship. Experienced professionals provide individual and family counseling on end-of-life issues and bereavement. Staff and volunteers facilitate support groups for children and adults. Speakers are available for community education. Services are delivered free of charge. *Contact: Gail Rink*

Visiting Nurse & Hospice Care of Santa Barbara

222 East Canon Perdido Street, Santa Barbara, CA 93101
(805) 963-6794

Services

Hospice Care is part of VNHCSB. It provides support and care for people moving through the final weeks or months of the life process. *“The Hospice team assists patients and their families so they may live each day as fully as possible.”*

Hospice Partners of the Central Coast

285 South Street, Ste 1, San Luis Obispo, CA 93401
(805) 782-8606

Hospice of San Luis Obispo County, Inc.

1432 Higuera Street, San Luis Obispo, CA 93401
(805) 544-2266, (805) 434-1164

Government Service Agencies

Santa Barbara County Public Health Department

Santa Barbara • 300 North San Antonio Road, Santa Barbara, CA 93110
(805) 681-5266

Santa Maria • 2125 South Centerpointe Parkway Santa Maria, CA 93455
(805) 346-8385

San Luis Obispo • 2191 Johnson Ave, San Luis Obispo, CA 93401
(805) 781-5500

Services

Geriatric Assessment Program (GAP) 681-5266

“GAP is a multidisciplinary approach to keeping frail elderly persons, age 60 and above, at home safely with appropriate supportive services.”

Preventive Health Care for the Aging (PHCA) 681-5266

For adults age 55 and over; a *“comprehensive health assessment by a Public Health Nurse to determine health needs and to develop a personal health plan to meet those needs.”*

In-Home Supportive Services (IHSS) 681-4550

San Luis Obispo 781-1790

“Provides household help and personal care to enable low income elderly or disabled persons to remain safely in their own homes.” You must be approved for MSSP in order to receive IHSS.

Multipurpose Senior Services Program (MSSP) 681-5311

“MSSP assists in identifying frail elderly at risk of institutionalization. Case management staff will coordinate and link community services to help the frail elderly remain in their own living environment. MSSP will augment and purchase services if necessary.” Medi-Cal benefits apply.

Chronic Disease Self-Management Program (CDSMP) 681-4550

This is a seven-week course teaching *“self-management skills needed to cope successfully while living with your chronic diseases, including: heart disease, arthritis, diabetes, chronic lung disease, high blood pressure, etc.”*

Adult Protective Services (APS) 681-4550

Santa Maria 346-8303; Lompoc & Santa Inez Valley 737-6020; SLO 781-1790
Investigates reports of alleged abuse, neglect and financial exploitation of adults in the person’s own home.

APS does not get involved with issues in skilled nursing and residential care facilities. See Long Term Care Ombudsman Services—for RCFE investigations.

Private Care Agencies

Private care agencies provide a variety of services for Alzheimer's care in the home. The services can include, but are not limited to: health and nursing care, personal care, bathing, cooking and feeding, activities and companionship, household chores, and full care management.

You can use agency services to completely manage the care for a person with Alzheimer's 24 hours a day, 365 days a year.

Or, a family caregiver might use an agency to provide companion care a few times a week – so that he/she can leave the house and go shopping, visit friends, take a hike, see a doctor, etc.

Many agencies provide their employees with Alzheimer's care training. However, finding the right people for your situation requires that you work closely with the Care Manager to find, train, and manage the caregivers – so that they fit comfortably and perform well with your particular needs.

*The list of private care management agencies
begins on the next page.*

*For further information on this topic,
see **Working with an Agency** in **Section 5** of this manual.*

Agency Reference Chart

(see chart on next page)

This chart is designed to help you understand how to explore the types of services different agencies provide.

If you hire independent professional caregivers through the referral services, the hourly rates can be significantly lower than hiring through private agencies. However, you become the employer/manager and do not receive any of the other agency services. The Real Help agency offers lower fees, *but only for low income seniors.*

Chart Key

*Information gathered in March 2006.
Services offered may change at any time.*

- (1) Services may include bathing, dressing, feeding, meal preparation, light housekeeping, errands and companionship.
- (2) Clinical supervision over every case includes care plan and follow-up.
- (3) The agency can evaluate the needs of the person and home, and bring together the necessary resources.
- (4) The agency sends screened applicants. The family is responsible for the professional caregiver's supervision, payroll, taxes, and employee insurance.
- (5) The employee's payroll, taxes, and employee insurance are included in the agency's fee.

In-Home Agencies in Santa Barbara County

Agency Name	Phone Number	Personal and Domestic Services (1)	RN Case Mgmt (2)	Complete Care Mgmt. (3)	Bath visits	Referral Service (4)	Payroll Service (5)
Addus Health Care (IHSS MediCal only)	962-4993	Yes	No	Yes	Yes	No	Yes
Assisted Healthcare Services	569-2000	Yes	Yes	Yes	Yes	No	Yes
Astera Care	969-7979	Yes	Yes	Yes	Yes	Yes	Yes
At Home Senior Services	736-8249	Yes	No	Yes	Yes	No	Yes
Nursecore	564-4221	Yes	Yes	No	Yes	No	Yes
Help Unlimited	962-4646	Yes	Yes	No	Yes	25% fee	Yes
Home Instead	560-6995	Yes	No	Yes	Yes	No	Yes
Independent Living Resource Center	963-0595	Yes	ILRC provides caregiver referrals. You hire, train, manage, and produce the employee payroll for caregivers in your home..				
In-Home Care Network	681-4609	This Santa Barbara County agency provides caregiver referrals. You hire, train, manage, and produce the employee payroll for caregivers in your home.					
LivHome	687-8766	Yes	Yes	Yes	Yes	Yes	Yes
MediTech	800-538-0900	Yes	Yes	Yes	Yes	No	Yes
PalsPlus	965-9868	Yes	No	No	No	Yes	No

Agency Name	Phone Number	Personal and Domestic Services (1)	RN Case Mgmt (2)	Complete Care Mgmt. (3)	Bath visits	Referral Service (4)	Payroll Service (5)
Real Help <i>(referrals only)</i>	965-1531	Yes	No	No	No	Yes	No
Santa Barbara Care Management	569-1010	Yes	Yes	Yes	Yes	No	Yes
Senior Planning Services	966-3312	Yes	Yes	Yes	Yes	No	Yes
Visiting Care & Companions	690-6202	Yes	Yes	No	Yes	No	Yes

The following agencies offer **emergency respite care** (can send caregiver over on short notice): **Asssited, Nursecore, Help Unlimited, Home Instead, LivHome, Santa Barbara Care Management**

In-Home Agencies in the Santa Maria Area

Agency Name	Phone Number	Personal and Domestic Services (1)	RN Case Mgmt (2)	Complete Care Mgmt. (3)	Bath visits	Referral Service (4)	Payroll Service (5)
Amdal In-Home Care	464-0108	Yes	Yes	Yes	Yes	No	Yes
At Home Senior Care	922-3644	Yes	No	No	Yes	Yes	Yes
Home Sweet Home	352-1313	Yes	No	No	Yes	Yes	Yes
In-Home Care Network	Lompoc 737-7775 x1256	Santa Maria 614-1256 x1256	This Santa Barbara County agency provides caregiver referrals. You hire, train, manage, and produce the employee payroll for caregivers in your home.				

In-Home Agencies in San Luis Obispo County

Agency Name	Phone Number	Personal and Domestic Services (1)	RN Case Mgmt (2)	Complete Care Mgmt. (3)	Bath visits	Referral Service (4)	Payroll Service (5)
ActivCare In-Home Support	772-7744	Yes	No	Yes	Yes	Yes	Yes
A Caring Touch	473-2809	Yes	No	Yes	Yes	Yes	Yes
A Coastal Touch	528-5156	Yes	No	Yes	Yes	Yes	Yes
All Home Care	473-4040	Yes	No	Yes	Yes	Yes	Yes
Amdal In-Home Care	464-0108	Yes	Yes	Yes	Yes	No	Yes
Central Coast Caregivers	461-5339	Yes	No	Yes	No	Yes	Yes
Comfort Keepers	528-8862	Yes	No	Yes	No	Yes	Yes
Core Extensions	545-5472	Yes	Yes	Yes	Yes	Yes	Yes
Family Home Care	481-6081	Yes	No	No	Yes	No	Yes
HOME Care-Giver Services	781-8156	No	Yes	Yes	Yes	No	Yes
Home Instead	773-3774	Yes	No	Yes	Yes	Yes	Yes
Linkages Care Management	547-9680	Manage only	No	Yes	No	Yes	Yes
LivHome	687-8766	Yes	Yes	Yes	Yes	Yes	Yes
Quality Caregivers	543-8860	Yes	No	Yes	No	No	Yes
Senior Living Consultants	556-0203	Senior living placement services (independent, assisted, dementia care, etc.)					

Adult Day Care

Friendship Center

89 Eucalyptus Lane
Santa Barbara, CA 93108
(805) 969-0859

Santa Maria Wisdom Center

1414 North Broadway,
Santa Maria, CA 93458
(805) 349-9810

Cozy Creek at Vista del Monte

3775 Modoc Road
Santa Barbara, CA 93105
(805) 687-0793

Senior Moments

2727 Thoroughbred Place
Arroyo Grande, CA 93420
(805) 489-5796

Lompoc Valley Haven

2800 Harris Grade Road,
Lompoc, CA 93438
(805) 733-9459

Palm Street House

1118 Palm Street
San Luis Obispo, CA 93401
(805) 544-1414

Solvang Valley Haven

1825 Alamo Pintado,
Solvang, CA 93463
(805) 688-0297

Cambria Care

St. Paul's Episcopal Church
2700 Eton Road
Cambria, CA 93422
(805) 927-4290

RCFEs / Attorneys / Physicians

*For the current listings on the following,
call the Alzheimer's Association office at (800) 272-3900, or:*

San Luis Obispo County (805) 481-9364

Santa Barbara County (805) 563-0020

Ventura County (805) 485-5597

- **Residential Care Facilities for the Elderly (RCFE)**
- **California Nursing Home web search:**
www.calnhs.org and www.calnhr.org
For the most current information, call
the Long Term Care Ombudsman (see page 135)
- **Attorneys Practicing Elder Law**
- **Physicians: Family, Internist, Neurologist, Psychiatrist**

Legal Document Services

Check the Yellow Pages under “**Legal Clinics**” and “**Legal Forms**” for business listings. Examples are:

- *About Justice Legal Document Services*
- *America’s Documents*
- *Liberty Legal Document Services, Etc.*
- *We The People Legal Document Services*

The Alzheimer’s Association does not endorse, nor recommend, any particular company.

Caregiving Supplies

Santa Barbara

How to Find Most Resources

For wheelchairs, scooters, walkers, stair lifts, platform lifts, hospital beds, portable toilets (commodes), etc., go to:

“*Medical Equipment & Supplies*” in the Yellow Pages.

Check with companies like: *Apria Healthcare, Mobility Masters of Santa Barbara, Pacific Coast Medical Supply, Santa Barbara Medical Supply,* etc.

Also, go to “**Pharmacies**” in the Yellow Pages.

Check with stores like *Federal Drug Co., Coast Village Pharmacy, Sansum Clinic Pharmacy,* etc.

Santa Barbara Healthcare

P.O. Box 50143, Santa Barbara, CA 93150

(805) 969-5467

This company sells, and delivers to your door, **durable equipment** for homecare: hospital beds, wheelchairs, lifts, walkers, and much more.

Caregiving Supplies (continued)...

Visiting Nurse & Hospice Care of Santa Barbara

222 East Canon Perdido Street, Santa Barbara, CA 93101
(805) 963-6794

The **VNA Loan Closet** provides an **equipment loan service** providing things like: wheelchairs, walkers, the occasional hospital bed, etc. When people no longer have need for equipment and leftover supplies, they donate them to this service.

We Care

1027 North Cindy Lane, Carpinteria, CA
(805) 566-3430

This company sells, and delivers to your door, **personal care supplies**. They offer discounted prices on things like sanitary undergarments, toilet and bathing supplies, etc.

<h2>San Luis Obispo and Santa Maria areas</h2>

ACI Medical

104 El Cerrito, Nipomo, CA 93444
(805) 929-5876

Durable medical equipment: wheelchairs, beds, seat lifts, walkers, etc. They sell and rent supplies.

Apria Healthcare

1265 West McCoy Lane, Santa Maria
(805) 325-9219

Durable medical equipment (wheelchairs, beds, seat lifts, walkers, etc) and respiratory therapy.
They sell and rent supplies.

Central Coast Supply

1440 West Grand, Grover Beach
(805) 544-0933, 481-3326

Fair Oaks Pharmacy

1051 East Grand, Arroyo Grande
(805) 489-4243

Caregiving Supplies (continued)...

HealthPlus Pharmacy

948-A Foothill, San Luis Obispo
(805) 543-5950

Lincare

715 Betteravia, Santa Maria
(805) 922-8466

Lincare

2945 McMillan, San Luis Obispo
(805) 543-2665

Max Care

4825 El Camino, Santa Maria
(805) 928-0566

Max Care

4825 El Camino, Atascadero
(805) 4660286

Med-Mart

12328 Los Osos Valley Road, San Luis Obispo
(805) 594-1332

Med World

1524 West Branch, Arroyo Grande
(805) 489-1354

Mobility Masters

(805) 528-2249, (800) 464-1973
Call for catalogue and Buyer's Guide for shopping at home.
Call for in-home demonstrations of equipment.

Valley Medical Pharmacy

1414 South Miller, Santa Maria
(805) 922-1747

Additional National Services

Alzheimer's Disease Education and Referral	800-438-4380
Community Information and Referral	800-352-3792
Elder Law Hotline	800-231-5441
Eldercare Locator	800-677-1116
Medi-Cal information	916-636-1980
Santa Barbara	805-671-4520
Lompoc	805-737-7018
Santa Maria	805-346-7104
Medicare and Medicaid information	800-633-4227
National Caregiving Foundation	800-930-1357
National Institute of Neurological Disorders	800-352-9424
National Stroke Association	800-787-6537
The National Council on Aging, Inc.	800-375-1014
Veterans Administration	800-827-1000

This web site is for comparison of nursing homes:

www.medicare.gov

Click on *Nursing Home Compare*.

Note that some inaccuracies have been reported with information presented, so use this as a starting point, and then go visit the facilities—get to know them first hand.

Three items for this visit...

Patient's Name _____

Date of this visit _____

Doctor's Name _____

Doctor's phone # _____

	The Situation/Condition	The doctor's diagnosis, treatment, prescription, suggestions, etc.
1.		
2.		
3.		

Family Medical History

Patient's Name _____

Person's name, relationship	Name of Condition, age of occurrence	Doctor's Name, address, phone	Treatment	Complications	Overall Outcome

The Medical Team

Patient's Name _____

Specialty	Name	Phone	Street	City & State	Notes

The Family

Patient's Name _____

Relationship	Name	Phone	Street	City, State, zip	Notes

Legal & Financial Team

Patient's Name _____

Relationship	Name	Phone	Street	City, State, zip	Notes

Caregivers

Patient's Name _____

Name	Phone	Street	City, State, Zip		Notes
				Date began _____ Date finished _____ Agency name _____	
				Date began _____ Date finished _____ Agency name _____	
				Date began _____ Date finished _____ Agency name _____	
				Date began _____ Date finished _____ Agency name _____	
				Date began _____ Date finished _____ Agency name _____	
				Date began _____ Date finished _____ Agency name _____	
				Date began _____ Date finished _____ Agency name _____	
				Date began _____ Date finished _____ Agency name _____	

Friends & Neighbors

Patient's Name _____

Relationship	Name	Phone	Street	City, State, zip	Notes

The barber, gardener, plumber, etc.

Service	Name	Phone	Street	City, State, zip	Notes

Public Service Organizations

Service	Name	Phone	Street	City, State, zip	Notes