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Introduction

Alzheimer’s disease can strike people under the age of 50, but most commonly occurs in those over the age of 65. The effects of this disease can have an enormous impact on the families and friends of those diagnosed, 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 by 2050. 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
- Where to begin with 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
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SECTION 1: EDUCATE YOURSELF ABOUT ALZHEIMER’S DISEASE

WHAT IS ALZHEIMER’S DISEASE?

Alzheimer’s disease is

- The most common irreversible dementia
- A progressive, dementia-causing, fatal disease of the brain where brain cells are being destroyed and not replaced
- The cause of 100,000 deaths in the U.S. each year
- An emotional challenge for victims and families
- An enormous financial burden for families
- A growing economic challenge for the U.S.
- 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. Currently these include:

- Aricept\textsuperscript{TM}
- Exelon®
- Razadyne®
- Namenda®
- Other drugs are in various stages of testing

Call the Alzheimer’s Association office and ask for drug fact sheets. Talk to a physician who specializes in dementia diagnosis and treatment. (Referrals to physicians are available.)
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 below are examples of the irreversible and reversible causes of dementia.

**Irreversible, Treatable**
- Alzheimer's Disease
- Creutzfeldt-Jacob Disease
- Vascular Dementia
- Frontotemporal Dementia
- Parkinson's Disease
- Lewy Body's Disease
- Huntington's Disease

**May Be Reversible**
- Depression
- Normal-Pressure Hydrocephalus
- Vitamin B12 Deficiency
- Infections
- Hormonal Imbalance
- Thyroid Malfunction
- Malnutrition

**Brain Injury**
SELECTED IRREVERSIBLE DEMENTIAS

Alzheimer’s disease

Discovered in 1907 by a German doctor after whom the disease is named, Alzheimer’s disease is a progressive, degenerative disease of the brain that causes gradual decline in intellectual ability, including memory, problem solving and judgment (dementia). Eventually, the disease leaves people 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

Often referred to as mad cow disease, Creutzfeldt-Jakob disease is a rare, fatal brain disease caused by infection. Symptoms are failing memory, changes in behavior and lack of muscular coordination. Creutzfeldt-Jakob disease progresses rapidly, usually causing death within a year. No treatment is currently available.

Vascular dementia

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

Frontotemporal dementia

Frontotemporal dementia (formerly Pick’s disease) is a rare brain disease that closely resembles Alzheimer’s disease, with personality changes and disorientation that may precede memory loss. Diagnosis is difficult and can be confirmed only upon autopsy.

Parkinson’s disease

Parkinson’s disease is a disease affecting control of muscle activity, resulting in tremors, stiffness and speech impediment. In late stages, dementia can occur including Alzheimer’s disease. Anti-Parkinsonian 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 Alzheimer’s and Parkinson’s. Usually, dementia symptoms are initially present followed by the abnormal movements associated with Parkinson’s disease. 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.

<table>
<thead>
<tr>
<th>SELECTED REVERSIBLE DEMENTIAS</th>
</tr>
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</table>

**Depression**

Depression is a psychiatric condition marked by sadness, inactivity, difficulty with thinking and concentration, feelings of hopelessness, and, in some cases, 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 over-the-counter medications. Misuse of these medications or use of medications that are not compatible with other medications can cause symptoms of dementia.

**Normal-pressure hydrocephalus**

Normal-pressure hydrocephalus is a rare disease caused by an obstruction in the flow of spinal fluid. Symptoms include difficulty in walking, memory loss, and incontinence. Normal-pressure hydrocephalus 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 become malnourished. This is particularly a problem when an individual lives alone. At its worst, malnutrition can contribute to dementia.
Other health problems can often mimic Alzheimer’s

- Stoke
- Metabolic changes
- Depression
- Head injury
- Medication interactions
- Hypothyroidism

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

- Ask the doctor to explain the tests and how long it will take to get a diagnosis.
- 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)

How do I get 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.”
• 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?
• What medications are available 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 the treatment

Your doctor may prescribe medication or other treatments. It is your job to keep track of how things are working (or not working) and report back 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?

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.
Communication tips for follow-up visits

- Be prepared. Make a list of the types of issues you want to discuss with the 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.
Is it something that mimics the disease?

<table>
<thead>
<tr>
<th>Common Medication For:</th>
<th>Can Cause:</th>
</tr>
</thead>
<tbody>
<tr>
<td>High blood pressure,</td>
<td>Confusion, memory loss, depression, fatigue,</td>
</tr>
<tr>
<td>Heart medications</td>
<td>disorientation, nervousness, hallucinations</td>
</tr>
<tr>
<td>Depression</td>
<td>Short-term memory problems, impaired attention</td>
</tr>
<tr>
<td></td>
<td>span, confusion, agitation, delirium, anxiety,</td>
</tr>
<tr>
<td></td>
<td>insomnia, sleepiness, disorientation, irritability</td>
</tr>
<tr>
<td>Sleeping Problems</td>
<td>Confusion, depression, disinhibition, decreased</td>
</tr>
<tr>
<td></td>
<td>coordination</td>
</tr>
<tr>
<td>Arthritis</td>
<td>Depression, psychosis, paranoia</td>
</tr>
<tr>
<td>Diabetes</td>
<td>Acute mental changes</td>
</tr>
<tr>
<td>Ulcers</td>
<td>Short-term memory loss, anxiety, disorientation,</td>
</tr>
<tr>
<td>Pain</td>
<td>depression</td>
</tr>
<tr>
<td>Multiple medications</td>
<td>Can add to any of the above!</td>
</tr>
</tbody>
</table>

- Ask your pharmacist about possible medication side effects.
- Borrow a book about medications from the library.
- Talk to your doctor.
## ARE ALL PEOPLE 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 and David Troxel

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### ALZHEIMER’S DISEASE IS

- Real
- A disease
- 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 sixth leading cause of death 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, Symptoms and Stages.

On the bright side

A person with AD may become:

- 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

AD provides us with opportunities to learn:

- Compassion and patience
- Tolerance and kindness
- How to communicate with the language of emotion. 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.”

Challenging symptoms and behaviors

- 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 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
YOUNGER-ONSET ALZHEIMER’S DISEASE

Younger-onset Alzheimer’s (also known as early-onset) 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. Younger-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 younger-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.

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

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

It is important to know

- 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 younger-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 younger-onset support groups in your area.

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.
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 on page 28)

• 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 Medi-Cal, and Social Security Disability.
• Explore and plan for how your family will address the needs of your spouse and children, education costs, housing and healthcare, and all the other normal family income and 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 your needs change

• 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.
PARTICIPATING IN CLINICAL TRIALS

“As a caregiver and a person who cares about the future, you have an opportunity to participate in vital research that could change the course of this disease and improve the lives of all those it affects. Here’s how:

**Take part in studies specifically for caregivers**

Quality-of-life studies provide insight into the stresses and effects of caring for a person with dementia. These studies explore ways to improve quality of life.

**Participate in studies as a healthy volunteer**

Researchers gain insights by comparing the patient groups to healthy volunteers, people with no known significant health problems. Healthy volunteer participation is vital in advancing research.

**Encourage the person with dementia to participate**

Clinical trials enable people with the disease to play a more active role in their health care by accessing potential treatments before they are widely available. As a person living with Alzheimer’s, you hope for a cure. You hope new treatments will come along that will improve your quality of life. And you hope future generations will not have to endure what you must while living with dementia.

Participating in clinical trials gives us optimism for today and promise for the future. They provide some participants with access to cutting-edge treatments and expert medical care. And some day they will lead us to the end of this devastating disease.

**Finding a clinical trial that is right for you**

The Alzheimer’s Association offers TrialMatch®, a free, easy-to-use clinical studies matching service that connects people with Alzheimer’s disease, caregivers, healthy volunteers and physicians with current studies. TrialMatch® uses a continued updated database of 130+ Alzheimer’s clinical trials includes both pharmacological (drug) and non-pharmacological (non-drug) studies being conducted at nearly 500 trial sites across the country.

Access TrialMatch® online at alz.org/trialmatch or by calling 800.272.3900.

“I never had the ability to help anyone with Alzheimer’s disease until I got the disease and participated in a clinical trial. It would be hard to overstate the importance of getting involved.”

Ron Grant, Living with Alzheimer’s disease and TrialMatch® user
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 4, but then act out as though he is in stage 6.

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

She 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.
Alzheimer’s disease symptoms get worse over time. Experts have identified seven stages that describe how a person’s abilities change from normal function through advanced Alzheimer’s. It is important to keep in mind that stages are general guides, and symptoms vary greatly. Every person is unique, but we can speak about some common patterns of the illness. Those with Alzheimer’s live an average of eight years after their symptoms become noticeable to other people, but survival can range from three to 20 years, depending on age and other health conditions.

This seven-stage framework, adopted by most doctors and the Alzheimer’s Association, is based on a system developed by Barry Reisberg, M.D., clinical director of the New York University School of Medicine’s Silberstein Aging and Dementia Research Center.

**STAGE 1: NO IMPAIRMENT**

**Normal function**

The person does not experience any memory problems. An interview with a medical professional does not show any evidence of symptoms.

**STAGE 2: VERY MILD DECLINE**

*May be normal age-related changes or earliest signs of Alzheimer’s*

The individual may feel that he or she is having memory lapse, forgetting familiar words or the location of everyday objects. But no symptoms can be detected during a medical exam or by friends, family or co-workers.

**HOW YOU CAN HELP in stages 1 to 4**

- 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 on page 61 in this manual)
STAGE 3: MILD COGNITIVE DECLINE

Early-stage Alzheimer’s may be diagnosed in some, but not all, individuals at this point

Friends, family or co-workers begin to notice difficulties. During a detailed medical interview, doctors may be able to detect problems in memory or concentration.

Common stage 3 difficulties

- Noticeable problems coming up with the right word or name
- Trouble remembering names when introduced to new people
- Having noticeably greater difficulty performing tasks in social or work settings
- Forgetting material that one has just read
- Losing or misplacing a valuable object
- Increasing trouble with planning or organizing

STAGE 4: MODERATE COGNITIVE DECLINE

Mild or early-stage Alzheimer’s

At this point, a careful medical interview should be able to detect clear-cut problems in several areas:

- Forgetfulness of recent events
- Impaired ability to perform challenging mental arithmetic, for example, counting backward from 100 by sevens
- Greater difficulty performing complex tasks, such as planning dinner for guests, paying bills or managing finances
- Forgetfulness about one’s own personal history
- Becoming moody or withdrawn, especially in socially or mentally challenging situations

STAGE 5: MODERATELY SEVERE COGNITIVE DECLINE

Moderate or mid-stage Alzheimer’s

Gaps in memory and thinking are noticeable, and individuals begin to need help with day-to-day activities. At this stage, those with Alzheimer’s may:

- Be unable to recall their own address or phone number or the high school or college from which they graduated
• Become confused about where they are or what day it is
• Have trouble with less challenging mental arithmetic, such as counting backward from 40 by subtracting fours, or from 20 by twos
• Need help choosing proper clothing for the season or occasion
• Still remember significant details about themselves and their family
• Still require no assistance

HOW YOU CAN HELP in stages 5-6
• 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 or phrases such as 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 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 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 6: SEVERE COGNITIVE DECLINE

Moderately severe or mid-stage Alzheimer’s

Memory continues to worsen, personality changes may take place and an individual needs significant help with daily activities. The person may:

- Lose awareness of recent experiences as well as their surroundings
- Remember their own name but have difficulty with their personal history
- Distinguish familiar and unfamiliar faces but have trouble remembering the name of a spouse or caregiver
- Need help dressing properly and may, without supervision, make mistakes such as putting pajamas over daytime clothes or shoes on the wrong feet
- Experience major changes in sleep patterns such as sleeping during the day or becoming restless at night
- Need help handling details of the toilet (for example: flushing the toilet, wiping or disposing of tissue properly)
- Have increasingly frequent trouble controlling their bladder or bowels
- Experience major personality and behavioral changes, including suspiciousness and delusions (such as believing the caregiver is an impostor) or compulsive, repetitive behavior such as hand-wringing or tissue shredding
- Tend to wander or become lost

STAGE 7: VERY SEVERE COGNITIVE DECLINE

Severe or late-stage Alzheimer’s

In the final stage of this disease, individuals lose the ability to respond to the environment, to carry on a conversation and, eventually, to control movement. They may still say words or phrases.

At this stage, individuals need help with most of their daily personal care, including eating or using the toilet.

They may also lose the ability to smile, to sit without support and to hold their heads up. Reflexes become abnormal. Muscles grow rigid. Swallowing is impaired.
HOW YOU CAN HELP in stage 7

- 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.
# Alzheimer’s Stages at a Glance

<table>
<thead>
<tr>
<th>STAGE 1</th>
<th>STAGE 2</th>
<th>STAGE 3</th>
<th>STAGE 4</th>
</tr>
</thead>
<tbody>
<tr>
<td>No impairment</td>
<td>Very mild cognitive decline</td>
<td>Mild cognitive decline</td>
<td>Moderate cognitive decline</td>
</tr>
<tr>
<td>No unusual social problems.</td>
<td>Feeling a little embarrassed over small lapses of memory in social occasions.</td>
<td>Performance issues in social or work settings noticeable to family, friends or co-workers. In example: repeating questions or retelling stories.</td>
<td>Withdrawn, especially in socially or mentally challenging situations. Losing interest in activities that until recently were found pleasurable, like hobbies.</td>
</tr>
<tr>
<td>No unusual memory or cognitive problems.</td>
<td>Occasionally forgetting familiar words or names.</td>
<td>Noticeable problems coming up with the right word or name.</td>
<td>Forgetting details of one’s own personal history.</td>
</tr>
<tr>
<td>Misplacing keys, eyeglasses or other everyday objects.</td>
<td>Forgetting material that one has just read or heard.</td>
<td>Forgetting details of one’s own personal history.</td>
<td></td>
</tr>
<tr>
<td>Difficulty concentrating.</td>
<td>Difficulty retaining or memorizing new information.</td>
<td>Difficulty performing complex tasks, such as planning dinner for guests, paying bills and managing finances.</td>
<td></td>
</tr>
<tr>
<td>Difficulty remembering names when introduced to new people.</td>
<td></td>
<td>Forgetting recent occasions, conversations or current events.</td>
<td></td>
</tr>
<tr>
<td>Losing or misplacing a valuable object.</td>
<td>Difficulty performing challenging arithmetic; for example, counting backward from 100 by sevens.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Storing items in unusual places and forgetting having done so.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>STAGE 5</td>
<td>STAGE 6</td>
<td>STAGE 7</td>
<td></td>
</tr>
<tr>
<td>-----------------------------------------------------</td>
<td>----------------------------------------------</td>
<td>-------------------------------------------------------------------------</td>
<td></td>
</tr>
<tr>
<td><strong>Moderately severe cognitive decline</strong></td>
<td><strong>Severe cognitive decline</strong></td>
<td><strong>Very severe cognitive decline</strong></td>
<td></td>
</tr>
<tr>
<td>Personality changes that may include moodiness,</td>
<td>Significant personality changes and</td>
<td>Loss of ability to respond to their environment, the ability to</td>
<td></td>
</tr>
<tr>
<td>depression, agitation, obsessive thinking,</td>
<td>behavioral symptoms, including</td>
<td>speak and, ultimately, the ability to control movement.</td>
<td></td>
</tr>
<tr>
<td>inappropriateness and lack of judgment or common</td>
<td>suspiciousness and delusions;</td>
<td></td>
<td></td>
</tr>
<tr>
<td>sense.</td>
<td>hallucinations; or compulsive,</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>repetitive behaviors such as</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>hand-wringing or tissue shredding.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unable to recall their own address or phone number</td>
<td>Distinguishing familiar and unfamiliar</td>
<td>Do not recognize familiar faces; may not recognize their own faces.</td>
<td></td>
</tr>
<tr>
<td>or the name of their high school.</td>
<td>faces but having trouble remembering the</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>name of a spouse or caregiver.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Becoming confused about where they are or what day</td>
<td>Remembering own name but having difficulty</td>
<td>Loss of capacity for recognizable speech, although words or phrases may</td>
<td></td>
</tr>
<tr>
<td>it is.</td>
<td>with personal history.</td>
<td>occasionally be uttered.</td>
<td></td>
</tr>
<tr>
<td>Unable to retain or memorize new information,</td>
<td>Little awareness of recent experiences and</td>
<td>Needing help with eating and toileting. General incontinence of urine.</td>
<td></td>
</tr>
<tr>
<td>including conversations and events.</td>
<td>events as well as of their surroundings.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Having trouble with less challenging mental</td>
<td>Major changes in sleep patterns such as</td>
<td>Reflexes become abnormal and muscles grow rigid.</td>
<td></td>
</tr>
<tr>
<td>arithmetic; for example, counting backward from 40</td>
<td>sleeping during the day and restless at</td>
<td></td>
<td></td>
</tr>
<tr>
<td>by fours or from 20 by twos.</td>
<td>night.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Needing help choosing proper clothing for the</td>
<td>Making mistakes such as putting pajamas</td>
<td>Swallowing is impaired. Loss of ability to smile.</td>
<td></td>
</tr>
<tr>
<td>season or the occasion.</td>
<td>over daytime clothes or shoes on wrong</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Forgetting names of public figures and acquaintances.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Forgetting details about themselves and family.</td>
<td>Difficulty when toileting: flushing,</td>
<td>Loss of ability to walk without assistance.</td>
<td></td>
</tr>
<tr>
<td>Getting lost in familiar places.</td>
<td>wiping and proper disposal of tissue.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Loss of interest in personal hygiene.</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Having increased episodes of urinary or</td>
<td>Loss of ability to sit without support.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>fecal incontinence.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Tendency to wander and getting lost.</td>
<td>Loss of ability to hold head up.</td>
<td></td>
</tr>
</tbody>
</table>
CARING FOR FAMILY MEMBERS WITH ALZHEIMER’S DISEASE RAISES IMPORTANT LEGAL CONCERNS

As you care for your loved one, you will need to have the appropriate legal documents in place so you can make decisions and take responsibility for her care.

Many people have produced end-of-life instruments such as wills, family trusts, life insurance, etc. However, it is also very important for everyone to plan ahead for the possibility of becoming disabled 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 someone becomes disabled and eventually incapacitated due Alzheimer’s disease, the law requires that the people 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, appropriate people can take charge and manage our care and personal resources accordingly. These include:

- 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 to authorize others 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

**Advance Health Care Directive**

(Similar documents may have expired. Make sure your documents are current and valid.)

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 capable when filling out these documents.

**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 or 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 to learn how to use this benefit.

**Conservatorship of the Person**

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. 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.
WHAT PAPERS TO BRING WHEN CONSULTING WITH PROFESSIONALS

Have the following collected together and stored in a safe place:

Legal

- House and car titles
- Military veteran 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 accountant names
- Insurance policies and Social Security records
- Tax returns
- Inventory of personal and household valuables

Contact the Alzheimer’s Association to ask for referrals for local elder law attorneys and fiduciary agents.
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 to get a clear picture of your current financial condition. This will help you when talking about your financial affairs with attorneys, bankers, professional estate planners, tax accountants, financial planners, elder care professionals, doctors or family members.

You will need to gather 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.

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.
STEP ONE

Gather together

- 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:

A. **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 on Alzheimer’s caregiving.

B. **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)

<table>
<thead>
<tr>
<th>Category</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Checking Accounts</td>
<td></td>
</tr>
<tr>
<td>Savings Accounts</td>
<td></td>
</tr>
<tr>
<td>Bank CD Accounts</td>
<td></td>
</tr>
<tr>
<td>Investment Portfolio</td>
<td></td>
</tr>
<tr>
<td>Cash Account</td>
<td></td>
</tr>
<tr>
<td>Investments</td>
<td></td>
</tr>
<tr>
<td>Retirement Fund</td>
<td></td>
</tr>
<tr>
<td>Life Insurance Cash Value</td>
<td></td>
</tr>
<tr>
<td>Mortgage Equity</td>
<td></td>
</tr>
<tr>
<td>Other Assets</td>
<td></td>
</tr>
</tbody>
</table>

**TOTAL ASSETS** $ 

**FINANCIAL LIABILITIES** (money we owe)

<table>
<thead>
<tr>
<th>Category</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Personal Loans</td>
<td></td>
</tr>
<tr>
<td>Credit Card Balances</td>
<td></td>
</tr>
<tr>
<td>Mortgage Principal</td>
<td></td>
</tr>
<tr>
<td>Auto Loans</td>
<td></td>
</tr>
<tr>
<td>Other Debt</td>
<td></td>
</tr>
</tbody>
</table>

**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** $
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)

<table>
<thead>
<tr>
<th>Salary/wages</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Retirement plan</td>
<td></td>
</tr>
<tr>
<td>Social Security</td>
<td></td>
</tr>
<tr>
<td>Interest</td>
<td></td>
</tr>
<tr>
<td>Dividends</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
</tr>
<tr>
<td><strong>TOTAL INCOME</strong></td>
<td></td>
</tr>
</tbody>
</table>

2) EXPENSES (monthly or yearly)

<table>
<thead>
<tr>
<th>Alzheimer's homecare</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregiver wages</td>
<td></td>
</tr>
<tr>
<td>Employment taxes (withholding, SSI, Workers' Comp, etc.)</td>
<td></td>
</tr>
<tr>
<td>Supplies (personal care items, special needs accessories, etc.)</td>
<td></td>
</tr>
<tr>
<td>Agency fees, daycare facility fees, etc.</td>
<td></td>
</tr>
<tr>
<td><strong>Total Alzheimer's homecare</strong></td>
<td></td>
</tr>
<tr>
<td>Auto (gas, repairs, license fees, payments, parking tickets, etc.)</td>
<td></td>
</tr>
<tr>
<td>Banking and financial (bank fees, credit card fees, brokerage fees, etc.)</td>
<td></td>
</tr>
<tr>
<td>Household (groceries, supplies, repairs, gardener, pool service, subscriptions, etc.)</td>
<td></td>
</tr>
<tr>
<td>Insurance (auto, home, life, health, caregiver liability, etc.)</td>
<td></td>
</tr>
<tr>
<td>Medical (doctors, chiropractors, medications, lab costs, supplies, etc.)</td>
<td></td>
</tr>
<tr>
<td>Interest (loan &amp; credit card interest)</td>
<td></td>
</tr>
<tr>
<td>Mortgage/Rent/Property Taxes</td>
<td></td>
</tr>
<tr>
<td>Professional services (lawyer, accountant, financial planner, etc.)</td>
<td></td>
</tr>
<tr>
<td>Category</td>
<td>Amount</td>
</tr>
<tr>
<td>-------------------------------</td>
<td>--------</td>
</tr>
<tr>
<td>Personal</td>
<td></td>
</tr>
<tr>
<td>(clothing, restaurants, entertainment, toiletries, haircuts, gym, tithing, memberships, donations, books, gifts given, etc.)</td>
<td></td>
</tr>
<tr>
<td>Taxes (property, state and federal income tax)</td>
<td></td>
</tr>
<tr>
<td>Travel (train, plane, motels, dining, etc.)</td>
<td></td>
</tr>
<tr>
<td>Utilities (water, electric, gas, trash service, home alarm, cable TV and internet, etc.)</td>
<td></td>
</tr>
<tr>
<td>Other (loan principal payments, etc.)</td>
<td></td>
</tr>
<tr>
<td><strong>TOTAL EXPENSES</strong></td>
<td></td>
</tr>
</tbody>
</table>

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

Subtract Total Expenses from Total Income:
WHY SHOULD I FUSS WITH DOING THIS?

You will create a tool that is necessary to help with planning and making decisions regarding Alzheimer’s homecare.

Many elder care expenses may qualify as tax deductible 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
- Fiduciary agents
- 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, much 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 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.
Applying for these programs can be a challenge to your self-esteem; however, please remember that your taxes are paying for these services.

**Supplemental Security Income**

Administered by Social Security. This program provides income for people without a substantial work history. You must be over age 65 or have a disability. For more information, call 800.772.1213.

**Social Security Disability Income**

Another program of the Social Security Administration, it provides income for people under the age of 65 who cannot work because of a disability. For more information or to apply, call 800.772.1213.

**Medi-Cal**

This is 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 pays for doctor visits, therapy, testing, hospitalization and prescription drugs. Persons receiving Social Security 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 2014, the spouse living at home may:

- Own their own home
- Own their own car
- Keep at least $117,240 of the couple’s assets – community spouse resource allowance 2014 rate
- Keep $2,931 of their income per month – minimum monthly maintenance needs allowance 2014 rate
**In-home support services.** This county program provides low-income people with disabilities help with activities of daily living. It provides caregivers, home health aides and attendant care. Services must be needed to help someone remain safely at home. If you receive Social Security or Medi-Cal, you may be eligible without a share of cost.

**Multi-service senior program.** This program provides social and health care management services for those 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

WHAT ARE CHALLENGING BEHAVIORS?

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

Sometimes 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 and have 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, which are difficult to cope with.

When your loved one is becoming confused, upset and distressed with momentary emotional upheaval, it is important 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 to **understand reason and logic**. He lives in a world of **feeling and emotion**. He loses control of his will and his mind. Remember always that the disease is causing this behavior.
COMMON CAUSES OF DIFFICULT OR CHALLENGING BEHAVIOR

**Health problems**

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

**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 or physical clutter

**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

**Communication**

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

**Perception of reality**

- What the person with dementia sees (hallucination) or thinks (delusion) may not be reality, but seems real to them
1 - 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.

2 - 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.

3 - Make up a story to help them relax

If he wants to drive the car, you can say: It is broken. Wait till the store brings the part this afternoon.

Or if he wants to fix the TV, say: I’ve already called a repairman. He’ll be here on Saturday.

If she is asking for her daddy, say: Oh, Dad went on a business trip this week.

4 - Re-direct

Change the subject 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.
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 often 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 bowl 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: Most likely, this phase will come, go and pass.
SLEEPING DIFFICULTIES AT NIGHT

Your loved one may have trouble sleeping at night for a variety of reasons

- Too warm or cold; hunger and thirst
- Her brain is no longer able to regulate her body clock
- Incontinence 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!

Steps to take, depending upon the cause

- If you sleep in a different room, use a room monitor (like those used for infants) so 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. 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

1. Do not argue
2. Use finesse and do not be afraid to fudge the truth
3. Make up a story to help them relax
4. Redirect (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.
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.

**When pacing**

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

**When rummaging**

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

*Most likely, this too will 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?
  - Angry parents?
  - The enemy soldiers?
  - A frightening noise?

Use the Four Handy Helpers

1. Do not argue
2. Use finesse and do not be afraid to fudge the truth
3. Make up a story to help them relax
4. Redirect (change the subject and/or activity)

- Double-check the house or yard security
- Alert the neighbors
- Enroll in the MedicAlert® + Alzheimer’s Association 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
MEDICALERT® + ALZHEIMER’S ASSOCIATION SAFE RETURN® PROGRAM

MedicAlert® + Alzheimer’s Association Safe Return® is a 24-hour emergency response service for wandering and medical emergencies.

Because the person with Alzheimer’s frequently cannot communicate clearly, including their name and address, this is an invaluable assurance to the caregiver. People in any stage of Alzheimer’s disease can benefit.

Call the Alzheimer’s office and ask for the MedicAlert + Safe Return brochure. It contains everything you need for entry into the program. And go to alz.org; click on the We Can Help link and then the MedicAlert® + Alzheimer’s Association Safe Return® link to sign up online.

- The program maintains a 24-hour hotline for calls about a lost registrant.
- Participants wear an identification bracelet, or necklace, with the 800 number.
- 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.

“We don’t have to worry about that. Dad never wanders out of the house alone.”

How many times have we heard a family member say that... and then one day, it happens, and Dad is gone.
**WANTING TO DRIVE THE CAR**

**IT'S THE LAW.** If a diagnosis of Alzheimer’s has been made, California law requires the physician to report it to the Department of Motor Vehicles.

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 driver license prior to the appropriate testing.)

This can be particularly helpful because you can let the state be the bad guy who takes the 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.

**Should we let Dad keep driving?**

*It means so much to him.*

The diagnosed person needs to have his driving evaluated by the 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?
- Worse case scenario: Someone is injured or killed.

Contact the Alzheimer’s Association and ask for the free booklet, “At the Crossroads: A guide to Alzheimer’s Disease, Dementia & Driving.”
EMBARRASSING ME OR OTHERS

There may be public episodes of

- Inappropriate sexuality
- Cussing and 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-sized handouts are available to you at the Alzheimer’s Association 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.
So, he wants to fix things even when they are not broken!
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 metabolic phenomenon, 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

- 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 may be caused by a variety of issues

- Forgetting how to feel safe with water
- Loss of visual or 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 or 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 only then take her 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, as this can cause increasing emotional challenge; wait and try later.
- A daily bath or shower may be unnecessary. Between regular baths, a daily sponge bath at the sink works fine.
- Try the bath products now available such as pre-treated, non-rinse, disposable wash cloths or dry shampoo.
- If you have access to a Jacuzzi or spa tub, she might find that to be more appealing than a conventional bath or shower.
- A back-rub with lotion may convince her 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.

Contact the Alzheimer’s Association and ask for the handout on 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 soppy-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.
WILL NOT EAT

• Check his mouth, gums, teeth and dentures
• Watch for signs of irregular bowels and constipation
• Try a complete, balanced nutrition/protein drink. If she does not like it, try a different brand, type (rice, soy, egg, whey, etc.) 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!
• He may want extra attention, which not eating can accomplish

In case eating problem persists

• There may be an underlying medical problem
• Discuss this with the physician

I’ve made up my mind, so listen up!

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.
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 at self-protection or to 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

1. Do not argue
2. Use finesse and do not be afraid to fudge the truth
3. Make up a story to help them relax
4. Redirect (change the subject and/or activity)

Tune into 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 to 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 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, light-hearted 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 presents a behavior, story, or question repeatedly. Your patience may wear very thin.

Understand

- It is the disease causing him 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 her behavior
- You can change your own thoughts and feelings about her behavior

Do

- Take a break
- Experiment with different kinds of music to soothe the person and reduce the anxiety that may be driving the behavior
- Get your broad-view perspective refreshed
- Read Section 4 (on page 67) in this manual about taking care of yourself, and take action on the suggestions
- Limited financial help for respite may be provided by the Alzheimer’s Association so you can get a break
- Learn about your local adult day care facility
- Contact the Alzheimer’s Association Helpline at 800.272.3900
- 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 6-year-old. At age 6, 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 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 room to have them removed. It would have been a good idea 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 else 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
- 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, but don’t forget to do it.

Contact the Alzheimer’s Association and ask for more tips. Work at finding something 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 puzzles 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 or 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 (fold laundry, dust, sweep). Even though the person may not be able to do the task correctly, that is O.K. 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 familiar movies on Netflix or similar services. Movies and TV shows can be downloaded on demand, 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 needs to be permitted to do as much for himself as he can
- Praise him for whatever he accomplishes
- Watching TV may become frightening. Flawed perception may cause him to think TV events are in the room. He may enjoy “Wheel of Fortune” and “Jeopardy” long after he can no longer enjoy more dramatic shows with stories in them.
PLAN FOR THE DAY

This includes both activities of 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

- Get up at the same time every morning.
- Grooming and dressing may take an hour or more.
- Breakfast activities can include reading the morning paper and discussing current events.
- Morning activity could include a walk, grocery shopping, a haircut.
- Lunch and 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 activities can be similar to lunch time.
- Evening activities can include 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 FLEXIBLE**

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.*
SHE LIVES A LONG DISTANCE FROM ME

You are realizing that 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 her area to provide for in-home care
- Hire a geriatric care manager
- Arrange for her to move into a residential facility in her home area
- Bring her 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
- She 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 her
- 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 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
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.

Don’t wait until it is too late.
The words of John Donne, the 19th century poet, ring true today. They are especially true for caregivers of those 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.

Do

- 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

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

No Man Is An Island

No man is an island, Entire of itself.
Each is a piece of the continent, A part of the main.
If a clod be washed away by the sea, Europe is the less.
As well as if a promontory were.
As well as if a manor of thine own Or of thine friend's were.
Each man's death diminishes me, For I am involved in mankind.
Therefore, send not to know For whom the bell tolls,
It tolls for thee.

John Donne
SECTION 4: TAKING CARE OF YOURSELF

You may ask

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

You may have thoughts such as

- 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

- 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, Alzheimer’s Association, Los Angeles Chapter
THE CAREGIVER’S GOALS

Adopt goals 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. Each 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 into the situation.

Caregiving is too large a job for any ONE person alone

Even professional caregivers take turns with their duties.

- Many agencies are state and federally funded; your tax dollars working for you!
- Others, such as 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 woman 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 and Dad. All my siblings live far away. Of course, I’m the one to do this caregiving.
AVOID CAREGIVER BURN-OUT

You are the #1 Priority

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 believing, 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
- Civic organizations
- Relatives
- Weekly hobby or activity groups
- Church

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
- Eating healthily
- Exercising
- Regular medical check-ups

Give yourself private time and space

Give yourself permission to take a break, a day off or a 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?

Respite, pronounced res'pit, means a time of rest and relief.

To you, it means

Placing your loved one in the care of someone else, for a limited time, so you can give yourself some time off.

The respite care may be provided by a

- Friend
- Relative
- Volunteer
- Companion sitter
- Adult day care center or a 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 your loved one.

Even though it may be challenging to leave your loved one for this purpose, it is in his 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

Call the Alzheimer’s Association office to find out if respite care grants are currently available for you.

800.272.3900
Reasons for using adult day care

- Adult day care provides respite for the caregiver and allows the caregiver an invaluable source of respite
- Socialization and activities for the person with the diagnosis
- Day care centers provide 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 Association to find the adult day center nearest you.

800.272.3900

“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 15 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, there is an open discussion where participants present specific questions and situations. Attendees 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.

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 shared
- Participants learn how to listen and respect each other’s situation

Support groups can be a good source of

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

Call the Alzheimer’s Association to find a support group near you.

800.272.3900
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

*Support groups are for touchy-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 type 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 Association 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 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 YOU do not become distressed.

**Do not ignore signs of distress within yourself**

- 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 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
- Remember: the person you are caring for cannot change their condition
- You can decide how you react to daily situations that arise
- Get some help with household chores, yard work, shopping, and 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 and symptoms of caregiver depression:

- Fear
- Guilt
- Grief
- Denial
- Anger
- Diarrhea
- Fatigue
- Irritability
- Headaches
- Sleep problems
- Withdrawal
- Weight gain or loss
- Upset stomach
- Sense of hopelessness

What can I do about this?

- Understand that your emotions are normal and understandably present
- Learn stress management methods
- Talk with:
  - A trusted friend or family member
  - A support group
  - Alzheimer's Helpline: 800.272.3900
  - Your minister
  - 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 DEMENTIA

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 anymore.
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
- 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 or 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 anyone else.

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. 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 Bell and 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**

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

Perhaps it is time to let Mom wear her slippers. Her spirit may be trying to express a momentary sense of identity, personal will or 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 her faith, her belief in being connected with a higher power. Find ways to give her an ongoing experience with their rituals, religious writings and familiar symbols. If you share that particular religious orientation with her, 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 so-called normal adult attentions from our loved one’s 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. Bell and Troxel suggest that this kind of statement 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, dementia care specialist
The spirituality of comfort and joy . . .

A visiting nun was talking with a gentleman 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.

SECTION 5: HIRING & MANAGING IN-HOME CAREGIVERS

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 in-home care 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.

- 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 that require careful consideration. Everyone has their own story of what works best for them. There are potential benefits, and challenges, with both options, and 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, such as:

• 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, R N , LVN , BSN , LCT , CNA , etc.?
- What hourly rate will I pay you, and how much do you pay the caregiver?
- What other costs or 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?**

A m I the boss, or a person at the agency?

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 YOURSELF**

Professional caregivers can be found through some agencies. They send potential employees over for you to interview and hire privately on your own.

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 W 2 forms
- Always hire people on a TWO-WEEK TRIAL BASIS. If 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 your loved one’s life and an easy reference guide.

Life story

- Age
- Names of parents, brothers and sisters, mates, children, etc.
- Where he grew up
- Whether or not he went to college and where
- Business or profession(s)
- Favorite places she has 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 her, 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, it is hoped, 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, who should be called? (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 you both understand what is expected. It can be a good tool for discussion and clarification of expectations.

Keep a daily log

Agencies will (you hope) 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 such as 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.

**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.

*See the logs we have provided in SECTION 8 (on page 101.) They are especially useful for doctors and other health care professionals to review.*
**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 have been told, professional caregivers are employees. They are **not** independent contractors. Caution: If a caregiver files a worker’s 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:

1. Having workers' compensation insurance through a private insurance company such as homeowner’s or tenant’s.
2. Filing reports and making payroll deposits at different times throughout the year to government agencies such as 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. Check out 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 or 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 INTO A RESIDENTIAL FACILITY?

KEY ISSUES TO CONSIDER IN ADVANCE

**Hard Choices**

People with Alzheimer's will get to a point where they require 24-hour care, 365 days a year. This requires they:

- a. Live in a private home with appropriate, well-managed, 24/7 in-home care, or
- b. Live in a residential care facility for the elderly, 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.

**It is time to make the move into an residential care facility**

- When he 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 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

Call the Alzheimer’s Association and ask for a list of licensed homes and placement agents in your area.
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

After the settling-in and adjusting, many residents in well-managed care facilities 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 a residential care facility 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.
- 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

Residential care facilities are also commonly referred to as board-and-care homes or assisted living facilities. These homes are for people who are not able to live safely on their own but who do not require skilled nursing. Many care facilities for the elderly 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

Skilled nursing facilities 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 skilled nursing facilities 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 skilled nursing facility that specializes in Alzheimer’s disease and related dementias. These may also be called memory care units. For those with progressive dementia who are too mobile for the regular facility, 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 people whose symptoms include challenging behaviors such as persistent wandering or violent, disruptive behavior. They are distinguished from skilled nursing facilities by having doors that lock from the inside and secured walking areas.

SOME THINGS TO LOOK FOR

When evaluating a facility, consider

- 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
SECTION 7: EXTENDED FAMILY AND FRIENDS

EVERYONE IN THE FAMILY IS AFFECTED

In Alzheimer’s Association education programs, we train professional caregivers to become aware of the impact of the disease 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

Each family will experience its own story.

Alzheimer’s disease can develop in people as young as 30 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.
FAMILY RELATIONSHIP ISSUES ARISE

Many families experience varying degrees of interpersonal struggle. Old patterns of parent-child and sibling relationship challenges can rise up and complicate Alzheimer 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, 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. 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.

- 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!
Ways to make information available

- Write a periodic note or email and send copies to selected people
- Arrange for a family member to write the note or make periodic phone calls to selected people
- Invite family members and friends to attend a support group, an information workshop or class, conferences and events or Alzheimer’s Association Walk to End Alzheimer’s®

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.
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 someone 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
- Read books on the subject; study the educational brochures available at the Alzheimer’s office; read the Alzheimer’s Association newsletters
- Attend a family caregiver support group
- Attend the caregiver education programs offered by the Alzheimer’s Association
- Become an Alzheimer’s advocate and share their story
- Learn about clinical trials through TrialMatch®
- Attend the annual Alzheimer’s Association Walk to End Alzheimer’s®

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 AND 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 only I would have known... Friends and neighbors need to know.

Keep everyone informed.
Be candid and share the news.
You may be surprised with all the support you get.
Howard hesitated to ask...

Howard and Emily had lived next door to the Cartwrights for 10 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 he 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 all right.

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, take care of the yard, and other caregiving chores. They also learned how to maintain a friendship with Ben through his progressing symptoms.
SECTION 8: CARE LOGS

The Care Logs provided on the following pages can be used to collect and organize important information about the patient with dementia, medications, doctors, family members and care professionals.

Having this information organized and readily available is important when communicating with everyone in the team of professionals assisting the patient and family members.
Three items for this visit...

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<tr>
<th>The Situation/ Condition</th>
<th>The doctor's diagnosis, treatment, prescription, suggestions, etc.</th>
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Patient's Name ____________________________ Date of this visit __________

Doctor's Name ____________________________ Doctor's phone # __________
## CARE LOG

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<th>Date</th>
<th>Time of Occurrence</th>
<th>Changes in physical health, memory, mood, behavior</th>
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# MEDICATION LOG

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<th>Side Effects</th>
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## Family Medical History

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# The Medical Team

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# The barber, gardener, plumber, etc.

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