

**THE DEMENTIA
^ CAREGIVER'S
LITTLE**

BOOK OF HOPE



HOPE

HELP ♥ HEART

LIGHT ♥ GROWTH ♥ LOVE



A Guide for the Pathless Path from:
DEMENTIA CAREGIVER RESOURCES, INC.

By: Karen (Karle) Truman, Ph.D.

Additional Comments on The Dementia Caregiver's Little Book of Hope

*"Without your "RED TIPPED CANE" (**The Dementia Caregiver's Little Book of Hope**) in the darkness, I don't think we would have been able to navigate the passages of the caves in this disease. May God Bless and Keep you." --- PAUL AND KELLY A. - Caregivers*

*"A diagnosis of dementia shreds future dreams and plans. '**The Dementia Caregiver's Little Book of Hope**' is a loving guide assisting families to make new and vibrant plans for a continuing journey of 'light' and 'courage.'" --- LaRee Ewers*

Making Tired Eyes Smile® Creative Expressions for Senior's with Alzheimer's

*"This is a "must-have" book for any caregiver or healthcare professional. Karen delivers information with compassion to her caregivers. **The Dementia Caregivers Little Book of Hope**' is an invaluable resource tool that speaks to your mind, heart, and spirit." --- KIM LINDER*
Senior Holistic Living, LLC and The New Age of Caregiving (Blog)

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The Dementia Caregiver's Little Book of Hope www.dementiacaregiverresources.org

DEMENTIA
THE ^ CAREGIVER'S
LITTLE
BOOK OF HOPE

A Guide for the Pathless Path

Karen (Karle) Truman, Ph.D.

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MEET OUR FLAMINGO FAMILY

We would like to introduce Felix, Fala, and Feather Flamingo:

FELIX means happy or lucky and was even the name of several early Popes!

FALA means crow in the Native American language, and was the name of FDR's beloved dog.

FEATHER is the baby. This is our special gift....we just know Feather will "tickle" you and is destined for FUN things in life!

We feel these names represent our spirit. We all reach for happiness and luck. We want to share and "crow" about the guiding supportive ideas we have inside this book; and we want caregivers to know it is still permissible to have fun.

Our wish is that you read this book with an open heart and mind. Use the ideas that may be helpful for you. The pathless path is not easy, but this book may make the journey a little less bumpy. Our ♥ heartfelt wish for you is to have continued...*Light for the Journey - Courage for the Soul*

About the Flamingo Logo: Live and plastic flamingos have a special place in Florida history. They are featured on countless postcards, in tourist attractions, and as lovely lawn ornaments. They are fun, full of mischief, "flabulous," and shout PINK. The flamingo serves as our non-profit official logo and we use it on our stationary, business cards and on all of our training materials. We wear this logo embroidered on shirts and know that the flamingo has given us a look that people remember. We are the "FLAMINGO PEOPLE" and we are more than willing to accept that title. We know how to take a joke!!!



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Karen (Karle) Truman, Ph.D., President

Jeff Truman, MS Ed., Editor

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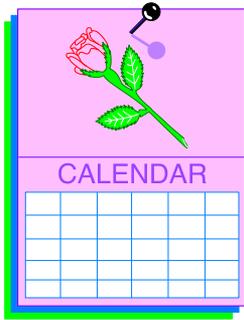
This book is dedicated to my mom **Eva Helene Karle**. She taught me how to love deeply, to gather no moss, to skinny dip, to laugh at silly things, to have girlfriends, to play and work hard, to share, to worship, to be silent, to have compassion, and to always bring new experiences into life and embrace them.



Introduction

WHO WE ARE

- About the Author
- Vision and Mission Statements
- Our Gifts to You on Your Caregiving Journey
- How We Help
- Contact Information
- Donations and Bequests
- Alzheimer’s Foundation of America (AFA)



“My journey began in 1959 when my maternal grandmother was still in Iowa.

The family had to make hard decisions and placed her in a Catholic nursing home.

I was just a little girl, but it made a big impression on what my life’s work was eventually going to be.”

--- KAREN (KARLE) TRUMAN



ABOUT THE AUTHOR

Karen (Karle) Truman, Ph.D. is the President and Founder of *Dementia Caregiver Resources, Inc.* She has been on the Alzheimer's pathless path since 1959 when her grandmother was placed into a nursing home. She then witnessed her mother, several aunts, and uncles also stricken with this terrible mind-robbing disease. Her mission and passion is to educate, support and provide resources to family and professional caregivers in a compassionate and kindhearted manner. In 2007, she co-authored a 400 page dementia specific company training manual for a national corporation. She has also been a presenter for the professional attendees, at national disease specific conventions. She won a 2006 *North American Mature Publisher's Association* (NAMPA) award for her monthly column -- *The Caregiver's Path*.

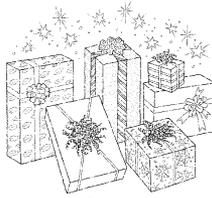
VISION

Empowering Dementia Caregivers
to Reclaim Their Lives!

MISSION

We clearly see a need for dementia specific referrals, education, support, and counseling services.

Our goal is to provide caregivers with validation and encouragement to continue on their caregiving journey.



**OUR GIFTS TO YOU ON
YOUR CAREGIVING JOURNEY**

HOPE

FOR CAREGIVERS LIVING THE “LONG GOODBYE”

HELP

**FOR THE MANY CONFUSING
SIDE ROADS ALONG THE PATH**

HEART

**FOR YOUR LOVED ONE...
KNOWING THEY CANNOT CHANGE BACK**

LIGHT

FOR THE JOURNEY - COURAGE FOR THE SOUL

GROWTH

**FOR THE LIFE LESSONS YOU WILL BE TAUGHT ...
EVEN THOUGH YOU WILL PROTEST LOUDLY**

LOVE

**WILL BE GIVEN TO YOU MANY TIMES OVER ...
AND FROM UNEXPECTED SOURCES**



HOW WE HELP

Dementia Caregiver Resources, Inc. was established in 1997. We are a 501(c)(3) non-profit organization dedicated to helping caregivers who care for patients who have a form of dementia. We are here to assist you on your caregiving journey. Knowing when to ask for help from family, friends, clergy, and the community can ease the caregiver burden. We provide caregiver support for Alzheimer's, Parkinson's, Lewy Body, Huntington's, and other forms of dementia. We are experienced experts in helping you find solutions for your questions. We understand tough placement issues; know about veteran benefit programs; Medicare/Medicaid; end of life issues; and much more.

Dementia Caregiver Resources, Inc. does the following things:

- Conducts Florida mandated Alzheimer's trainings for assisted living facilities, skilled nursing homes, home health agencies, adult day care providers, and Hospice staff
- Offers online courses for professional's continuing education
- Facilitate ongoing support groups at multiple locations
- Speaks to church groups, associations, long-term care communities, professional groups, and TV and radio programs
- Counsels families and professionals in crisis
- Participates in the AFA Long-Term Memory Care Program
- Provides referrals to local, state & federal (often "hidden") resources for day care, in-home services, and veterans benefits
- Creates and distributes our book, monthly newsletter, and other resource materials
- Organizes caregiver getaways and empowering events
- Maintains memberships and duties with professional organizations (i.e.: *Alzheimer's Foundation of America (AFA); Guardian Association.; Better Living for Seniors, affiliated with Area Agency on Aging*)

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DONATIONS AND BEQUESTS

Your donations are tax deductible and necessary in order to continue our special work. We would greatly appreciate having our organization named:

- In Memory of or In Honor of your Loved One
- For Special Event Donations (Birthday, Anniversary)
- To Make a Difference for fellow Caregivers
- In Charitable Bequests
- As a beneficiary in your will

Special Note: 100% of your donation goes towards caregiver services. No donations are used for salaries.

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Dementia Caregiver Resources, Inc. is a Member Organization of:



Alzheimer's Foundation of America

322 Eighth Avenue - 7th Floor * New York, NY 10001

1.866.AFA.8484 -- www.alzfdn.org

"Together for Care...in addition to Cure."

*AFA has the following ongoing programs, publications, and projects.
Visit their website or call them for current information.*



National Memory Screening Day is a collaborative effort spearheaded to promote early detection of Alzheimer's disease and related illnesses, and to encourage appropriate intervention. AFA carries out this event with organizations and healthcare professionals across the U.S.

AFA Quilt to Remember is the nation's first grand-scale quilt that pays tribute to the deceased and individuals living with Alzheimer's disease, as well as their caregivers and healthcare professionals. It is an ongoing project, intended to continually grow in size with each quilt panel contribution from individuals and organizations and is displayed across the country to raise awareness of the disease. *Visit:* www.alzquilt.org.

AFA teens seek to mobilize teenagers nationwide to raise awareness of Alzheimer's and to engage teenagers in the cause.
<http://www.afateens.org/>

ALZHEIMER'S PREVENTION WEB SITE

<http://www.alzprevention.org/index.php>

Care ADvantage Magazine

To receive a **FREE** subscription to **Care ADvantage** magazine visit:
www.afacareadvantage.org or call 1.888.AFA.8484

Chapter 1

DEMENTIA 101

What is Dementia?

Stigma about Alzheimer's May Delay Diagnosis

Stages of Alzheimer's

Common Dementia Distress Issues

The Different Names of Dementia

Aluminum

Over 150 Identified Dementia's *and Counting...*

Brain Bank Programs

Lewy Body Dementia (LBD)

Depression, Delirium, Mild Cognitive Impairment

Diabetes, Thyroid, and Metabolic Diseases

Dehydration in Older Adults



*I have not lost my mind -
It is backed up on a disk
... Somewhere! --- UNKNOWN*

BRAIN

WHAT IS DEMENTIA?

Dementia comes from Latin origins. It is also known as *morosis* in Greek, *dotage* in Middle English, and *demence* in French. Chronic Forgetfulness was written about as early as the 9th Century B.C. in Egypt. *It was also mentioned in written historical findings dating from:*

- 3rd Century in Rome
- 14th Century in England
- 18th Century during the French Revolution - dementia became law in the Napoleonic Code: *'There is no crime when the accused is in a state of dementia at the time of the alleged act'* (Kennard, 2006)
- 19th Century in Germany

It is the progressive decline in cognitive function due to damage or disease in the brain beyond what might be expected from normal aging. Dementia is a non-specific illness. It literally means *away from mind* and is used to describe a group of symptoms and behaviors. Dementia signs include the loss of intellectual abilities like thinking, remembering, attention span, and reasoning.

Dementia Symptoms can include the following:

- Memory Loss
- Confusion
- Wandering
- Depression
- Disorientation
- Poor Hygiene
- Poor Judgment
- Suspiciousness
- Personality Changes
- Unable to initiate activities
- Agitation or sudden emotional outbursts

There are many kinds of dementia. It is essential to identify the cause of the problem as there are different ways to treat and manage the disease. **Not all dementia is the same... just as all flowers are not daisies.** Getting a proper diagnosis is one of the most important steps on your caregiving journey. That way you will know exactly what to expect from the disease and what to do for your Loved One as it progresses. It is not their fault and they are not doing this on purpose. It is the disease "talking". Little by little, the losses become so severe that they totally interfere with a persons daily functioning. They cannot make good decisions for self-care anymore. Providing care may become a way of life for you and your family.



STIGMA ABOUT ALZHEIMER'S DISEASE MAY DELAY DIAGNOSIS

A recent online AFA survey included 539 people who are currently caring for a parent or spouse with Alzheimer's. Among the findings:

1. Caregivers' concern about Alzheimer's **stigma** (*shame or disgrace*) delayed diagnosis by up to six years.
2. Patients typically had Alzheimer's symptoms for two years and saw two doctors before getting diagnosed with Alzheimer's.

Stigma wasn't the only hurdle. Many caregivers mentioned their lack of knowledge about Alzheimer's disease and/or the patient's resistance to seeing the doctor as delaying diagnosis. Some caregivers said they *didn't want to face the possibility* that something was wrong with their loved one. Overall, more than half of caregivers (57%) mentioned stigma or *denial*, the 2006 survey shows.

www.harrisinteractive.com/news/newsletters/clientnews/2006_AFA.pdf

The Known Types of Alzheimer's Disease are:

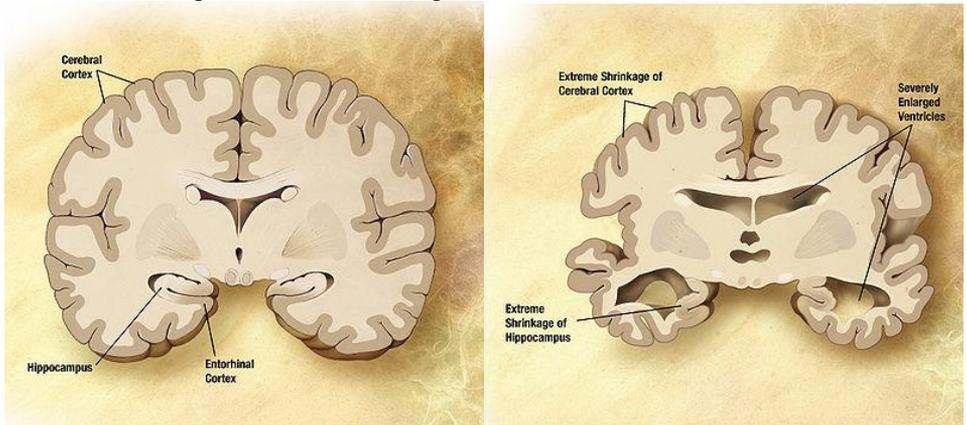
EARLY ONSET 5 to 10 percent of persons in families who have a mutation in one of three inherited genes develop symptoms before age 65. They can develop Alzheimer's in their 30s, 40s, and 50s. This is known as "early onset" Alzheimer's and causes the disease to begin at a much earlier age. If someone has one of those three genes, it would be very unusual for them to not develop Alzheimer's before age 65.

LATE ONSET More than 90 percent of Alzheimer's develops in people older than 65. This form of Alzheimer's is called "late-onset" Alzheimer's, and its development and pattern of damage in the brain is similar to that of early-onset Alzheimer's. The course of this disease varies from person to person, as does the rate of decline. In most people with Alzheimer's, symptoms first appear after age 65. Late-onset Alzheimer's disease strikes almost half of all people over the age of 85 and may or may not be hereditary.

The causes of late-onset Alzheimer's probably includes genetic, environmental, possibly old trauma, and lifestyle factors. Although the risk of developing Alzheimer's increases with age, Alzheimer's and dementia symptoms is not a part of normal aging. There are also some forms of dementia that aren't related to brain diseases such as Alzheimer's, but are caused by systemic abnormalities such as metabolic syndrome, in which the combination of high blood pressure, high cholesterol, and diabetes causes confusion and memory loss.

Risk factors for Alzheimer's include age and our genetic profile. Future research will reveal whether health, lifestyle, and environmental factors can help prevent Alzheimer's. Factors can include our physical activity, diet, and damage to the vascular system. We don't know what starts the Alzheimer's process but, changes in the brain seem to begin as many as 10 to 20 years before any obvious signs of forgetfulness appear. As nerve cells die throughout the brain, affected regions begin to shrink. By the final stages of Alzheimer's, damage is widespread, and brain tissue has shrunk significantly.

On the left is an image of a normal brain and on the right, a brain that shows shrinkage due to the ravages of Alzheimer's disease.



Source: ADEAR: "Alzheimer's Disease Education and Referral Center, a service of the National Institute on Aging."

STAGES OF ALZHEIMER'S



From the time of diagnosis, a person usually lives from three to twenty years, with an average of eight years. The three main stages of Alzheimer's have these defining characteristics.

Early-stage Alzheimer's (Mild)

Memory loss or other cognitive deficits are noticeable, yet the person can compensate for them and continue to function independently.

Mid-stage Alzheimer's (Moderate)

Mental abilities decline, the personality changes, and physical problems develop so that the person becomes more and more dependent on caregivers.

Late-stage Alzheimer's (Severe)

Complete deterioration of the personality and loss of control over bodily functions requires *total* dependence on others for even the most basic activities of daily living.

Studies have shown that ongoing lifestyle factors such as a nutritious diet, exercise, social engagement, and mentally stimulating pursuits is important throughout our life span. Old trauma from injuries or emotional events (death of a Loved One, PTSD, etc.) can also play a role, as well as environmental pollutions and chemicals that this person may have been exposed to. All of these kinds of things as well as genetics can factor into the getting Alzheimer's mix.

The length of time spent in each stage will vary from person to person. The stages, signs and symptoms may appear randomly. Because the stages overlap, it is difficult to definitively place a person in a particular stage. However, the progression is always toward a worsening of symptoms. The stages identify groups of symptoms that reflect more and more mental deterioration and ever increasing dependence on caregivers. The end result of Alzheimer's is death. Death can be caused by the inability of the brain to keep the body going, or by another injury/disease along the path. Two of the most common reasons are pneumonia or infections.

TROUBLE

COMMON DEMENTIA DISTRESS ISSUES

1. *"I Want To Go Home."*
2. *"I Just Had A Bath/Shower."*
3. *"People Are Stealing From Me."*
4. *"I Don't Have Any Money."*
5. *"Where Are The Car Keys?"*
6. *"Who Are All Of These People?"*
7. *"Where Did Everybody Go?"*
8. *"Am I going to Die Here?"*
9. *"They don't Feed Me".*
10. *"You Are Poisoning Me."*
11. Asking the same questions over and over
12. Confused & Lonely & Scared
13. Wandering
14. Rummaging through things or hiding things
15. Depression, Anger, Belligerence, Aggressiveness
16. Hallucinations, Illusions, Paranoia
17. Eating or swallowing problems and/or refusal to eat
18. Difficulty taking medications
19. Constant "Exit Seeking"
20. Think they are different age (usually much younger)
21. It is not because they WON'T do something -
It is because they CAN'T
22. Bad emotional behavior may mean something is wrong physically
23. Cannot initiate their own activities
24. Upset sleep cycle
25. Impaired Immune System
26. Sensory Overload = too much noise in environment
27. Loss of Memory (**Amnesia**)
28. Struggle to complete familiar tasks (**Apraxia**) i.e.: chewing, swallowing, walking, using forks, toothbrush, etc.
29. Inability to recognize internal signals (**Agnosia**) i.e.: full bladder, chest pain
30. Unable to understand (**Aphasia**) spoken or written words

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THE MANY DIFFERENT NAMES OF DEMENTIA



Dr. Alois Alzheimer (1864-1915) was a German psychiatrist and neuro-pathologist. At a scientific meeting in November 1906, Dr. Alzheimer presented the case of “Frau Auguste D”, a 51-year-old woman first brought to see him in 1901. Auguste had developed problems with memory, suspicions that her husband was unfaithful, difficulty with language, communication, and understanding what was said to her. Her symptoms and behaviors grew worse, and within a few years, she was bedridden. She died in 1906 of infections from bedsores and pneumonia. Dr. Alzheimer had never before seen anyone like Auguste D. He gained the family’s permission to perform an autopsy. In her brain, he saw dramatic shrinkage, especially of the cortex - the outer layer involved in memory, thinking, judgment and speech. Under the microscope, he discovered fatty deposits in blood vessels, dead and dying brain cells, and abnormal deposits in and around cells.



Frau Auguste D.

In 1907, Alzheimer published his observations about Frau Auguste. In 1910, Emil Kraepelin, a psychiatrist noted for his work in naming and classifying brain disorders, proposed that the disease be named after Dr. Alzheimer. <http://www.whonamedit.com/doctor.cfm/177.html>
[http://www.alzheimerbc.org/awareness06/Alzheimer bio.pdf](http://www.alzheimerbc.org/awareness06/Alzheimer_bio.pdf)



It has been over 100 years since this disease was named.

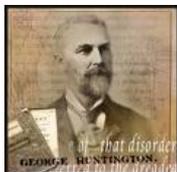
Dr. Alzheimer was identifying the
PLAQUES and **TANGLES** that are known
as the “**HALLMARKS**” of Alzheimer’s disease.

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James Parkinson (1755 - 1824) was an English physician, geologist, paleontologist and political activist. He is most famous for his 1817 work, "An Essay on the Shaking Palsy", the first profile of the disease which now bears his name, Parkinson's.

<http://www.nndb.com/people/591/000096303>



George Huntington (1850 - 1916) was an American physician. In 1872 he writes a landmark paper entitled "On Chorea." Using personal accounts of his father's patients, Huntington provided a classic description of Huntington's disease (HD) symptoms and emphasizes HD's hereditary nature. Significant interest in HD, especially its genetic component, occurs due to George Huntington's paper. <http://hopes.stanford.edu/basics/timeline/r3.html>



Arnold Pick (1851-1924) was a German neurologist and psychiatrist. In 1892, Arnold Pick described a man who had presented in life with progressive loss of speech and dementia. When the patient died his brain was found to be atrophied. This shrinkage had been caused by brain cells dying in localized areas. This feature of localization is very different to Alzheimer's disease where the atrophy is more generalized. In Pick's disease the frontal and temporal lobes are most affected. Swollen brain cells, known as Pick cells, together with the presence of abnormal staining within cells, Pick bodies, are the hallmark of this disease.

http://alzheimers.about.com/od/diagnosisissues/a/arnold_pick.htm?once=true&



John Langdon Haydon Down (1828-1896) was a British doctor. John Langdon Down was quite liberal and advanced for a Victorian gentleman. He vigorously defended the higher education of women and denied that it made them more liable to produce feeble minded offspring. His ethnic classification of idiots led him to maintain that if a mentally defective member of a white race could show the racial features of a non-white race, it proved that racial differences were non-specific. He used this argument to refute the apologists for Negro slavery in the Southern States at the time of the American Civil War and to support the concept of the unity of mankind. He is best known for his classification of what is known as Down syndrome, named after him. In 1866 he wrote a paper entitled "Observations on the Ethnic Classification of Idiots" in which he put forward the theory that it was possible to classify different types of conditions by ethnic characteristics. https://www.amazines.com/John_Langdon_Down_related.htmlhttp://en.



Frederick Henry Lewey (1885 - 1950) (born *Friedrich Heinrich Lewy* - He is consistently referred to as "*Lewy*", although he changed his name during the US years, ending up with *Lewey*), was a prominent neurologist. Lewy bodies or abnormal protein structures were first described by him in 1912. These are a characteristic indicator of Parkinson's disease and Dementia with Lewy bodies. Because Lewy bodies are also often found in the brains of those diagnosed with Alzheimer's, Parkinson's, Down syndrome, and other disorders, researchers agreed in 1995 to use the term "Dementia with Lewy Bodies" to describe both a single disease (sometimes called "pure DLB") and a spectrum of disorders with similar or related pathology. <http://www.springerlink.com/content/57g95062774m8h21/>
www.caregiver.org/



O. Binswanger **Otto Ludwig Binswanger** (1852 - 1929) was a Swiss psychiatrist and neurologist. Binswanger wrote over 100 publications, most notably on epilepsy and hysteria. Binswanger's disease (BD) is also called sub-cortical vascular dementia characterized by loss of memory and intellectual faculties.

www.ninds.nih.gov/disorders/binswangers

The history of vascular dementia can be traced back to cases of dementia post apoplexy described by **Thomas Willis** in 1672. During most of the 18th and early 19th century, “brain congestion” (*due in all likelihood to the effects of untreated hypertension*) was the most frequent diagnosis for conditions ranging from stroke to anxiety and to cognitive decline; and bloodletting became the commonplace therapy.

<http://journals.cambridge.org/action/displayAbstract.jsessionid=3214AE492B6F6AF4A1B0EC7A98C616EF.tomcat1?fromPage=online&aid=273998>



ALUMINUM

Aluminum is the third most abundant element on earth. It is in our food, water and air. Is there a possibility that exposure to aluminum – whether eating and drinking from aluminum cans, cooking with aluminum pots and pans, wrapping food in aluminum foil, using aluminum based baking powder, toothpaste, antiperspirants, or antacids - may increase our chances of getting Alzheimer's? According to the most recent studies, the significance of increased aluminum intake with regard to onset of AD has *not* been determined. Aluminum does turn up in higher amounts than normal in some autopsy studies of Alzheimer's patients, but not in all. Could this be because the special materials and substances used in the laboratory may contain aluminum? It is not absorbed well by the body. Fear that aluminum in the diet or absorbed in other ways has been a topic of conversations for several decades. However, scientists still say that it is uncertain whether exposure to aluminum plays a role in Alzheimer's disease.

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OVER 150 IDENTIFIED DEMENTIA'S *and counting...*

BIG FOUR: ALZHEIMER'S; LEWY BODY; FRONTOTEMPORAL; VASCULAR

Possible REVERSIBLE Forms of Dementia

Dehydration - Can cause mental confusion that may look like dementia.

Emotional Problems - Apathy, confusion, and forgetfulness associated with *depression* are sometimes mistaken for dementia.

Infections - *Meningitis* and *Encephalitis* are infections of the brain or the membrane that covers it, and can cause confusion, memory loss or sudden dementia. Untreated *syphilis* can cause dementia and may damage the brain.

Medications - Some medications have side effects that mimic the symptoms of dementia. A medication may trigger a reaction in a person whose liver fails to eliminate the drug normally and interactions among two or more drugs may lead to reversible symptoms of dementia as well.

Metabolic Abnormalities - Decreased thyroid function (*hypothyroidism*) can result in apathy or depression that mimics dementia. There may be a slowing down of mental abilities and possible short term-memory loss.

Hypoglycemia is a condition in which there isn't enough sugar in the bloodstream. This can cause confusion and/or personality changes.

Pernicious anemia is caused by an inability to absorb vitamin B-12 and can cause cognitive changes.

Normal-Pressure Hydrocephalus - Cerebrospinal fluid builds up in the ventricles of the brain and the brain tissue is compressed even though the fluid pressure remains normal. It is often misdiagnosed as Parkinson's, Alzheimer's, or senility due to its chronic nature and symptoms. It may be treated by draining the excess fluid via a shunt leading into the abdomen.

Nutritional Deficiencies - *Diuretics* (water pills) can cause B1 deficiencies (thiamin) as can *chronic alcoholism* (*Korsakoff's syndrome*) which can impair mental abilities. Severe deficiency of *niacin* (vitamin B3) may cause *pellagra*, a neurological illness with features of dementia. Low *folic acid* (vitamin B9) levels are associated with declining mood. A decline in *estrogen* production among menopausal females can result in depression. Vitamin B12 deficiency can cause short-term memory loss, and is sometimes accompanied by fatigue, low-

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back pain, sore tongue or burning feet. Blood tests may be normal, even though a person has pernicious anemia, or a B12 deficiency.

IRREVERSIBLE Dementia's

Alzheimer's (AD) - Problems with memory, reasoning, judgment, personality, language, loss of initiative, and loss of self. It is the most common form of dementia.

Depressive Pseudo-Dementia - is a type of depression which appears superficially as a problem with memory and which is relatively common in older people and may be confused with the presence of dementia.

Down's Syndrome - Person has almost identical clinical and neuropathologic characteristics of Alzheimer's. Down's will invariably develop into Alzheimer's by late 40's or early 50's. It is on the same chromosome as AD.

Familial Idiopathic Basal Ganglia Calcification (IBGC, Fahr disease) - is an inherited neurologic condition characterized by basal ganglia and extra-basal ganglia brain calcifications, parkinsonism, and neuropsychiatric symptoms, psychosis, personality & behavior changes.

Fronto-temporal Diseases - Pick's Disease, Supranuclear Palsy, and Corticobasal Degeneration. Many possible problems, including:

Uninhibited and socially inappropriate behaviors, major increase in appetite leading to constant eating and weight gain, loss of awareness or concern about behavioral changes, personal appearance & hygiene issues, loss of speech and language compulsive or repetitive behaviors (such as pacing, collecting things, or hand washing), and oral fixation - wanting to put things besides food into their mouths.

HIV/AIDS - Also called *AIDS Dementia Complex* - Symptoms can include headache, fever, stiff neck, altered consciousness, seizures, stroke, speech/sight problems, loss of motor control, change in dream patterns, anxiety and cysts, also painful sensory neuropathy.

Huntington's Disease (HD) - Disease of the mind and body, always inherited from a parent - movement disorder called "chorea", person may appear intoxicated, severe emotional changes, depression, disinhibitions, hallucinations, and psychiatric episodes. Juvenile and adult onset from ages 2-70. Average age for adult onset is 37.

Lewy Body (LBD) - Loss of memory, incontinence, sleep disorders, slowness, tremors, hallucinations, restless leg, stiffness and falls.

Mild Cognitive Impairment (MCI) - Person has increasing difficulty forming new memories, depression, irritability, anxiety, aggression and

apathy had been considered a normal part of aging but now appears to be a early indicator of Alzheimer's disease.

Multi-infarct or Vascular Dementia - Problems with recent memory, getting lost in familiar places, problems handling money & following directions. Heart disease, strokes, temporal ischemic attacks (TIA's).

Parkinson's (PD) - Chronic, disabling disorder of the nervous system. Unable to move quickly, shuffling, swallowing & speech problems, small hand-writing, uncontrollable tremors, and later-onset dementia.

Prion Diseases include: *Creutzfeldt-Jakob (Human form of Mad-Cow Disease); Gerstmann-Straussler-Scheinker syndrome (GSS); Fatal familial Insomnia; Kuru; and Alpers Syndrome.* Characteristics include: loss of motor control, dementia, paralysis, death typically follows from pneumonia.

There are many more "identified" forms of dementia -- too many to list here. This is why it is imperative to get a "proper diagnosis". Knowing that we have done everything possible for our Loved One(s) will make a difference on so many levels.

Organic Brain Syndrome

Organic Brain Syndrome (OBS) is a general diagnostic term. OBS was once used to describe symptoms of different forms of dementia that could not be diagnosed under any other category. The *DSM-IV*, the Diagnostic and Statistical Manual -Volume Four fails to recognize OBS as a legitimate diagnosis The *DSM-IV* is a reference authority manual for doctors to look up codes for medical diagnostic purposes.



FOOTBALL PLAYERS' BRUISED BRAINS WILL BE DONATED TO SCIENCE

Several retired pro athletes will bequeath their brains (*after death*) to the Center for the Study of Traumatic Encephalopathy, a joint program between the Boston University School of Medicine and Sports Legacy Institute. The center recently announced that the brain of former NFL Houston Oiler linebacker John Grimsley was found to have similarities to that of an 80 year old boxer who had dementia for 20 years.

Source: St. Petersburg Times - 09/28/2008



BRAIN BANK DONATIONS

The brain bank studies tissue samples from people who suffered from neurodegenerative diseases, including: Alzheimer's, Parkinson's, Lewy Body, and Huntington's. By providing brain tissue - today - we are giving hope to future generations. By taking this important step, you will also provide vital family medical history. After the brain autopsy is complete, a diagnostic neuro-pathological report will be sent to the family which will *confirm* or *correct* the clinical diagnosis. This report will tell you *exactly* what your Loved One had.

The Harvard Brain Bank, Mayo Clinic, and Mt. Sinai Medical Schools can help you with further brain bank information. Call: **The Florida Brain Bank Program** at **1.305.674.2018** or the **Alzheimer Resource Center** in Orlando at: **1.800.330.1910** for more information. Having a family meeting and discussing the possibility of a brain bank donation is an important step towards finding a cure. To be considered as a brain bank donor, a family will have a "proper" diagnosis; be pre-registered; and have all medical records. The identity of each donor will remain strictly confidential. Brain donation does not conflict with most religious perspectives and will not interfere with an open casket or other traditional funeral arrangements. Call the **Harvard Brain Bank 1.800.272.4622** for a brochure outlining Religious Perspectives.

IMPORTANT NOTE: *Once a person is diagnosed with a form of dementia, the only organ he or she can donate is the brain. Other organ donations (i.e.: cornea, liver, tissue) are not recommended due to the unknown causes of Alzheimer's. There may be a viral connection.*



LEWY BODY DEMENTIA (LBD) is a slow progressive neuro-degenerative brain disease. LBD is a “spectrum disorder” meaning it can occur alone or in combination with Parkinson’s disease, or co-exist with Alzheimer’s disease. LBD is not a rare disease. It accounts for up to 20% of dementia cases in the US... with only 30-50% of LBD cases being accurately diagnosed, even in dementia specific centers. Lewy bodies refer to abnormal structures within the nerve cells of the brain. This part of the brain is involved in higher functions such as sensory perception, motor commands, reasoning, conscious thought, and language. Typically the person will receive a diagnosis of vascular dementia or Alzheimer’s. Early and accurate diagnosis is important because Antipsychotic drugs (*Risperdal; Zyprexa; Seroquel; Haldol; Thorazine*) may cause extreme adverse reactions in those with LBD. Cholinesterase inhibitors (i.e.: *Aricept; Exelon, Razadyne*) may improve alertness and cognition and potentially reduce hallucinations and behavioral symptoms.

One day the person may be active and talkative and the next day they are almost mute, drowsy, or even in a stupor. Graphic hallucinations and delusions may also be experienced. There is no therapy currently available to stop the progression of this disease. There may be difficulties in attempting to treat both the Parkinsonism and psychiatric symptoms because prescribing and increasing medication(s) for one tends to make the other more severe.

The Main Features of Lewy Body can include the following: Repeated falls, fainting and/or sudden muscle twitching hallucinations of sound, touch, smell and taste; incontinence and sexual difficulties; delusions; anger, sadness and depression; swallowing, choking and weak voice; progressive memory loss; loss of initiative/ loss of dexterity; language difficulty; slow movements, frozen stance; small handwriting; stooped - leaning to one side or forward; blank facial expression; restless leg syndrome and/or tremor; altered depth perception; and REM sleep disorder. *For more information visit: www.lbda.org*

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DEPRESSION, DELIRIUM & MILD COGNITIVE IMPAIRMENT

Three possible conditions that are confused with Alzheimer's are *depression, delirium, and mild cognitive impairment*. Key features of **Depression** include sadness and low mood. It affects how you think and behave and can cause a variety of emotional and physical problems. You may not be able to go about your usual daily activities. Depression is often accompanied by poor: *concentration, attention span, and memory* which may suggest dementia.

- Persons with depression often *complain constantly* about their memory.
- Persons with dementia generally *do not complain* about problems with memory because they are unaware of the problem. Source: NEUROLOGY 2005;65:E26-E27

If a person develops rapid confusion and changes in thinking -- neurologists call this **Delirium**. This could be caused by intoxication (alcohol), infections, or drugs/medications that affect or involve the brain. Usually it is possible to separate dementia from delirium. Some persons who have *Dementia with Lewy bodies* (DLB) experience fluctuations and periods of heightened confusion that can look like delirium. Dementia usually develops slowly and the underlying cause may not always be obvious or correctable.

Mild Cognitive Impairment (MCI) is a disorder of thinking, but daily functioning is still preserved. A person with MCI will have problems with their normal daily activities. Neurologists believe that *mild cognitive impairment* is the stage before the development of true dementia.



... Joy and sorrow are inseparable . . . together they come and when one sits alone with you . . . remember that the other is asleep upon your bed. --- KHALIL GIBRAN

The *Dementia* Caregiver's Little Book of Hope www.dementiacaregiverresources.org



DIABETES, THYROID, AND METABOLIC DISEASES

Dementia due to metabolic causes is a loss of mental function that can occur with **diabetes**, **thyroid disease**, and other **metabolic disorders**. Symptoms include temporary or permanent confusion and changes in memory, intellectual functions, and judgment and/or reasoning abilities.

Some things to look for include:

- Changes in vision
- Language difficulties
- Personality changes
- Loss of bladder control
- Decreases in: Feeling, hearing and movement
- Difficulty making sense of person, place, or time

Some other symptoms may include:

- Gain weight inappropriately and/or are unable to lose weight with diet/exercise
- Feel fatigued and exhausted, feel run down, sluggish, lethargic
- Hair is coarse and dry, breaking, brittle, falling out
- Skin is coarse, dry, scaly, and thick
- Have a hoarse or gravelly voice
- Have puffiness and swelling around the eyes and face
- Pains, aches in joints, hands and feet
- Feel depressed; restless, worthless, sad
- Lost interest in normal daily activities
- Are more forgetful - Difficulty concentrating
- Have another endocrine disease or autoimmune disease
- Diagnosed with Chronic Fatigue Syndrome or Fibromyalgia
- Are female and over 60
- Are near menopause or menopausal
- Are a smoker
- Have been exposed to radiation or treated with lithium
- Have been exposed to certain chemicals

An estimated 27 million Americans have thyroid disease and more than half are undiagnosed. 23.6 million Americans have diabetes.

Sources: <http://thyroid.about.com>; <http://www.diabetes.org/home>



DEHYDRATION IN OLDER ADULTS

Dehydration occurs when your body loses too much fluid. This can happen when you stop drinking water or lose large amounts of fluid through diarrhea, vomiting, sweating, or exercise. Not drinking enough fluids can cause muscle cramps. You may feel faint. Usually your body can reabsorb fluid from your blood and other body tissues. But by the time you become severely dehydrated, you no longer have enough fluid in your body to get blood to your organs, and you may go into shock, which is a life-threatening condition. You may also be more likely to get a urinary tract infection (UTI) if you do not drink enough fluids, or you have diabetes. Monitor older adults closely for the early symptoms of dehydration any time they have illnesses that cause high fever, vomiting, or diarrhea. *The early symptoms of dehydration are:*

- A dry mouth and sticky saliva
- Reduced urine output with dark yellow urine
- Acting listless or easily irritated

Older adults have an increased chance of becoming dehydrated because they may:

- Not drink because they do not feel thirsty
- Have kidneys that do not work well
- Choose not to drink because of the inability to control their bladders (incontinence)
- Have physical problems or a disease which makes it hard to drink or hold a glass
- Painful to get up from a chair
- Painful or exhausting to go to the bathroom
- Difficult to talk or communicate to someone about their symptoms
- Take medication that increases urine output
- Not have enough money to adequately feed themselves

Dehydration can occur in anyone of any age, but it is most dangerous for babies, small children, and older adults.

<http://www.webmd.com/fitness-exercise/tc/dehydration-topic-overview>

Chapter 2

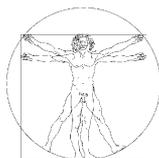
MEDICAL INFORMATION

What is a Personal Health Record (PHR)
Physician Appointments
Memory Disorder Clinics
Medications and Assistance
Pre-Admission Screening
To Admit or Not to Admit
Placement



“When my mom passed away from Alzheimer’s disease in 2000, her brain was autopsied through the Florida Brain Bank Program. It gave me a most important gift... peace of mind. She did indeed have Alzheimer’s and I had done everything possible for her. It is an irreversible neuro-degenerative disease process”.

--- KAREN (KARLE) TRUMAN



WHAT IS A PERSONAL HEALTH RECORD (PHR)

A Personal Health Record (PHR) is a complete and accurate summary of the health and medical history of an individual. It is vital to collect as much health history as we can *before* our Loved Ones can no longer access their long and short-term memories. A PHR is accessible online to anyone you authorize to view the information. PHR's can be stored on a disc, printed on paper, or put on a "zip drive" for future reference. They contain a diverse range of data from many sources and usually include:

- Emergency contacts, names of doctors and health providers
- Living Will, Advance Directives, Durable Power of Attorney
- Allergies and adverse drug reactions
- Prescriptions, over the counter medications, and herbal blends
- Illnesses, surgeries, hospitalizations, and other procedures
- Vaccinations and Laboratory test results
- Insurance and Family history

In addition to storing an individual's personal health information, some PHRs provide added-value services such as drug to drug interactions, electronic messaging between patients and providers, and authorization for organ donations. A personal health record permits you to securely gather, store, manage, update and share your family's health data... *when you want, where you want, and with whom you choose.*

Why Should You Create A Personal Health Record?

To easily gather, store, and manage lifelong personal health information; To share this important information with family members and authorized care providers; and to maximize health benefits for you and your Loved Ones

Where Can I Get A Personal Health Record?

There are many internet websites that offer PHR's. Microsoft, WebMD, NIH, and Google Health offer services to assist you in setting up an account (*for free*), and all of the information and support you may need to get your PHR completed.

1. Microsoft® HealthVault™ <http://www.healthvault.com/>
2. WebMD <http://www.webmd.com/phr>
3. National Institutes of Health <http://medlineplus.gov>
4. Google Health <http://www.google.com>

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PHYSICIAN APPOINTMENTS

For a Loved One with a dementia, waiting in a doctor's office can seem like an *e-t-e-r-n-i-t-y*. Doctor visits can be very stressful on the office staff, the patient, other patients, and most especially on the caregiver. Calling ahead and telling a staff member that your Loved One has "special" needs may help to avoid long waits. A caring and understanding staff can speak volumes to an exhausted caregiver. Having to entertain a patient for long periods of time is not fun. The doctor who keeps his or her schedule on time will make a caregiver's job much less stressful.

Some things to include on your visit:

- **Bring a list** of all medications
- **Talk to the physician** *without* your Loved One in the room if necessary or call ahead
- **Ask questions** about the patient assistance programs for medications that may be available
- **Have the doctor sign any necessary forms** for adult day care, handicap parking, assisted living, or skilled nursing home placement
- **Ask for referrals** to support groups, veteran's benefits, respite care, and other community resources
- **Keep a diary** of medication side-effects, behaviors, mood swings, depression, and other daily events



*"Never use the sign-in pen
at a doctor's office...
After all sick people go there!"*

--- RACHEL Mc



MEMORY DISORDER CLINICS

Getting a proper diagnosis should be one of the very first and most important steps you will take on this journey.

Dementia isn't always due to Alzheimer's. Before you conclude that a Loved One's memory loss and confusion stem from an irreversible disease process, get a thorough medical evaluation at a *Memory Disorder Clinics* (MDC's). These clinics are found all across the United States at medical schools, teaching hospitals, and public and private not-for-profit hospitals. These special clinics assess patients and their caregivers with thorough physical, neurological, psychiatric, lab work, MRI's, CT scans, and neuro-psychological testing. An interdisciplinary team of specialists meets after all of the tests are completed to give a diagnosis with a 90 - 95% degree of accuracy. They will also follow-up with the family and discuss an appropriate future care plan.

Florida Department of Elder Affairs has the current list of MDC's in Florida on their website: <http://elderaffairs.state.fl.us/> 850.414.2000

Note: Scientists have developed sophisticated imaging systems that may help measure the earliest changes in brain function or structure to identify people in the very first stages of Alzheimer's, well before they develop apparent signs or symptoms.

Because of the many stages and ongoing decline of our Loved Ones, it is advisable to have them re-evaluated periodically. It will be in everyone's best interest to see if medications need changing, new research advances could help, and to make sure all of their health needs are addressed. You may also want to explore research opportunities such as:

- **National Institutes of Health - Clinical Trials** are held all over the U.S. and are free for participants, and sometimes they compensate you for your time investment. <http://clinicaltrials.gov/>
- **Comprehensive NeuroScience** (CNS) conducts FREE Memory Screenings for *Dementia Caregiver Resources, Inc.* They also have clinical studies across the U.S. - Contact them at: 727.576.8474 <http://www.cnswebsite.com/>

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MEDICATIONS AND ASSISTANCE

There are four (4) major Alzheimer's medications that are currently available. Although these current drugs cannot change the progressive loss of cells, they may help minimize or stabilize symptoms and possibly delay the need for nursing home care. The FDA approved two classes of drugs to treat the cognitive symptoms of Alzheimer's disease. The first Alzheimer medications to be approved were cholinesterase inhibitors.

1. Aricept® (donepezil hydrochloride), was approved in 1996
Pfizer & Eisai, Inc. 1.800.226.2072

2. Exelon® (Rivastigmine), was approved in 2000
Novartis 1.800.277.2254

3. Razadyne® (formerly Reminyl) (Galantamine) (approved in 2001 under the trade name **Reminyl®** and renamed in 2005)
Ortho-McNeil Neurologics 1.800.526.7736

4. Memantine (Namenda) is classified as an uncompetitive low-to-moderate affinity N-methyl-D-aspartate (NMDA) receptor antagonist.
Forest Pharmaceutical 1.800.851.0758

Note: Tacrine (**Cognex®**), was approved in 1993 but is rarely prescribed because of side effects, including possible liver damage.

Special Assistance Programs may help pay for medications, utilities or other medically necessary services, programs, and related items.

- Patient assistance programs for all of the pharmaceutical companies that are currently available. www.needymeds.com
- The National Council on the Aging has programs for people 55 and over that may pay for *prescriptions, health care, utilities* and other *essential services* or items: call 1.202.479.1200 or visit: www.benefitscheckup.org or www.benefitscheckuprx.org



PRE-ADMISSION SCREENING PROCESS

Placement of our Loved One can be difficult. Each situation is unique. If you have questions about Florida admissions policies and procedures, go to the Agency for Health Care Administration website:

<http://ahca.myflorida.com/>

Some facilities have admission guidelines that follow these ideas.

The following persons may not be allowed to enter certain communities:

- Persons who were asked to leave a previous community
- Persons deemed to be at risk for elopement (unless being screened for a secure unit)
- Persons with inappropriate sexual behavior(s)
- Persons identified as a sexual predator
- Persons currently on medications noted to be chemical restraints per state regulations
- Persons with new G-Tube requiring tube feeding; not previously established
- Persons requiring a strict renal diet
- Persons requiring any therapeutic diet other than the standard diets that are offered

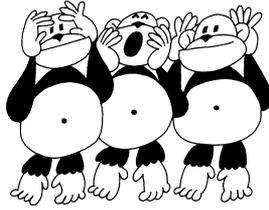
Additionally, individual company policies may prohibit admission for persons with the following diagnoses:

- | | |
|------------------------------------|-----------------------------|
| ➤ Korsakoff's Disease | ➤ Binswanger's Disease |
| ➤ Huntington's Disease | ➤ Creutzfeldt-Jakob Disease |
| ➤ Lewy Body Disease | |
| ➤ Mental Retardation | |
| ➤ Parkinson's Disease | |
| ➤ Personality Disorder | |
| ➤ Pick's Disease | |
| ➤ Progressive Supranuclear Disease | |

Dementia Secondary To:

1. Head Trauma – or Subdural Hematoma
2. Cerebral Anoxia
3. Alcoholism
4. Psychosis

This page is just to inform you that your Loved One may not get admitted to the facility you would choose. Sometimes we have to accept the things we cannot change, as placement may be beyond our control.



TO ADMIT OR NOT TO ADMIT

It is difficult to *accept* the truth about our own humanness and our own capabilities. It can be hard to admit that we are powerless to change the course of the disease. The truth is, no matter how much care we provide or how much of our own lives we neglect our Loved One(s) will never be the same. Often caregivers continue to provide care *far beyond* their physical and emotional capabilities. Now is that dreaded moment when caregivers must be ready to take and get help. Perhaps placement would actually be beneficial for your Loved One. You may even see them blossom with the addition of more social interactions, better nutrition, and increased attention to their related health care issues. *Promises to never put a Loved One in a “home” may need to be reconsidered...* when these promises were made, you didn't know what the circumstances would be like today. Go visit some recommended long-term care communities to change your pre-conceived stigma of the “Nursing Homes” as you may have thought of them in the past. Look for a place that is clean, has friendly staff, and that you would visit often. Using resources such as the Senior Living Guide(s); Area Agency on Aging; Senior Helpline; 211; Elder Law offices; internet searches; and word of mouth can all be helpful when searching for the right long-term care community.

The number one caregiver emotion is GUILT. Guilt means you did something wrong. Placement is not “wrong,” but instead one of the hardest decisions that you will ever have to make. It takes a lot of courage. We can change *feelings of guilt* to *feelings of regret* by understanding that it is the circumstances of a terrible disease.

After Placement If you have a complaint or need help, these are some guidelines for the order in which to pursue the issues:

1. Administrator and/or Doctor
2. Long-Term Care Ombudsman 1.888.831.0404
3. Agency for Health Care Administration 1.888.419.3456
4. Abuse Hotline 1.800.96.ABUSE (1.800.962.2873)

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PLACEMENT

Caregivers who get help early and have a strong support system through community, special programs, friends and family are more likely to be able to delay placement. Statistics have proven that seeking resources like counseling, respite opportunities, adult day care and attending support groups can help keep a Loved One at home longer. When a caregiver has a conflicted relationship with their Loved One forgiveness of past issues sometimes make these decisions harder. It is easier to make a placement decision when your entire support system (i.e.: husband/wife; sister/brother; children; medical team; support groups; spiritual advisors, etc.) is involved. The issues will have been explored and actually spoken out loud together. The **earlier** in the disease process that these discussions take place, the **easier** it will be to make a decision when the actual time for placement comes. It is better to make a choice when it is not made in *crisis* mode. The decision to place a Loved One in a care facility has been called the hardest decision one will EVER have to make. The caregiving journey does not end when you place a Loved One. How does a primary caregiver make such a HUGE decision? What should s/he consider? Perhaps the doctor says: “*You can no longer continue to do this at home*”. Can this be seen as a failure of caregiving skills, a betrayal of a promise, or an inability to cope? Do finances demand that placement is the only option? Has a family decision been made, or has another reason intervened? Every placement situation has its own breaking point.

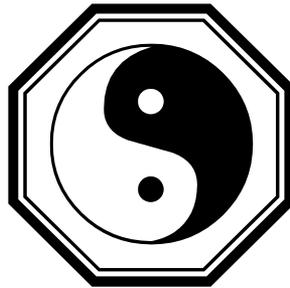
The Top Reasons Families Place a Loved One in a Facility

Need for more skilled care and assistance; Dementia-related behavior problems; The health of the caregiver; Incontinence; Finances; Depression (Statistics show over 1/3 of caregivers have clinical depression)

Chapter 3

CAREGIVER ADVICE AND SUPPORT

Language and Communication Tips
Activities of Daily Living
Anticipatory Grief
Depression and Caregiving
Caregiver Burnout
Sundowning
Support Groups
The 10 Secrets of Success
Caregiver Ten Commandments



*“Your meetings are so grounding -
It's the only place I can go
and feel absolutely safe.”*

--- CAROL C.



LANGUAGE AND COMMUNICATION

Did you know that as much as 90% of our communication takes place through nonverbal communication such as gestures, facial expressions, and touch? When a person has a disease like Alzheimer's, answering questions becomes very hard to do. By the time you finish the question - they may have forgotten the beginning of the sentence. By understanding this - we can become more tolerant and patient while waiting for a response.

Non-verbal communication is particularly important for a person with dementia who is losing their language skills. When a person with dementia behaves in ways that cause problems for caregivers, they are usually trying to communicate something. Persons with Alzheimer's disease often revert back to their earliest spoken and understood language. You may have to prompt them to "speak English please". Their *long-term* memories are usually very good. It is the *short-term* memory losses that are a hallmark of this disease process.

Caring for someone with dementia can be frustrating. This frustration may make it hard for you to think of that person in the same way that you did before s/he became ill. The person you're caring for may not know you anymore and may also have behavior problems which could include:

- Accusations of stealing or unfaithfulness
- Rummaging in another person's personal space
- Yelling
- Trying to hit others
- Constantly exit seeking
- May be too ill to have a "normal" conversation
- Cannot follow simple directions
- Cannot ambulate, dress, eat or toilet by themselves

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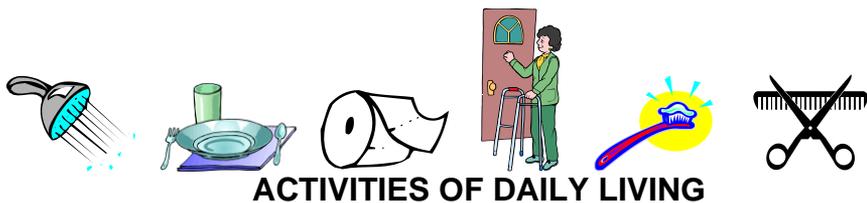
Some things you can do or look for...

- **Never argue** with a person who has dementia
- Check for hearing & sight problems
- Repeat your instructions
- Turn off background noises and distractions (TV, Radio)
- 😁 Smile! They will react as you do
- Allow time for response
- Use eye contact
- Touch with tenderness
- Always identify yourself
- Reassure person that they are in a safe place
- Encourage
- Treat with dignity & respect
- Address person by first name
- Get on their level and use direct eye contact
- You may have to repeat the question in different ways
- Response time may take several minutes
- Use gentle touch to keep them focused
- Ask *simple-specific (Closed Ended)* questions like: Would you like Apple or Orange juice? Blue or green?
- Try to not overwhelm the person with (*Open Ended*) questions like: "What do you want to wear? To eat? etc."



*“Watch your thoughts, for they become words.
Watch your words, for they become actions.
Watch your actions, for they become habits.
Watch your habits, for they become character.
Watch your character, for it becomes your destiny.”*

--- UNKNOWN



Activities of daily living allow a person to feel that they still have something to offer, a sense of accomplishment, praise for a job well-done, and encouragement. By creating an environment of well-being, dignity, and good self-esteem you may avoid catastrophic behaviors and outbursts.

- Dressing
- Grooming
- Eating
- Bathing
- Transferring
- Toileting
- Incontinence
- Sleeping
- Intimacy

When a Loved One needs help with (i.e.: lifting, turning, cooking, paying bills, incontinence, etc.), we are experiencing emotional roller-coaster rides, depression, disease progression, and making life-care decisions. Even our own health issues can be overwhelming. When a person can no longer do some of these activities for themselves, family caregivers or guardians will have to step in and make new decisions, and/or you may have to consider placement.

PLAN

For the Future

Families often agonize over the decision of placement for weeks, months and sometimes years... asking themselves was it the right decision and/or the right time?



ANTICIPATORY GRIEF

Anticipatory grief is what you may experience when your Loved One has changed so dramatically from the person you once knew because they now have a progressive, degenerative, and irreversible brain disease. The handwriting is on the wall...but that does not make coping with these life changes any easier. Anticipatory grief is both the easiest and the hardest kind of grief to experience. Because you have time to prepare, you can begin to envision and rehearse your life without your Loved One. This gift of time offers the opportunity to resolve regrets, make amends and heal relationships.

Anticipatory Grief may cause us to reflect upon:

Life without our Loved One; Starting over; Financial and legal concerns; Companionship changes; Changed patterns of social, eating and personal habits; Control over our environment and independence Caring for ourselves and our Loved One; and the Family structure

Signs and Symptoms of Anticipatory Grief

Having overwhelming Feelings and Emotions may include:

Sadness and emptiness; suicidal thoughts; can't stop crying; difficulty in making decisions; weight loss or gain; guilt; denial; and anger; emotional roller-coaster; depression; numbness; anxiety and fear; poor concentration; memory problems; loneliness; trouble sleeping; aches and pains; hopelessness; helplessness; and loss of interest in previously enjoyed activities

What You Can Do

Working through the anticipatory grief process can be done. It will take hard work and self-discipline. Though we often seek advice from others, many spiritual traditions teach that the answer lies within.

Some suggestions to assist you in this healing process include:

Exercising; writing in a journal; planning for the future; seeking spiritual advisement; joining a support group; seeing a counselor and/or a doctor; and talking it out with friends, family; Making changes as necessary and creating new social avenues.

Some final thoughts... **Don't be afraid to ask for help.** Build an outreach network. Write down the names of all the people that could be a part of your network. Consider family members, friends, neighbors, support groups, health care providers, and members of your faith community. Consider any other contacts (i.e.: Veterans; social groups) who could be helpful additions to your network. *You are not alone on the pathless path.*



DEPRESSION AND CAREGIVING

More than 50% of all caregivers face depression at some point. Living with the stress of the ongoing care needs of our Loved One; financial jeopardy; our own health deterioration; lost work time; changes in relationships; loneliness; little appreciation for what we are doing; and family issues can all take a major toll on our lives. Feeling that things are out of control may make you frustrated by: a lack of money, anger at the disease, too few resources, or unable to effectively plan, manage, and organize your Loved One's care. Stress, anger, guilt, and grief related to caregiving can lead to depression. If you are feeling or experiencing depression, please talk to your doctor, or see a mental health counselor to discuss medications or other options.

Signs of Depression can include:

-  Difficulty Concentrating
-  Anxiety /Irritability
-  Digestive Problems
-  Problems Sleeping
-  Aches & Pains
-  Social Withdrawal

Resources to assist you can include:

Online and in-person support groups; health team, helplines (i.e.: 211); spiritual advisors; books; community/county/state and federal programs.



It is not because they
“**Won’t**” do something...
it is because they “**Can’t**.”

URGENT

CAREGIVER BURNOUT

If you care for a person with dementia, you face even greater risks for health problems than other caregivers. You are particularly at risk for *Caregiver Burnout*...*a state of complete mental and physical exhaustion*. Caregiver Burnout is brought on by the physical, mental, emotional and financial stresses of providing ongoing care, over a long period of time.

Burnout Symptoms may include:

- Withdrawal from friends, family and other loved ones
- Loss of interest in previously enjoyed activities
- Feeling depressed, irritable, hopeless, and helpless
- Changes in appetite or weight
- Changes in sleep patterns
- Getting sick more often
- Feelings of wanting to hurt yourself or your Loved One
- Emotional and physical exhaustion

Possible Causes of Burnout

Role Reversal - Many people are confused when thrust into the role of caregiver. It can be especially difficult for an adult child to step in to become his/her parent's care provider and decision maker, or be thrust into new responsibilities from a previous role as dependent spouse, sibling, friend, etc.

Unrealistic Expectations - Caregivers may have unrealistic expectations and hope that their increased involvement will have a positive effect on the health of their Loved One.

Self-Imposed Burdens - Sometimes caregivers place unreasonable burdens upon themselves; they may see providing the best care as their *exclusive* responsibility. *No one can do it as well as me, and I will not give it up until death do us part*...unfortunately the death may be that of the caregiver and *not* the care receiver.

Becoming Sick - Many caregivers refuse to recognize that they are suffering burnout and become exhausted, get sick, and die first.

Financial Problems - Giving up your job, moving, finding resources, applying for Medicaid or food stamps, paying bills and trying to make sense of new legal matters will take their toll and create more stressors. On top of this, you may be caring for a person who seems ungrateful and resentful even though they cannot manage on their own.



WHAT YOU CAN DO TO PREVENT CAREGIVER BURNOUT

Find someone you trust such as a family member, friend, or clergy to talk to about your feelings and frustrations

Accept the fact that you may need help with caregiving, and ask others for help

Be realistic about the progression of your Loved One's disease process

Take care of yourself! Balance in your life is extremely critical now

Talk to professionals -- they may have solutions you need now

Take advantage of respite care services. Respite care provides a temporary break for caregivers. This can range from a few hours of in-home care to a stay in a nursing home or assisted living facility

Know your limits...do a reality check of your personal situation

Educate yourself. The more you know about the disease progression, caregiving and practical advice, the more effective you will be in continuing to provide care for your Loved One

Use humor, laughter and lighten up to help you cope with stress

Stay healthy by eating right and getting enough exercise and sleep

Accept your feelings, even negative feelings such as frustration or resentment about increased responsibilities. Anger towards your Loved One is normal. This does not mean you are a bad person or a bad caregiver. *You are really angry at the disease - not the person who cannot change - no matter how much we want them to*

Join a support group. Sharing your feelings and experiences with others in the same situation can help you manage stress, locate helpful resources, and reduce feelings of frustration and isolation

Where Can I Get Help With Caregiver Burnout?

If you are already suffering from stress and depression, ask your doctor for referrals and information, call 211 a national Helpline/Hotline. Stress and depression are treatable disorders. If you want to prevent burnout, consider turning to the following resources for help with your caregiving:

- Adult Day Care
- Home Health Services; Private Duty Aides
- Nursing Homes or Assisted Living Facilities
- Caregiver Support Services
- Geriatric Care Managers
- Area Agency(s) on Aging

Every County in the U.S. is served by the National AAA



SUN-DOWNING

Experts say that all types of agitating behaviors are forms of communication. Your Loved One is trying to tell you something even though the disease has robbed them of other ways (i.e.: talking, pointing) of telling you. Perhaps they are frightened or fatigued and do not know how to express it in words. Some experts believe that agitated behavior is *the inability to deal with stress*. Sundowning is a state of increased agitation, activity, and negative behaviors which usually happen late in the day through the evening hours. It used to be thought that sundowning was caused by dusk and shorter days. However, research now indicates that being overly tired and hurting may have more to do with sundowning behaviors.

Make sure that your Loved One is well-rested: a nap or "quiet time" may work wonders. If they cannot or will not nap, an hour quiet time (reduced stimulation and activity) will help. Use a recliner, turn off the TV, turn on some soft music, and then perhaps read or gently massage their back, feet, or arms.

Limit outings and activities to the morning hours: Plan trips to doctors, programs, special outings, and any other activities during the earlier part of the day. This should be followed with a time of decreased stimulus and quiet time to allow time to wind down and relax.

Decrease the length and amount of stimulus: Even during the earlier part of the day your Loved One can only tolerate so much stimulation and commotion. Take steps to eliminate over-stimulation such as television, children, loud noises, quick movements, and too many things going on at one time. Sometimes excessive stimulation cannot be avoided. When that happens, allow them to retreat to a quiet area.

Identify and minimize physical discomfort: Other types of physical discomfort can also play a part in sundowning. Hunger, being wet or soiled, feeling cold/hot and other sources of discomfort can increase agitation, especially in the late afternoon and early evening. Light snacking during the day can be helpful. Apples and other fruits can help replace lost energy – even if your Loved One is pacing back and forth, that does not mean they have an endless supply of energy. Make sure that personal needs are attended to and that the climate is at a comfortable level.



SUPPORT GROUPS

A support group is a **safe** place to talk, share, cry, form friendships, and find information. Fellow caregivers have “been there and done that”. They have experience and understand what you are going through. Coping skills, stress management, referrals to special programs, and personal growth are all on the agenda. Gathering strength in a non-judgmental friendly environment with people who are on the same path, offers caregivers renewed hope. Some support groups may offer caregiver outings, respite opportunities, educational programs, wellness retreats and pamper days. Finding a group that is right for your needs is important. There are also online groups that you can access anytime of day or night. Please know that others “get it”, care about your experiences, and truly understand what your journey is all about. You will need this kind of emotional support as your Loved One continues to decline. *Some quotes from support group members:*

- Joining this group saved my life!
- I feel more armed and less dangerous!
- To KNOW that I am not alone.
- I can actually laugh again!
- The support group was a great way for me to get out of the denial trap

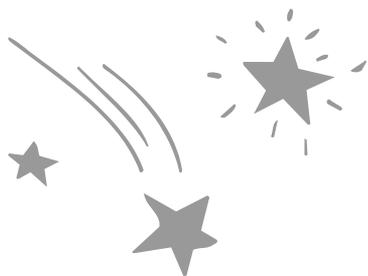


"It is one of the most beautiful compensations of life, that no man can sincerely try to help another without helping himself." --- RALPH WALDO EMERSON

THE 10 **SUCCESS**

AUTHOR UNKNOWN

1. *Never ARGUE* - Instead, **AGREE**
2. *Never REASON* - Instead, **DIVERT**
3. *Never SHAME* - Instead, **DISTRACT**
4. *Never LECTURE* - Instead, **REASSURE**
5. *Never say: "REMEMBER"* - Instead, **REMINISCE**
6. *Never COMMAND or DEMAND* - Instead, **ASK** or **MODEL**
7. *Never CONDESCEND* - Instead, **ENCOURAGE** or **PRAISE**
8. *Never say: "YOU CAN'T"* - Instead, **DO WHAT THEY CAN**
9. *Never say: "I TOLD YOU"* - Instead, **REPEAT**
10. *Never FORCE* - Instead, **REINFORCE**



“Life is not measured by the number of breaths we take, but by the moments that take our breath away”
--- UNKNOWN



CAREGIVER TEN COMMANDMENTS

AUTHOR UNKNOWN

- I Thou shalt not be perfect or even try to be.
- II Thou shalt not try to be all things to all people.
- III Thou shalt sometimes leave things undone.
- IV Thou shalt not spread thyself too thin.
- V Thou shalt learn to say “NO”.
- VI Thou shalt schedule time for thyself and thy support network.
- VII Thou shalt switch thyself off and do nothing.
- VIII Thou shalt not even feel guilty for doing nothing or saying “NO”.
- IX Thou shalt be boring, untidy, inelegant and unattractive at times.
- X Especially, thou shalt not be thine own worst enemy, but be thine own best friend.

Chapter 4

PRACTICAL GUIDANCE

Ten Warning Signs

Home Alone

Safety & Hidden Dangers

Project Lifesaver International for Wanderers

The Simple Clock Test

Fragrance Free Zones

Odor Identification Study

Role Reversals

Reactions and Redirections

Driving with Dementia?

The Family Meeting

Geriatric Care Managers



*“Get your facts first,
then you can distort
them as you please.”*

--- MARK TWAIN



"10 WARNING SIGNS" TO DETERMINE IF HELP IS NEEDED

1. Changed eating habits within the last year resulting in weight loss, having no appetite, or missed meals?
2. Neglected personal hygiene resulting in wearing dirty clothes, body odor, bad breath, neglected nails and teeth, sores on the skin?
3. Neglected their home so it is not as clean or sanitary as you remember growing up?
4. Exhibited inappropriate behavior by being unusually loud or quiet, paranoid, agitated, and making phone calls at all hours?
5. Changed relationship patterns such that friends and neighbors have expressed concerns?
6. Had physical problems such as burns or injury marks resulting from general weakness, forgetfulness, or possible misuse of alcohol or prescribed medications?
7. Decreased or stopped participating in activities that were previously important to them such as bridge or a book club, dining with friends, or attending religious services?
8. Exhibited forgetfulness resulting in unopened mail, piling newspapers, not filling their prescriptions, or missed appointments?
9. Mishandled finances such as not paying bills, losing money, paying bills twice or more, or hiding money?
10. Made unusual purchases such as buying more than one magazine subscription of the same magazine, entered an unusual amount of contests, increased usage of purchasing from television advertisements? Visit: www.n4a.org



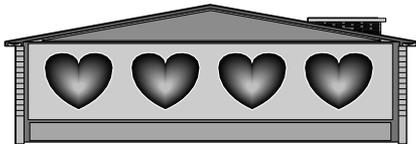
*Always do right...
this will gratify some
and astonish the rest.* --- MARK TWAIN

HOME *Sweet* HOME ALONE?

Prepare for the possibility that you may have to have outside help come into the home, arrange respite care, and have other family/friends available. Even though your Loved One may protest and say s/he wants to remain alone; you are the best judge of this important safety decision.

Some very important questions to discuss, ponder, and argue about when making decisions about leaving your Loved One home alone can include the following:

- Can they call 911?
- Will they be destructive?
- Will they let in strangers?
- Could they harm themselves?
- Are they frightened when alone?
- Can they recognize family and friends?
- Can they safely use the bathroom alone?
- Will they wander or constantly seek an exit?
- Can they prepare a meal without assistance?
- Can they distinguish smoke alarms and seek safety?
- Do they have medical issues (i.e.: taking medications/giving shots, wound care, etc.) that needs supervision?



**A lot of our Loved Ones say:
“I WANT TO GO HOME!”**

“Home” in this case, usually means where they used to be in their mind, not a physical place.



SAFETY & HIDDEN DANGERS

Creating a safe environment can help to reduce injuries, wandering, and other problems *before* they have a chance to happen.

Things to consider as possible safety concerns or hazards:

- Knives (Put out of sight)
- Unplug Appliances
- Install “off” switch on stove
- Hot Water Thermostat should be set below ↓105°
- Spoiled Food items in refrigerator
- Smoking Materials and Alcohol
- Garbage Disposal Switch
- Medications or Herbals
- Electric Blankets/Heating Pads
- Paints, Bug Sprays, Chemicals & Mowers
- Medicine Chest Items
- Power Tools, Blades, Saws
- Disguise door with STOP sign
- Remove locks on doors (bathroom, bedroom, closets, etc.)

Remember: *About 60% of dementia patients will wander or become disoriented even in the safest environment.*

For those who wander, these ideas may assist you

PROJECT LIFESAVER INTERNATIONAL

Project Lifesaver has been successful in 100% of its searches to date, “*bringing Loved Ones home*” in an average response time of less than 30 minutes. Visit: www.projectlifesaver.org or call 1.877.580.5433

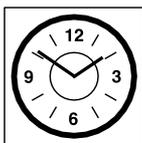
Pinellas, Pasco and Hillsborough Counties are participating in this program and are ready to sign up your Loved One. There is a cost, but partial financial assistance may be available. Call: 727.586.6806

Visit these websites for more ideas on helping you to get through this stage of the disease.

<http://alzstore.com/>

<http://www.seniortechnologies.com/products/wanderguard/>

http://alzheimers.about.com/od/caregivers/a/wander_caregive.htm



THE SIMPLE CLOCK TEST

This is a simple test that can be used as a part of a neurological test or as a screening tool for Alzheimer's and other types of dementia. The person is asked to:

1. Draw a clock
2. Put in all the numbers
3. Set the hands at ten past eleven

Scoring System for Clock Drawing Test

The Alzheimer's disease cooperative scoring system is based on a score of five points.

1. 1 point for the *clock circle*
2. 1 point for all the *numbers* being in the *correct order*
3. 1 point for the *numbers* being in the *proper special order*
4. 1 point for the *two hands* of the clock
5. 1 point for the *correct time*

A normal score is four or five points. The test can provide huge amounts of information about general cognitive and adaptive functioning such as memory, how people are able to process information, and their vision.

Simple Word Test Identifies Early Onset of Alzheimer's

In a recent study 96 people with Alzheimer's disease and 40 healthy people were interviewed. All the participants were about the same age and came from the same social and cultural backgrounds. They were first asked to name all the *animals* they could think of in *one minute*. They were then asked to name all the types of *fruit* they could remember in *one minute*. The researchers found that people with early Alzheimer's were able to list only 10 to 15 words in contrast to the 20 to 25 words in the healthy group.

The Relationship between Word Recall and Alzheimer's

During childhood we learn words at different ages. Words like cat and dog are learned before the age of 5, whereas words like giraffe and zebra are learned later on and used less frequently. In the study, people in the early stages of Alzheimer's consistently forgot words they learned later in their lives. The researchers found that the pattern of word loss was so consistent that they could identify people with Alzheimer's on their word 'loss' alone. *Source: About.com Updated: April 17, 2006*



FRAGRANCE FREE ZONES

No Scents Make Good Sense

Wearing perfume, cologne, after-shave, or other heavy scents is offensive to many people especially when caring for patients we are transporting, serving, escorting, hovering over, dressing, bathing, administering medications, and performing other activities. Patients are “captive” in their own environment. Please understand and respect that a lot of persons have scent allergies or asthma. There are “No Fragrance” zones in many public settings. You can *give* someone a headache or make them nauseated just by walking past them. Scents are very powerful, and may also have (good or bad) memories attached.

- Often, users of scented products are unaware of how strong their scent is because they are unaffected by the chemicals
- Users may also be unaware that the chemicals in their scent can cause an allergic reaction for some people. Reactions can vary from mild to severe and can interfere with daily activities and being able to stay at an event, school or work
- Dementia Caregiver Resources, Inc. believes that all medical settings, public buildings, and work places should be fragrance-free. People with allergies, multiple chemical sensitivities (MCS) and asthma can become quite ill when exposed to certain scents
- Be respectful of people with allergies
- Ask yourself – do you want to make someone sick?
- Keep the air clean and safe for everyone

IMPORTANT!



Please do not wear scents when you are visiting, working with, or transporting patients. It is also advised to not allow the patient to have access to these items. Alzheimer’s patients may get confused and try to eat or drink from the pretty bottles and jars.



ODOR IDENTIFICATION STUDY

A study conducted by the **American College of Neuropsychopharmacology** tested the *inability* to identify the smell of the following odors.

1. **Lemons**
2. **Strawberries**
3. **Smoke**
4. **Soap**
5. **Menthol**
6. **Cloves**
7. **Lilac**
8. **Pineapple**
9. **Natural Gas**
10. **Leather**

These tests predicted which patients with *minimal to mild cognitive impairment* (MMCI) would later develop Alzheimer's.

Source: <http://www.news-medical.net/?id=6833>



ROLE REVERSALS

Making life care decisions for our parents and other Loved Ones is a very hard thing for sons and daughters and husbands and wives to do. Perhaps that person who now has a dementia was always the “boss”. They were in charge of finances, the head of the household, the parent, or an older sibling. The burden has now shifted to you. You are forced to make choices for another that you are not prepared to make. The decisions are hard. Your emotions are raw. The protesting by others *not* standing in your shoes is persistent. It will be much easier if you have made some plans, have a family meeting, and get your Loved One’s legal/financial documents in order.

One of the most difficult developmental issues of middle age can be that of “making peace” with our parent(s) for past emotional hurts, abuse, or other issues. When a parent has a form of dementia, you may be able to heal and start an entirely new relationship. *Shoulda - coulda - woulda*, shame, and guilt all stem from a lack of love, so try to not “*should*” on yourself too often.



*Forgive those who hurt you in the past...
you will feel so much better.
They have already forgotten about it.*



REACTIONS AND REDIRECTIONS

Behavior issues may arise when a person feels threatened due to something or someone in their environment. Analyze the situation and follow some of the guidelines below:

- Is everyone safe?
- What emotions are you showing?
- Remember to enter *their reality*
- Do you have to leave the room to calm down the situation?
- Can you offer food or beverage to change an atmosphere of anger?
- What is causing the fear? Can you discuss this issue further to see if there is valid reasoning behind the behavior?



**Men typically cover their fears with *anger*...
Women with *tears* and *anxiety*...**

Remember the five *R*'s

- R*emain calm
- R*espond to feelings
- R*eassure the person
- R*emove yourself
- R*eturn later

*“We are what our thoughts have made us;
so take care about what you think.*

Words are secondary.

Thoughts live; they travel far.

--- SWAMI VIVEKANANDA



DRIVING WITH DEMENTIA?

Deciding when to ask for the keys or having your Loved One give them up is a very hard issue for caregivers to address. *Look for changed driving patterns that could include:* Confusing the gas and brake pedals; stopping in traffic for no reason; multiple accidents and/or violations; increased agitation when driving; trouble navigating turns; uses a “co-pilot”; difficulty maintaining lane position; or getting lost in familiar places. Ask yourself one question: “*Would you put yourself or your child or grandchild in the front seat with this driver?*” If you would not, then please do not allow this person to continue to have the keys. You may be saving the life of someone else!



Ask the doctor to suggest or write a prescription that says: **Name: _____ should “stop driving”.**

Did you know that the Florida *Department of Highway Safety and Motor Vehicles* has a medical reporting form for the general public to report impaired drivers? This form states the following: **“Any physician, person, or agency having knowledge of any licensed driver’s or applicants mental or physical disability to drive...is authorized to report such knowledge to the Department of Highway Safety and Motor Vehicles.”** The report is confidential; and no civil or criminal action may be brought against any physician, person or agency that provides this information. (Section 322.126 (2), (3) - Florida Statutes)

To get the form -- Call, Fax, see the website or write to:

Phone: 850.617.3814 or Fax: 850.617.5165

See website: <http://www.floridagrandedriver.com/index.cfm>

Division of Driver Licenses Attn: *Medical Review Section*

Neil Kirkman Building, MS 86 - Tallahassee, FL 32399-0500

For more information and to request a **FREE** brochure called: “*At the Crossroads: A Guide to Alzheimer’s disease, Dementia & Driving*”.

Visit: <http://www.thehartford.com/alzheimers/index.html>

The *Dementia* Caregiver’s Little Book of Hope www.dementiacaregiverresources.org

THE FAMILY meeting

A family meeting may be the last thing you want to conduct, but it can clear the air on so many levels. Since there could be multiple topics that have to be included, it is necessary to focus on the most important and pressing issues of the day. Have an agenda clearly written out and copies for each participant. It is vital to stick to the topics, have short discussions, and start and end the meeting at the scheduled times.

Have the meeting in a place where there will be few distractions, no small children allowed, or any other frequent interruptions. This will offer the best kind of meeting setting. When meetings go on too long they may become just a gripe session -- anger and resentment start to show. It may be difficult to cover all of the issues in one meeting, so additional meetings may have to be arranged. Stick to the agenda and the time frames and keep the meeting on track. This will bring the best results for a difficult situation. It may be challenging for all the family members to travel to the location of the meeting, so perhaps arranging a conference call, or using speaker phones could be helpful. Having someone videotape or audiotape the meeting and then mailing tapes to the different family members may be necessary. There is a technology called *Web conferencing* that can bring everyone together through the computer.

Change is hard for most people, especially our older family members. They may protest loudly. You may have to bring in an outside person (i.e.: social worker, mediator, clergy, etc.) to assist with the meeting process. There are many resources available. Find something that works for your situation. You are doing this out of love and concern for your Loved One who would want the same quality of care for you if the situation was reversed.



Once you make a decision, the universe conspires to make it happen.

--- RALPH WALDO EMERSON

An agenda may include the following topics:

- How much will the care cost?
- Personal feelings about caregiving
- Medical history and current health reports
- Is the Loved One still competent to drive?
- Who can help with what tasks and when?
- What does the person who is ill want and need?
- How can we improve our Loved One's quality of life?
- How much time does each family member have to visit?
- What happens to other family members if another one dies?
- Primary caregiver is overwhelmed -- where do they find respite care?
- Help with errands; (i.e., taking the Loved One to doctor's appointments).
- Who else can help? Have we explored all possible programs and benefits?
- Can a long-distance family member help out with \$\$ rather than direct care?
- If you cannot do direct care, can you make necessary phone calls and paperwork?
- If our Loved One has to move, who can assist with this task? How & when can you help?

Have an e-mail or telephone tree for regular updates and news.



PROFESSIONAL GERIATRIC CARE MANAGERS

Geriatric Care Managers (GCMs) are professionals in health and human services. They are specialists who help families care for older relatives. They have additional training in a number of fields related to long-term care issues with a focus on aging and elder care and can include: nursing, gerontology, social work, and/or psychology. They encourage as much independence as possible. The GCM acts as a guide and advocate -- identifying problems and offering solutions, from assessment needs to addressing the life changes of a family affected by Alzheimer's Disease, Parkinson's, Lewy Body or other forms of dementia. Costs are usually based on hourly rates and may be offset by long-term care insurance, VA or other programs and benefits.

Visit: <http://www.caremanager.org/>

Chapter 5

LEGAL and FINANCIAL KEYS for SUCCESS

Why You Need an Elder Law Attorney

Why You Need Certain Legal Documents

Verifications (That You May Need) for Public Benefits

Medicaid and **Medicare**

Financial Considerations

Guardianship 101

Family and Medical Leave Act

Planning Ahead

*"Our destiny rules over us,
even when we are not yet aware of it;
it is the future that
makes laws for us today."*

--- FRIEDRICH WILHELM NIETZSCHE



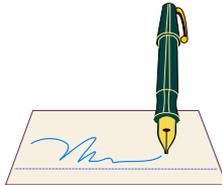
WHY YOU NEED AN ELDER LAW ATTORNEY

Even if you are NOT an Elder

Elder Law attorneys focus their practice on estate planning, probate, tax questions, disability, long-term care, trusts, durable power of attorney, living wills, health care surrogates, guardianship, Medicare/Medicaid eligibility, and incapacity. Pre-planning and drafting legal documents while we are healthy and *before* diagnosis of a dementia (i.e.: Alzheimer's, Parkinson's, Huntington's, etc.) or another disease is critical. Planning for incapacity is a subject that no one wants to discuss, but we must...so please make an appointment. An Elder Law attorney specializes in helping families who want to make sure they can create documents ahead of time that will avoid the perils and pitfalls of financial, legal and placement concerns. They use a collection of legal "tools" to meet the needs of clients. Deep sighs of relief can often be heard because now you know exactly what your financial obligations and options include. It is important to consult with an Elder Law Attorney in your state. Each state has specific laws and may not always be in accord with another state's documents.



Yearly updating of information in wills, bank accounts, and other documents is so important - especially if there have been any recent births, deaths, or divorces. *Peace of mind is priceless.*



"I took the time to write out and express my wishes. Please take the time to honor them."

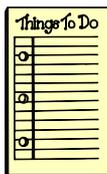
--- JAMES W



WHY YOU NEED TO CREATE CERTAIN LEGAL DOCUMENTS

Keep them current - alleviate guilt, mistakes and unknown wishes!

1. **Will** - If you die without a will, the state may decide who gets your estate - or who will raise your children - or even who gets the family jewelry? *When in doubt spell it out ...by spelling out exactly who gets what and how much - ahead of time - you may avoid unnecessary conflict and emotions for the family. (Don't leave \$\$ to a deceased family member or ex-spouse!)*
2. **Durable Power of Attorney** - The purpose of a Durable Power of Attorney (DPOA) is to give authority to someone else to act on your behalf as if they were you. The person who holds a DPOA "stands in" for you and acts as your agent. For example, a person holding a DPOA can write a check and sign his name to draw funds from your bank account. This same person can also sell or purchase property on your behalf, including your home. Simply, this person can legally do anything you can do, so be very careful *who* you choose!
3. **Health Care Surrogate** - A Health Care Surrogate designation authorizes someone to make medical decisions on your behalf. You direct what kind of choices are to be made, including decisions to withhold or end medical treatment when death is imminent. Health Care Surrogate Designation only becomes effective if you can not express your desires regarding medical treatment.
4. **Living Will** - A legal document that conveys your wishes to not be kept alive by artificial means.
5. **Do Not Resuscitate Order (DNR)** - A DNR is a form developed by the Department of Health to identify people who do not wish to be resuscitated in the event of respiratory or cardiac arrest.
6. **Final Instructions** - If you have specific wishes in mind for the final disposition of your body, it needs to be written down, and be available to your next of kin. *Questions to consider before death can include:* Cremation or burial; Pre-need contract; or pre-registered for a Brain bank donation?



VERIFICATIONS THAT YOU MAY NEED FOR PUBLIC BENEFITS

When applying for Medicare, Medicaid, Food Stamps, Veterans Benefits, and other public assistance programs, you may be requested to provide the following verifications:

- **Identification** - Driver's license, birth certificate, Social Security cards, citizenship papers, etc.
- **Health Insurance** - Medicare, Medicaid, Veterans or private insurance
- **Vehicle** - Title, registration and insurance card(s)
- **Homestead** - Deed, tax notice, mortgage documents and insurance info
- **Real Property** - Any mortgages, deeds, tax notices on any properties owned
- **Funeral/Burial** - Deeds for cemetery lots, prepaid contracts for burial or cremation
- **Bank Accounts** - Last three months bank statements for all accounts
- **Life Insurance Policies** - Copy of each policy and statement from each insurance company giving face value and cash value of each policy
- **Estate Planning Documents** - All documents associated with wills, trusts, powers of attorney and health care surrogates
- **Stocks, Bonds and Annuities** - Copies of original stock certificates and bonds and copies of brokerage statements for last three months. Verification of dividend income
- **Income** - Proof of all income from employment, social security, VA, retirement, pensions, unemployment, etc.
- **Nursing Home Information** - Name & address of nursing home, date of entry and last residential address prior to entry into nursing home
- **Utilities Information** - Copies of most recent electric, water/sewage and gas bills



MEDICAID and MEDICARE

Medicaid is the *state and federal* partnership that provides health coverage for selected categories of people with low incomes. Its purpose is to improve the health of people who might otherwise go without medical care for themselves and their children. Medicaid is different in every state. **Medicare** is a *federal* health insurance program for people who are age 65 or older or disabled. It is administered by the federal *Department of Health and Human Services, Centers for Medicare and Medicaid Services (CMS)*. Eligibility for Medicare is not based on the person's income or assets.

Eligibility Requirements for Programs May Include

- Be 65 years or older or disabled
- Be Medicaid eligible for the "Institutional Care Program" level-- *This level is determined by an assessment from the Florida Department of Elder Affairs (DOEA) and the Agency for Health Care Administration (AHCA)*
- Require some help with five or more Activities of Daily Living-- *Activities of Daily Living (ADL's) include: Eating, grooming, bathing, transferring in/out of bed or chair, and toileting*
- Require some help with four ADL's, *plus* require supervision or administration of medication(s)
- Require *total* help with two or more ADL's
- Have a *diagnosis of Alzheimer's* or another type of dementia and require some help with three or more ADL's
- Have a diagnosis of a degenerative or chronic nursing condition requiring daily nursing services

To get more information:

1. Statewide Helpline: 1.800.963.5337
2. Visit: <http://www.medicare.gov/>

In Love And Trust

FINANCIAL CONSIDERATIONS

It is always a good idea to check with your Elder Law attorney, the bank(s), and financial institutions before you take any actions. A Durable Power of Attorney dies when the person dies. At this time the **will** kicks into action. Be aware that a bank may freeze accounts until the estate is settled, and the court issues a legal document. Probate and other estate settlement procedures may have to be endured for many months. It is usually a good idea to wait for up to one year before removing the deceased persons name from accounts. *Remember to update your will and beneficiary designations.*

You may need to gather the following paperwork:

Bank Accounts; Certificates of Deposit; IRA's/Pension Plans; Earnings Statements; Social Security Information; House/Auto/Property Titles; Income Tax Returns; Stocks/Bonds/Mutual Funds; Insurance Policy(s); Wills; Special Trusts; Military Discharge Papers = DD-214.

Are you eligible for?

Credit Card Death Benefits; Fraternal Organization Benefits; Income Tax Refund; Life Insurance Benefits; Mortgage Insurance Benefits; Property Tax Homestead Exemption; Retirement Plan Benefits; Social Security Benefits; Unpaid Wages; Unused Vacation Time; Veterans Survivor Benefits?



*Find out if there is any liability on
the family for unpaid debts.*



GUARDIANSHIP 101

What is a Guardian?

A Guardian is a person appointed by the court to care for an incapacitated person (called a ward), and sometimes to take care of the ward's financial assets.

Who may serve as a Guardian?

Any adult resident of Florida can serve as guardian, as can certain institutions. A close relative of the ward who does not live in Florida can also serve as guardian. Persons who have been convicted of a felony or who are so ill they can't do the job cannot be appointed. If the family is able to agree on who should be the Guardian, the Court rarely rejects their choice. *You will have to take special classes in order to become a Florida Family or Professional Guardian.*

How is a person determined to be incapacitated?

Any adult may file with the court a petition to determine another person's incapacity setting forth the facts upon which they base their belief that the person is incapacitated. The court then appoints a committee of two or more health professionals, usually a physician, and a qualified lay person to examine the person and report its findings to the court. The court also appoints an attorney to represent the person alleged to be incapacitated. If the examining committee concludes that the alleged incapacitated person is not incapacitated in any way, the court will dismiss the petition. If the examining committee finds the person to be incapable of exercising certain rights, the court schedules a hearing to determine whether the person is totally or partially incapacitated. A guardian is usually appointed at the end of the incapacity hearing.

Why establish a guardianship?

If there is no valid **power of attorney** in force, then a Guardianship may be necessary to obtain access to assets such as bank accounts, public benefits, real estate, car titles, etc. The person may need special care; bills need to be paid; and in case authorities need to return the ward back to their home or facility.

For more information, visit: <http://guardianassociation.org/>



U.S. DEPARTMENT OF LABOR FAMILY AND MEDICAL LEAVE ACT

The Family and Medical Leave Act (FMLA) is designed to help employees balance their work and family responsibilities by allowing them to take reasonable unpaid leave for certain family and medical reasons. It also seeks to accommodate the legitimate interests of employers and promote equal employment opportunity for men and women.

FMLA applies to all public agencies, all public and private elementary and secondary schools, and companies with 50 or more employees. These employers must provide an eligible employee with up to 12 weeks of unpaid leave each year for any of the following reasons:

- for the birth and care of the newborn child of an employee
- for placement with the employee of a child for adoption or foster care
- **to care for an immediate family member (spouse, child, or parent) with a serious health condition**
- to take medical leave when the employee is unable to work because of a serious health condition

The Department of Labor administers FMLA; however, the Office of Personnel Management (OPM) administers FMLA for most federal employees. *Source:* <http://www.dol.gov/dol/topic/benefits-leave/fmla.htm>



A study of elderly spousal caregivers (aged 66-96) found that caregivers who experience caregiving-related stress have a 63% higher mortality rate than non caregivers of the same age.

Source: Family Caregiver Alliance

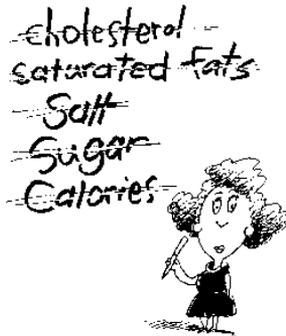
Chapter 6

WHOLE PERSON CONCEPT

Mind, Body and Spirit

Dandelions

Nutrition and Color Choices



*“The only way to keep your health
is to eat what you don’t want,
drink what you don’t like,
and do what you’d rather not.”*

--- MARK TWAIN



MIND, BODY and SPIRIT

There are seven major areas of the whole person concept. Living well with enhanced activities to nurture all aspects of our lives is the ultimate goal. These are categories of activities that can challenge the person physically, boost emotional well-being, create mental stimulation, and give purpose for the spirit.

1. **Community Activities** may include looking at the fall foliage or Christmas tree lights, dining out, family activities, and shopping. This kind of activity breaks the routine, prevents “Cabin Fever”, maintains ties with the outside world, provides opportunities to increase social ties, and gives that person a bit of excitement.

2. **Educational Activities** include playing word games, writing down thoughts, current events, intellectual pursuits, academic classes, and health care support groups. These can help the person to maintain verbal abilities, stimulates thought processes and challenges the person to stay connected with outside the world. These actions can assist persons with staying balanced in a home or facility environment.

3. **Diversional Activities** includes music, videos, movies, and other forms of entertainment. Diversional activities stimulate endorphins which increases feelings of well-being. These are helpful in speech therapy, to stimulate vocalization and communication, reduces stress, sets a calming or excited frame of mind/mood, decreases the escalation of pain, promotes enhanced rest, helps to retain remaining cognitive abilities and gives the nervous system increased positive energy.

4. **Physical, Therapeutic, and Recreational Activities** include bowling, exercise classes, walking, dancing and all kinds of motion. Participation in these activities maintains eye/hand coordination and motor skills. Provides a competitive atmosphere, promotes team spirit, exercises cognitive function, social interactions, increases feelings of belonging, improves and/or maintains range of motion, breathing, heart function, appetite, and energy level. Provides acceptable outlets for

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frustration, increases flexibility, endurance, and creates a more positive energy flow in the nervous system.

5. Social Activities include Birthday and Anniversary Celebrations, Tea Parties, and Intergenerational visits. Social Activities prevent isolation, promote a nurturing environment, meets the psycho-social needs, offers companionship, and provides a loving expression in a safe setting. The long term effects improve mood, behavior, and may enhance increased nutrition and hydration in a fun way.

6. Spiritual and Religious Activities can include attending services, prayer, nature walks, yoga classes, meditation, breath work, Bible study, and quiet reflective time. These kinds of activity improve a persons comfort levels, helps to balance behavior and mood swings, provides fellowship and offers a familiar “over-learned” memory that gives the person enhanced self-esteem.

7. Work Service and Life Skills involve persons with opportunities to participate in activities in which they can contribute their long time talents and abilities. Life Skill activities are tailored to each persons’ life-time knowledge and experiences.



DANDELIONS

The little girl parks a dandelion behind her ear. Or perhaps fixes the yellow disk into a buttonhole on her blouse. A bouquet of dandelions sets the table for tea with her dolls. She thinks a dandelion is beautiful. Her dad protests “It is a weed.” He attacks the dandelions with chemicals. The dandelions win.

Fast-forward five decades. The woman holds another weed in her hands. It is the disease Alzheimer’s. Researchers cannot eradicate the expansion of this persistent weed. In the midst of the decline the woman sees beauty. She wants to blow on the white orb as she did long ago, making a wish as the angel wings are released from the stem.

She wishes others could find the joy that remains.

Visit: www.alzsmiles.com

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NUTRITION AND COLOR CHOICES

The foods we eat, the choices we make, the availability of items, the four seasons, where you live, and other factors make a difference in our overall health. Each food item has been “issued” certain colors and tasks to make a difference in our bodies. By eating at least one food from every color - every day, we can help to promote optimum health. If you have specific needs, eat more foods from that color group.

VIOLET

Selflessness and Understanding

Cerebral and Upper Brain Functions

Lymphatic System

Foods include: Eggplant, purple grapes, raisins, passion fruit, plums, prunes, purple cabbage, purple onions, and elderberries

Herbs include: basil, heather, lavender, marjoram, mints, passionflower, rosemary, thyme and sage

INDIGO

Inspiration, Peace of Mind & Imagination

Brain, Pituitary gland, sinus, vocal cords, & lungs

Immune and Respiratory Systems

Foods include: Black soybeans, black beans, soy sauce, black olives, blackberries, boysenberries, black cherries, plums, raisins, and currants

Herbs include: Vanilla beans and violets

BLUE

Enthusiasm, Expression and Loyalty

Anti-aging and health promoting

Muscular and Skeletal Systems

Foods include: Black currants, blue grapes, blueberries, blue corn, boysenberry, black soybeans, grapes, plums, blue potatoes, prunes, and raisins

Herbs include: Borage flowers, chicory flowers, hyssop, catnip, kelp, juniper berries, and pansy

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GREEN

Healing and Heart

High in fiber - good for heart

Digestive System

Foods include: Asparagus, avocados, broccoli, celery, chives, okra, cucumber, green beans, green grapes, green peppers, green leafy vegetables, kiwi, lettuce, lime, parsley, peas, zucchini, and wheat grass

Herbs include: Rosemary, parsley, comfrey, nettles, alfalfa, tarragon, oregano, and mint

YELLOW

Happy, Warm, and Radiant

Liver, gall bladder, pancreas

Solar Plexus and Nervous System

Foods include: Golden apples, bananas, cantaloupe, corn, grapefruit, honey, lemon, vegetable oils, parsnips, pineapple, whole grains, nuts, yellow pepper, yams, and yellow squash

Herbs include: anise, chamomile, cinnamon, dill, lemongrass, saffron, evening primrose, and marigold

ORANGE

Passion, Optimism, and Tolerance

Antioxidants - vitamin C and carotenoids

Reproductive and Neuro-endocrine Systems

Foods include: Almonds, apricots, winter squash, carrots, cantaloupe, dates, mangoes, nectarines, oranges, papayas, peaches, persimmons, pumpkins, sweet potatoes, tangerines, walnuts and eggs

Herbs include: Ginger, coriander, cumin and paprika

RED

Energetic and Physical

Adrenals, colon, gonads, red blood cells, and legs

Circulatory System

Foods include: Red apples, beets, cherries, cranberries, red currants, radish, raspberries, kidney beans, red cabbage, red currants, red pepper, red plum, rhubarb, strawberry, tomatoes, watermelon and whole wheat.

Herbs include: Cayenne, hibiscus, and rose

R_x

AXONA is Accera's (a privately held biotechnology company) new product for people with mild to moderate Alzheimer's. Available in the U.S. by prescription only, Axona is marketed as a **MEDICAL FOOD**. This means it was not subject to FDA pre-market review and approval. Axona is designed to address the "*hypo metabolism*," or reduced use of glucose, seen in some areas of the brains of people with Alzheimer's. Glucose is the brain's source of energy. Axona is formulated as a powder, and is mixed with water to make a once-a-day drink. Axona is available by prescription, in the U.S. The product is **not** covered by most insurance plans or by Medicare, but is *currently* reimbursed as part of TRICARE military health benefits.



To read about putting other products, including coconut oil in the Alzheimer's patients' diet, see these articles:

- <http://www.tampabay.com/news/aging/article879333.ece>
- Dr. Mary Newport's Web site: www.coconutketones.com
- Accera's information on Axona: www.accerapharma.com
- The Alzheimer's Association statement on medical foods: www.alz.org/national/documents/statements_medicalfoods.pdf
- Caregiver discussions about coconut oil, MCT oil and Axona can be found at <http://alzheimers.infopop.cc/eve>



One of the most powerful pieces of artwork that touched my soul was done by a person who had Alzheimer's. It is a picture of a black and white cat saying: "ME - OW."

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Chapter 7

END OF LIFE

Final Goodbyes and End of Life Issues
Peace, Comfort, Hope and Endings
A Special Story



*“Why is it that we
rejoice at a birth and
grieve at a funeral?
It is because we are not
the person involved.”*

--- MARK TWAIN

FINAL GOODBYES AND END OF LIFE ISSUES

End of life issues were at the center of global headlines in 2005. The Terri Schiavo case sparked debates and her unusual set of circumstances prompted people to think about what they would want if they, too, were in such a desperate medical situation. Many people rushed to draw up living wills. Families picked sides and the unpleasant public spectacles and discussions got very ugly. The case also led to furious debates over the proper role of government in life-and-death decisions; and whether Congress violated principles of limited government and deference to individual states by getting too involved.

*Before we are sick, we should start asking questions, gathering information, making decisions, and authorizing a trusted person to act on our behalf as our Health Care Surrogate. This is critical information for your family and health care providers to know. Have discussions that include all members of the family that may be asked to make life or death decisions. It is hard to lose a Loved One, but it may be harder later to mend family disagreements. Denial of the harsh reality of an end of life situation is common. Pre-Conversations often simply do not happen. The message here is to talk things out in a rational way *before* they get out of control, full of drama and create family feuds.*

*Specific documents may need to be signed and notarized in order for the medical staff, EMS, health care workers or Hospice team to obey the laws of your state. **Questions to ask can include the following list:***

- Q.** Does your Loved One want aggressive care?
- A.** Have they signed specific documents such as: A **Living Will** and/or **Do Not Resuscitate** (DNR) Order that specifically states that Feeding tubes, CPR, and/or antibiotics are **not** to be surgically inserted, performed, injected, or administered into their body?
- Q.** Are you the one who was **chosen** to make decisions and act on their behalf?
- A.** **Honor** their wishes. Allowing a person a continued sense of dignity and respect and fulfillment of their wishes speaks silent volumes.
- Q.** Is this person **pre-enrolled** and accepted in a Brain Bank program?
- A.** Call the brain bank, and they will help with the arrangements.

What would you want done if the situation involved your wishes? Making choices based on our personal life experiences, hearing what others have done in similar circumstances, and talking things out in family meetings may help to ensure that your wishes are carried out. Most states honor the legal rights and documents of your home state, if death occurs while traveling.

PEACE, COMFORT, HOPE AND FINAL GOOD BYES

Our Loved Ones have suffered. We have suffered with them. The time to let go is now. We often need to tell them we will be ok without them here on earth, in order for them to be at rest. We continue to offer comfort and love. We can sit by their side, and make sure their last days are as peaceful as possible. We have all heard stories about persons who have looked up, and started talking to (unseen to us) angels or persons who have been long dead. They speak of the bright light and you just *know* that they are preparing to go “home”. Our final task for our Loved One is to allow them the peace, comfort and hope of ending their journey here on earth with dignity. They have had a lifetime of lessons in preparation for this final exam.

Hospice, Hospital or Nursing Home The staff will know what to do and help you make calls. Is there any jewelry that needs to be removed? Is there an organ donation or brain autopsy request? Do they have a pre-need contract with a funeral home?

Many things may happen when a Loved One passes away. Certain tasks need to be performed. Sorting through the legal, financial, personal effects, last wishes and raw emotions is very hard. Giving ourselves permission to cry, feel pain, mourn the loss and re-adjust will take time. We may not be thinking clearly, have unfinished business or even old hurts with our Loved One. Knowing who to call and what to do when we are in a state of panic and shock can be so helpful. These are some ideas for the caregiver’s pathless path. We may feel guilty for doing or saying something in anger the last time we saw them alive. Remember...your Loved One has forgiven you. It may be time that you forgave yourself. Sometimes we have to do some “Soul Work” which is a willingness to connect with what is dark, deep and unpleasant in order to start our healing journey. There are many books, groups and resources to help you with the grief and mourning phases that you may experience after your Loved One has passed.

Important Note Taking

Keep a log of every call you make to: Company; Organization; Person you spoke with; Date/Time; and note the Summary of conversation(s). Make duplicate copies of every paper, form, and document you send to insurance and other companies and mail everything *Certified Mail - Return Receipt*. When our Loved One passes away, we are in shock and grief. We may be functioning on pure emotional energies. We know we have to do certain things, but forget who we spoke with or what they said we had to do...so, this is just a reminder to take notes for future reference.

Calls You May Need To Make After Your Loved One Dies

Funeral Home, Cemetery, Family Members, Friends, Clergy, Hospice Veteran's Organizations, Day Care Program, Employer / Employee's Insurance Company(s) and the Social Security Administration to prevent anyone else from using deceased person's number.

Funeral Home May Ask For the Following Information and Items

Social Security Number; Date and Place of Birth/Death; Names of Family/Companions; Parent's names: First and Last with Mother's Maiden Name; Religious Affiliation; Education; Occupation; Military Service; Member of any veterans or fraternal Organizations/Clubs; Favorite Charity; Recent Photo; Bible; Clothing; Jewelry; and Glasses.

Final Resting Place and Special Requests

Bible or Book Passage(s); Flowers; Pallbearers; Pictures; Music Cemetery/Mausoleum/Columbarium; Family Plot; Scatter Cremains/ Urn; Out of State Burial; Headstone/Marker

Fellowship Meal Could Take Place At

Church Hall; Favorite Restaurant; Funeral Home Special Room Home; Service Organization Hall

The Death Certificate - Short and Long Versions

The Death Certificate has to be signed by a physician and registered with the Health Department. This will take several days to process. Order a minimum of 3-5 certified copies. If there are numerous financial transactions to complete, order the short form which will state: "*Without cause of death*".

A Florida Death Certificate "*With Cause of Death*" is confidential by Florida Law and most financial institutions do not require this information. Often a company just wants to see an original or certified copy, and if you enclose a self-addressed stamped envelope, they will return the original to you.

Send Thank You Cards Or Make Calls To...

Clergy/Hospice; Nursing Home/Assisted Living; Family/Friends; Food/Flower Donations; Charity Donations; Expressions of Sympathy
Acknowledge that these tasks may take a month or more to complete.

Endings are hard to face alone, please reach out for support and seek information along the journey. You are not alone.

SPECIAL RESOURCES:

1. **National Institute on Aging** Free Booklet: **End of Life: Helping with Comfort and Care** Visit: www.nia.nih.gov 1.800.222.2225
2. **PEACE AT LAST: Stories of Hope and Healing for Veterans and Their Families** (2009) Deborah L. Grassman; ISBN# 978-0-918339-72-0
3. Dr. Alan D. Wolfelt, **The Center for Loss and Life Transition** Visit: <http://www.centerforloss.com/> 1.970.226.6050



Taking Time to Sit with the Hurt

This incredible sadness comes over me at times.

I just stay with it.

I say 'Good, I'm sad, I need to be sad.'

*I just let it just hurt me inside for awhile
and then I'm over it.*

--- CAREGIVER QUOTE



A Special Story

One of my caregivers always came to group late. Shelly would peek in the door to see if we had started the group yet -- as if to ask permission to enter. His wife had early onset Alzheimer's and was only in her 50's when this cruel disease process started. He was at the nursing home every single evening and brought her a Wendy's Frosty. He recently was diagnosed with cancer and died.

A few weeks later, I was speaking with his son. He asked me if I knew that dad was chronically late for events. I said "Oh yes." He said, "Do you want to hear something funny?" I said "Of course." The son said: "Dad was late for his own funeral." I said "What?" He said they had to send dad back to Indiana on a plane. In Charlotte, there was a connecting flight. They bumped him because of weight limitations. So when he finally arrived in Indianapolis, he was late for the services which were scheduled to begin at 6PM.



Final Note:

*Shelly's wife Judy died two weeks later.
She KNEW spiritually that he was no
longer here in the physical form.*

Chapter 8

RESOURCES AND INFORMATION

Florida and National Veterans Information
Pinellas County Veterans Service Offices
Adult Day Care and Respite Care
Long-Term Care Community Diversion Program
Helpful Information
Handicap Plates or Placard
Florida Telecommunications Relay, Inc.
Handy Phone Numbers
Websites
Suggested Reading, Listening and Viewing
Age with Confidence Podcasts



*"To love a person is to learn the song
that is in their heart,
and to sing it to them
when they have forgotten."*

--- ANONYMOUS



FLORIDA AND NATIONAL VETERANS' INFORMATION

The **Florida Department of Veterans' Affairs** (FDVA) is a state agency created to assist all present and former members of the U.S. Armed Forces and their dependents and survivors in preparing claims for and securing such compensation, hospitalization, vocational training, employment assistance and other benefits or privileges they may have earned. All services rendered by FDVA are *without charge* to the claimant.

Florida Veterans Nursing Homes and Assisted Living

FDVA also provides long-term health care services through five veterans' nursing Homes (*Daytona Beach, Land O' Lakes, Pembroke Pines, Springfield, and Port Charlotte*) and one assisted living facility.

Admission

Basic admission requirements for all state veterans' homes in Florida include an honorable discharge, Florida residency for one year prior to admission, and certification of need of assisted living or skilled nursing care as determined by a VA physician. For additional admission or financial information, contact the FDVA at 727.518.3202 x562.

Certification of Discharge or Separation

The Clerk of the Circuit Court shall record, without cost, certificates of discharge or separation from the Armed Forces.

Disabled Parking Permit

An honorably discharged Florida veteran who has been determined by the VA or the Department of Defense to have a service-connected disability rating of 50% or more and has a signed medical statement of qualification -- verifying a permanent mobility problem, is eligible for a Disabled Parking Permit. (FS 320.0848(2)(e))

Burial, Headstone and Marker Information

1.800.697.6947 or *website:* www.cem.va.gov

Where to Find Help

FDVA Admin. Offices
11351 Ulmerton Rd. #311K
Largo, FL 33778-1630
727.518.3202

FDVA Benefits and Assist
9500 Bay Pines Blvd. #214
Bay Pines, FL 33744
727.319.7400

Veterans Benefits
1.800.827.1000
www.vba.va.gov



PINELLAS COUNTY VETERANS SERVICE OFFICES

The Pinellas County Veterans Service Offices assist veterans, their widows, and their eligible dependents with a variety of needs:

- Developing claims with the Veterans Administration to procure rightful benefits
- Obtaining discharge papers, marriage, divorce, death, birth certificates; doctor reports
- Filing appeals with the Veterans Administration

They offer guidance and assistance in applying for and obtaining VA benefits from various levels of government, primarily the Department of Veterans Affairs. This includes VA Health Care. They do not grant or deny claims. That authority rests with the federal agency that administers the program. They provide guidance and assistance in upgrading military discharges, and assist in obtaining copies of military personnel and medical records. The department also visits clients at home (or in nursing homes) through its Outreach Program. This program is especially helpful to older veterans and their surviving spouses. The Veterans Administration (VA) may allow your Loved One to stay in a facility for 13 days of *respite care* every six months. There are certain eligibility requirements and there may be waiting lists.

Main Office

2189 Cleveland St - Suite 201

Clearwater, FL 33765

727.464.8460 / TDD 727.464.4388

Mon-Fri 8am-5pm (Call for appointment)

St. Petersburg Office

501 1st Avenue N. - Suite 517

St. Petersburg, FL 33701

727.582.7828

Mon-Fri 8am-5pm (Call for appointment)

Tarpon Springs Office

Wednesday's only 8am-5pm

WorkNet Pinellas – Tarpon Springs Office

38500 US Hwy 19 North

Tarpon Springs, FL 34689 727.324.2848



ADULT DAY CARE AND RESPITE CARE

Adult day care and short-term *respite* care are becoming more affordable and easier to find. Caregivers are recognizing that they need a break. Seeking out what is available in your community is another important step on this journey. There are also day programs that are administered through county or other local sources. Private assisted living and nursing homes may also offer day programs. Home-health agencies have trained professionals that will come into your home while you run errands or just take a necessary nap! Socialization with others who have the same disease can allow your Loved One to stay at home much longer. S/he is happier, you have scheduled breaks from caregiving and there is something to look forward to. A Win/Win situation!

LONG-TERM CARE COMMUNITY DIVERSION PROGRAM

The Diversion Program is designed to provide community-based services to people who would qualify for Medicaid nursing home placement. Services provided include long-term care services, and Medicaid-covered medical services. Individuals that meet the following criteria are eligible to receive services under the Nursing Home Diversion Waiver:

- Age 65 and over
- Dually eligible for Medicaid and Medicare Parts A & B
- Live in the authorized program areas
- Be determined by the CARES (Comprehensive Assessment Revue and Evaluation for Long-Term Care Services) unit at the Department of Elder Affairs to be at nursing home level of care and meet one or more established clinical criteria

For more information call the CARES Central # 1.850.414.2000 or inquire by e-mail at: information@elderaffairs.org

Note: A person may meet the criteria and be eligible, but program openings may not be available and there may be a waiting list.

The *Dementia* Caregiver's Little Book of Hope www.dementiacaregiverresources.org

HELP!

HELPFUL INFORMATION

National Crisis Line - Help Line USA - 24/7
1-866-334-HELP (1.866.334.4357)

The Florida Department of Children & Families (DCF) has a toll-free number for Medicaid, food stamps, nursing home and other assistance programs. **1.866.762.2237**



The “211” system will eventually be in place in the entire state of Florida. By calling “211” you can find help in your county for *hurricane disaster evacuation(s)*, information about *special programs*, *referrals to agencies*, *suicide/crisis intervention*, and other resources you may need.

National Long-Term Care Resource Center - Ombudsman

An Ombudsman is an advocate for residents of nursing homes, board and care homes, and assisted living. Ombudsmen provide information about how to find a facility and what to do to get quality care. They are trained to resolve problems. If you want, the ombudsman can assist you with complaints. However, unless you give the ombudsman permission to share your concerns, these matters are kept confidential.

Under the federal Older Americans Act, every state is required to have an Ombudsman Program that addresses complaints and advocates for improvements in the long term care system. To find the ombudsman nearest you, contact the Ombudsman office. **1.202.332.2275**

Every Florida County has a **Special Needs Registry**. The telephone numbers of these offices are listed in the Florida Department of Elder Affairs (DOEA) *Disaster Preparedness Guide for Elders*, found online at: <http://elderaffairs.state.fl.us/does/english/disaster.html> or call **211**.

The Academy of Florida Elder Law Attorneys (AFELA) is a non-profit association which assists lawyers, bar organizations, and others who work with older clients and their families. Established in 1993, AFELA provides a resource of information, education, networking, and assistance to those who work with the many specialized issues confronting the elderly and the disabled. **1.850.656.8848**



FTRI FLORIDA TELECOMMUNICATIONS RELAY, INC.

Dementia Caregiver Resources, Inc. is proud to be a relay friendly business through FTRI. This means that we are a business partner committed to helping people who are deaf, hard of hearing, deaf/blind, or speech impaired. We can provide telephone access and support for consumer and business interactions. By dialing “711” you can access this free service.



HANDICAP PLATES OR PLACARD

You or your Loved One may be eligible for handicap plates or hanging placard for your vehicle. Certain requirements must be met and Florida Form **HSMV 83039** must be signed by an M.D., D.O.; D.C.; Division of Blind Services; Florida Dept. of Education, or Adjudication Office of Veterans Affairs. Visit: http://www.flhsmv.gov/dmv/disabled_pkg.html



Hard of Hearing, Deaf, Deaf/Blind, and Speech

Impaired individuals can take advantage of the FTRI equipment distribution (**FREE CLARITY PHONES**) program in the State of Florida. Call **1.800.222.3448** to find the nearest phone equipment service center for your area of Florida.

TELEPHONE



HANDY PHONE NUMBERS

- **Alzheimer's Disease Edu. & Referral**
1.800.438.4380
- **Alzheimer's Foundation of America**
1.866.232.8484
- **American Parkinson Disease Association**
1.800.223.2732
- **Elder Helpline**
1.800.963.5337
- **Florida Abuse Hotline**
1.800.96. ABUSE (1.800.962.2873)
- **Florida Brain Bank Program**
1.800.330.1910
- **Florida Telecommunications Relay**
1.800.222.3448 (Free Phones-deaf/speech)
- **Lewy Body Dementia Association**
Caregiver Helpline: 1.800.539.9767
- **National Academy Elder Law Attorneys**
1.520.881.4005
- **National Alzheimer's Association**
1.800.772.3900
- **National Area Agency on Aging**
1.202.296.8130
- **National Association of Professional Geriatric Care Managers**
1.520.881.8008
- **Senior Living Guide**
1.888.604.8433
- **The Alzheimer's Store**
1.800.752.3238



Join the **DO NOT CALL LIST** 1.800.435.7352

Residential, mobile or paging device telephone numbers can be included on this list. Visit: <http://www.800helpfla.com/aboutus.html>



WEBSITES

- **Alzheimer's Education & Referral**
www.alzheimers.org/ADEAR
- **Alzheimer's Foundation of America**
www.alzfdn.org
- **American Parkinson Disease Association**
www.apdaparkinson.org/
- **Center for Loss/Dr. Alan Wolfelt**
www.centerforloss.com
- **Dementia Caregiver Resources, Inc.**
www.dementiacaregiverresources.org
- **Dept. Health & Human Services**
www.dhhs.gov/
- **Florida Area Agencies on Aging**
www.elderaffairs.state.fl.us/doea/english/aaa
- **Guardian Association Pinellas**
<http://guardianassociation.org/>
- **Lewy Body Dementia Association**
<http://www.lbda.org/>
- **National Academy of Elder Lawyers**
www.naela.org/
- **National Alliance for the Mentally ill (NAMI)**
<http://www.nami.org/>
- **National Alzheimer's Association**
www.alz.org/
- **National Association of Professional Geriatric Care Managers**
<http://www.caremanager.org/>
- **National Family Caregivers Association**
www.nfcacares.org/
- **National Institute on Aging** www.nia.nih.gov
- **National Institute of Health**
www.nlm.nih.gov/medlineplus/alzheimers
- **No Sales Solicitation - Phone calls**
www.800helpfla.com/nosales.html
- **Sean W. Scott, Elder Law Attorney**
www.virtuallawoffice.com/
- **State of Florida** www.myflorida.com
- **The Tangled Neuron** www.tangledneuron.info/
- **Veteran's Affairs** www.va.gov/healtheligibility/

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SUGGESTED READING, LISTENING and VIEWING

- **A PLACE CALLED CANTERBURY: *Tales of the New Old Age in America*** (2008) Clendenin, Dudley; Viking Press; ISBN# 9780670018840
- **ALWAYS MY GRANDPA: *A Story for Children about Alzheimer's Disease*** Scacco, L. (2005) (ages 6-10) Magination Press/American Psychological Association; ISBN# 9781591473121
- **ALZHEIMER'S ACTIVITIES: *Hundreds Of Activities For Men And Women With Alzheimer's Disease And Related Disorders*** (2001) Rayve Productions Inc. B. J. Fitzray; ISBN# 1877810800
- **ALZHEIMER'S FOR DUMMIES** (2003) Patricia B. Smith, Mary M. Kenan, Mark Edwin Kunik, Leeza Gibbons, ISBN# 0764538993
- **ALZHEIMER'S FROM THE INSIDE OUT** (2007) Richard Taylor; ISBN# 1932529233
- **EXERCISE FOR FRAIL ELDERS** (2003) Elizabeth Best-Martini, Kim A. Botenhagen-Digenova; ISBN# 10: 0736036873
- **GRANDPA, DO YOU KNOW WHO I AM?** (2009) Home Box Office (HBO) 1.866.316.4814 www.hbo.com/alzheimers
- **I CANT CHEW COOKBOOK** (2003) J. Randy Wilson; ISBN# 13: 9780897934008
- **LIVING WITH LEWY BODY E-BOOK**
<http://livingwithlewybodyebook.blogspot.com/>
- **MAYO CLINIC ON ALZHEIMER'S DISEASE** (2001) Mayo Clinic (Corporate Author) Ronald C. Petersen, MD (Editor) ISBN# 0801868343
- **MEASURE OF THE HEART: *A FATHER'S ALZHEIMER'S, A DAUGHTER'S RETURN*** (2008) Mary Ellen Geist ISBN# 100446580929
- **PEACE AT LAST: *Stories of Hope and Healing for Veterans and Their Families*** (2009) Deborah Grassman; ISBN 978-0-918339-72-0
- **THE OFFICIAL PATIENT'S SOURCEBOOK ON DEMENTIA WITH LEWY BODIES** (2002) James N. Parker; Philip M. Parker (Editors) ISBN# 0597829977
- **RIDING A ROLLERCOASTER WITH LEWY BODY DEMENTIA**
Helen and Jim Whitworth <http://lbd.whitworth2.com/buybooklbd.html>
- **STILL ALICE** (2007) Lisa Genova, Ph.D.; ISBN# 139780595440092

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- **TALKING TO ALZHEIMER'S: *Simple Ways to Connect When You Visit with a Family Member or Friend*** (2001) Claudia J. Strauss, ISBN# 1572242701
- **THE COMPLETE GUIDE TO ALZHEIMER'S-PROOFING YOUR HOME** (2000) Mark Warner; Ellen Warner ISBN-13: 978-1557532022
- **THE FORGETTING: *Alzheimer's Portrait of an Epidemic*** (2002) David Shenk; Anchor Books, NY, ISBN# 0385498381
- **THE 36 HOUR DAY** (1999) Nancy Mace; Peter Rabins, MD ISBN# 0801861497
- **THERE'S STILL A PERSON IN THERE: *The Complete Guide to Treating and Coping with Alzheimer's*** (1999) Perigee Books; Michael Castleman, ISBN# 0399526358
- **VALIDATION BREAKTHROUGH** (2002) Naomi Feil; ISBN# 1-878812-81-5
- **WHAT'S HAPPENING TO GRANDPA?** (2004) Maria Shriver, Sandra Speidel (Illustrator) Little, Brown; ISBN# 0316001015
- **WHAT IF IT'S NOT ALZHEIMER'S: *A Caregiver's Guide to Dementia*** (2003) Lisa Radin (Editor) Prometheus Books, ISBN# 1591020875
- **100 Questions & Answers About Parkinson Disease** (2003) Abraham Lieberman, M.D.; Marcia McCall ISBN# 0763704334
- **Living with Memory Loss Resource Directory and Patient Guide** (2009) (Tampa Bay) Mona Johnson <http://www.tangledneuron.info/>

VIDEO'S

These are very powerful video's to watch

- **There is a Bridge**
<http://www.memorybridge.org/>
- **What is That?**
<http://www.youtube.com/watch?v=86pje8sF6qA>
- **HBO - The Alzheimer's Project**
<http://www.hbo.com/alzheimers/>
- **Complaints of a Dutiful Daughter**
<http://www.wmm.com/filmcatalog/pages/c127.shtml>

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Hosted by: Florida Elder Law Attorney **SEAN W. SCOTT**

With Co-Host: Karen (Karle) Truman, Ph.D.

The **AGE WITH CONFIDENCE PODCAST** features discussion and commentary on all aspects of the aging process and getting older. Whether you are old, getting older, or know someone who is, this podcast will help guide you through the perils and pitfalls of aging. Issues discussed include public benefits, social security, Medicare, Medicaid, Veterans benefits, caregiving, and aging resources. Available 24/7 **FREE** on [itunes](#)

These are some of the episodes that are currently available:

1. So Its' Parkinson's - Now What?
2. For Deposit Only - All About the Brain Bank
3. Hospice - Everything you ever wanted to know Parts 1 & 2
4. Aging Vision
5. Providing Care the Neighborly Way
6. Now Hear This
7. A Better Way To Get Better
8. Mental Health in Aging
9. Lewy Body Disease Primer
10. Florida Council on Aging
11. Making Tired Eyes Smile
12. Of Mice and Memory - Forgetting to Remember
13. Geriatric Care Management 101
14. New Uses for Home Health Care
15. Law Enforcement Resources
16. Comprehensive Neuroscience
17. Watching Your Dollars and Cents
18. Pharmaceutical Grade Jelly Belly's
19. Special Edition - Medicaid Live!
20. Think Differently - It's Never Too Late to Meditate
21. The Tangled Neuron

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Chapter 9

FACTS AND REFLECTIONS

Famous Faces of Alzheimer's and Parkinson's
Did You Know?
Those Four Pesky Emotions
Reflections for the Journey



*“When I was younger
I could remember anything,
whether it happened or not.”*

--- MARK TWAIN



FAMOUS FACES OF ALZHEIMER'S AND RELATED DISORDERS

- William J. Bell *Soap Opera Writer* (1927-2005)
- Charles Bronson *Actor* (1921-2003)
- Johnny Cash *Country singer* (1932-2003)
- Perry Como *Singer* (1912-2001)
- Aaron Copland *Composer* (1900-1990)
- Walter Cronkite *Journalist* (1916-2009)
- Benjamin O. Davis Jr. *1st Black General USAF* (1913-2002)
- James Doohan *Scotty on Star Trek* (1920-2005)
- Ralph Waldo Emerson *Essayist and Poet* (1803-1882)
- Peter Falk “Columbo” *Actor* 1927
- Michael J Fox *Actor* 1961
- Arlene Francis *Actor* (1907-2000)
- Estelle Getty *Actor* (1923-2008)
- Barry Goldwater *Senator* (1909-1998)
- Billy Graham *Evangelist* 1918
- Woody Guthrie *Folksinger* (1912-1967)
- William Hanna *Cartoon Director* (1910-2000)
- Rita Hayworth *Actor* (1918-1987)
- Katherine Hepburn *Actor* (1907-2003)
- Charlton Heston *Actor* (1924-2008)
- Jack Lord *Actor* (1920-1998)
- Douglas MacArthur *General U.S. Army* (1880-1964)
- Chairman Mao Tse Tung *Chinese Leader* (1893-1976)
- Burgess Meredith *Actor* (1908-1997)
- Vincente Minnelli *Director* (1903-1986)
- Muhammad Ali *Boxer* 1942
- Rosa Parks *Civil Rights Pioneer* (1913-2005)
- John Paul II *Pope* (1920-2005)
- Pauline Phillips *Dear Abby* 1918
- Otto Preminger *Director* (1906-1986)
- Maurice Ravel *Composer* (1875-1937)
- Ronald Reagan *Actor and President* (1911-2004)
- Sugar Ray Robinson *Boxer* (1921-1989)
- Norman Rockwell *Painter* (1894-1978)
- Margaret Thatcher *Former UK Prime Minister* 1925

“*What we cannot cure ~ We must endure*” CHARLTON HESTON

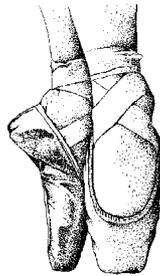


DID YOU KNOW...?

- As many as 5.3 million people in the United States are currently living with Alzheimer's
- There are an estimated 18 million people in the *world* with a form of dementia
- 10 million *baby boomers* will develop Alzheimer's
- Every 70 seconds, someone develops Alzheimer's
- Alzheimer's is the sixth-leading cause of death
- The direct and indirect costs of Alzheimer's and other dementias to Medicare, Medicaid and businesses amount to more than \$148 billion each year
- 9.9 Million people are unpaid caregivers
- The number of Alzheimer's cases is expected to *triple* to approximately 16 million by 2050
- African and Hispanic Americans may have a *higher* risk than Caucasian Americans
- Alzheimer's disease occurs *less* frequently in the Native American Crees and Cherokees and in Asians than in the general American population
- The most common risk factors for developing Alzheimer's are *age* and *family history*
- The *environment* and *early life* experiences may play a role in the development of Alzheimer's
- Some *viruses* – like the cold sore (Herpes Simplex Type 1) may interact with a gene that raises the risk of developing Alzheimer's
- Persons who have *Down's syndrome* develop a type of dementia that has the same clinical and neuro-pathologic characteristics of Alzheimer's, the difference is the early age of onset – 40's-50's
- Alzheimer's disease causes 50-60% of all dementias
- Lewy Body Dementia is a progressive brain disease and the second leading cause of degenerative dementia in the elderly.
- Pick's Disease or Frontotemporal dementia (FTD) is being diagnosed more frequently and can run in families

- People with *diabetes* have increased risk of “mild cognitive impairment” (MCI) – this may be an early transitional form of Alzheimer’s
- That *losing weight* may be an early indicator of developing Alzheimer’s
- That the brain shows signs of change *years* before symptoms of memory loss show up
- That *lonely, never married and widowed* persons are *twice* as likely to be diagnosed with Alzheimer’s
- That *stress* plays a significant role in the progression of Alzheimer’s

This kind of information guides us in creating life-long plans for a healthy lifestyle. This includes taking care of early growth and development, nutrition, education, socialization, environment, disease management, and stress reduction. Excellent physical, emotional, and spiritual self-care should be a primary goal throughout life.



*Life is not about waiting
for the storm to pass,
It's about learning how
to dance in the rain.”*

--- ANONYMOUS



THOSE FOUR PESKY EMOTIONS

The four major emotions which give us the most trouble are:

1. **ANGER**
2. **FEAR**
3. **ANXIETY**
4. **DEPRESSION**

We can help ourselves when we understand that we are not our thoughts. We often have been conditioned over the years to react in certain ways which have become our habits. Releasing old negative thought patterns and traumatic memories may be a good way to start changing and creating a brand new personal growth path.

In our current complicated lives, some good questions to ask are:

1. How can I look at this situation in a more rational way?
2. Is there a specific action plan you can take?
3. Is my anger/grief/fear/anxiety/depression causing me harm?
4. Am I harming or hurting others with my behavior(s)?
5. How is this serving me?
6. Is this a lifetime pattern?
7. Can I change with help?

Just knowing that there are supportive systems (i.e.: *respite care, support groups, grief counseling, medications, meditation, and other types of help*), can lift the caregiving burden. You are not alone on this journey down the pathless path.



THE SERENITY PRAYER

*“God grant me the serenity to
Accept the things I cannot change,
Courage to change the things I can,
and the Wisdom to know the difference.”*

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REFLECTIONS FOR THE JOURNEY



*By three methods we may learn wisdom:
First, by reflection, which is noblest;
Second, by imitation, which is easiest; and
Third by experience, which is the bitterest.*
--- Confucius



*“Life belongs to the living, and
he who lives must be prepared for changes.”*
--- JOHANN WOLFGANG VON GOETHE



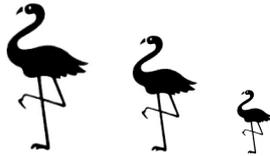
*Shakespeare “I fear I am not in my perfect mind. Methinks I
should know you and know this man; yet I am
doubtful; for I am mainly ignorant - What place this is;
and all the skills I have - Remembers not these
garments; nor I know not -
Where I did lodge last night.
Do not laugh at me”*

--- WILLIAM SHAKESPEARE (1605) KING LEAR, ACT IV, SCENE 7
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*“Do all the good you can.
By all the means you can
In all the ways you can
In all the places you can
To all the people you can
As long as you can”*

--- JOHN WESLEY



As you continue your journey our wish is that you will embrace the Three Graces. They will serve you well on the pathless path.

- 1. Tenderness*
- 2. Generosity*
- 3. Respect*

Light for the Journey - Courage for the Soul



Karen

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Sean W. Scott

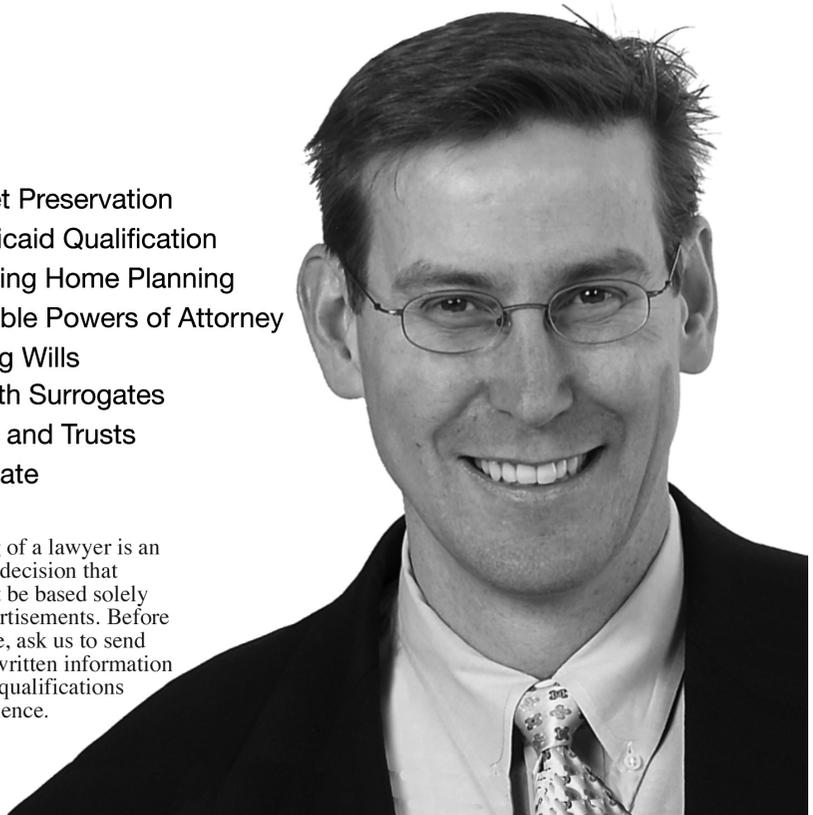
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- Medicaid Qualification
- Nursing Home Planning
- Durable Powers of Attorney
- Living Wills
- Health Surrogates
- Wills and Trusts
- Probate

The hiring of a lawyer is an important decision that should not be based solely upon advertisements. Before you decide, ask us to send you free written information about our qualifications and experience.



*“Dr. Karen (Karle) Truman’s book, ‘**The Dementia Caregiver’s Little Book of Hope**’, provides easy-to-understand information as well as another level of support for caregivers of a loved one with dementia. Karen teaches us that there are a wide variety of support systems available (i.e. support groups, respite care, grief counseling, medications, and other types of help) that can lift the care giving burden, and that no caregiver needs to be alone on this journey.*

--- **RONNIE GENSER** - The Lewy Body Dementia Association

*‘**The Dementia Caregiver’s Little Book of Hope**’ is the right book at the right time! It offers families generous resources and helpful details. This one small book is full of up to date and valuable information in support of caregiver’s needs. Karen (Karle) Truman is a Dementia Specialist whose incredible spirit and devotion to families puts her in a class of her own.*

--- **PEGGY CONNELLY** - National Director Dementia Services and Programs

*‘**The Dementia Caregiver’s Little Book of Hope**’ is a great resource and is an unusual combination of practical, spiritual and just fun advice.”*

--- **MARGARITA NUNEZ, M.D.** - Medical Director and Principal Investigator - Comprehensive NeuroScience St. Petersburg, Florida

*“Dr. Karen (Karle) Truman puts the “in” in info. ‘**The Dementia Caregiver’s Little Book of Hope**’ is my favorite resource for caregivers. It is clear, concise and easy to access. Every caregiver should have this guide.”*

--- **SEAN W. SCOTT, Esq.** Elder Law Attorney

