Alzheimer's Aid Society
OF NORTHERN CALIFORNIA

"THE BLUE BOOK"

2016 Edition

Forget-Me-Not

Caring & Sharing
Since 1981

A PRACTICAL GUIDE FOR ALZHEIMER'S CAREGIVERS

Our Mission:

We exist to provide support, education and compassion to patients and caregivers throughout the journey of Alzheimer's Disease, to support medical research, and to promote public awareness.

The Alzheimer's Aid Society of Northern California is a Non-Profit, Tax-Deductible 501(c)(3)corporation

Federal ID Number: 94-2721961

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OF NORTHERN CALIFORNIA

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A Member of
AFA®
ALZHEIMER'S FOUNDATION OF AMERICA

Alzheimer's Disease

Alzheimer's Disease was first discovered in 1906 by a German doctor named Alois Alzheimer. It is a disorder of the brain, causing damage to brain tissue over a period of time. Alzheimer's accounts for more than half of all organically caused memory loss. Age is the greatest risk factor. Alzheimer's affects almost 50% of all persons over age 85. At present, the cause of Alzheimer's is not fully understood, and researchers strive to find a cure. The disease progresses for up to twenty-five years before death.

The disease develops very slowly with primary symptoms of short-term memory loss and mild disorientation. These symptoms worsen over time. As the disease progresses, additional cognitive problems appear and behavioral or personality changes are often present.

The Importance of Early Diagnosis

Alzheimer's is diagnosed by testing for, and excluding, other conditions that can cause similar symptoms. It is an essential process, since some of these conditions can be treated or cured. If the final diagnosis is indeed Alzheimer's, then there are important steps to be taken. Medications can give the patient valuable years of independence and improve qualify of life.

Early Symptoms Of Alzheimer's Disease

Problems with Recent Memory
Forgetfulness that is interfering with day to day independence and the quality of life.

Disorientation of Time and Place
Losing sense of time passing, becoming confused in familiar settings, getting lost when driving.

Difficulty Performing Familiar Tasks
Problems in completing all the steps in a common task such as setting the table or any multi-step task. Difficulty balancing a check book or maintaining organization.

Problems With Language
Struggling to find common words, especially nouns. Losing train of thought in conversation.

Possible Changes in Mood, Personality, and Initiative
Withdrawing from social situations, inflexibility, frustration or anger, mood changes.

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Our History

THE ALZHEIMER'S AID SOCIETY OF NORTHERN CALIFORNIA

The Alzheimer's Aid Society was founded in 1981. At that time very little was known about the disease as it had not yet become the "household word" it is today. The Society began as a single support group for caregivers in a Sacramento living room. We existed at that time to provide support and education for the caregiver. Today we provide more than forty support group meetings throughout Northern California every month.

Our first Caregiver Conference was held at American River College in 1982, and our partnership with the Gerontology Program at ARC continues to this day. Dr. Barbara Gillogly, the Department Chair, has written many of the excellent articles you will find in this publication. Mini Seminars are offered in many of our outlying counties.

Beginning in the mid 80's, The Alzheimer's Aid Society began providing training to professional caregivers, medical personnel, law enforcement, and first responders. This paved the way in our communities for better understanding and fair treatment of persons with dementia.

As the 90's arrived, advancements in diagnostics and public awareness made it possible for patients to be diagnosed much earlier in the course of the disease. The Alzheimer's Aid Society expanded its mission to include patient support. Today our patient groups meet every week in Sacramento and Stockton. In 2011 we added Brain Exercise and Reminiscence groups, called "The Forget Me Not Club." Caregivers also belong to the "Forget Me Not Club" and they meet in an adjacent classroom. The facilitators of the patient groups are also available to meet one-on-one with patients to answer questions and assist with their issues and concerns.

Much has changed today as far as our understanding of the disease. There are now medications which can be helpful in improving or delaying the symptoms. There are programs and classes for the patient and the caregiver.

What has not changed is the devastating challenge patients and caregivers face with Alzheimer's Disease. It is a journey of level paths, perilous twists and turns, and ever-changing climates. We continue our focus of education and support to assist those on this journey to navigate the unfamiliar terrain and, hopefully, to find some meaning and joy along the way.

Please refer to the last page in this publication to learn more about our services. We invite you to phone our offices at any of the numbers below to speak to a peer counselor, resource specialist, or any of us on the staff:

800-540-3340
916-483-2002

You can reach us by email at:
info@AlzAid.org

Please visit our website at:
www.AlzAid.org

Sheryl Ashby
President, CEO,
Alzheimer's Aid Society
Of Northern California

FROM THE "BLUE BOOK" EDITOR

Sheryl Ashby C.E.O.

Dear Reader,

This revised edition of the "BLUE BOOK" has been a labor of love for everyone at the Alzheimer's Aid Society. Every article was written by a local professional and donated specifically for inclusion in this booklet. Please be sure to read the biographies of our writers on pages 4 and 5.

At the center of any story of dementia or Alzheimer's disease there usually lies fear. In the beginning there lies the occasional glimpse that something is wrong: increasing forgetfulness, changes in problem solving skills, or other signs that something isn't right. There will often be days where the patient and caregiver(s) both are quite certain that something is wrong only to be followed by days where everything seems to be fine. But, there is always that unsettling feeling, that haunting specter of uncertainty as to accomplishing normal daily living without cognitive incident.

When you get that diagnosis, there is both, relief and alarm. There is now a definitive answer as to what is wrong, and a label for the "thing" causing our distress. But, it does not, in and of itself, provide an understanding as to its treatment, path and outcome. This requires education. This enlightenment comes by way of others. An organization like the Alzheimer's Aid Society, for example, has support groups, educational tools, resources and offers guidance as to the course of the disease. Finding out that others are going on the same journey as you now find yourself can be comforting. The fact that you are not alone and that there are others similarly situated and available to help you to understand the road ahead can give you the resolve to continue the good fight.

Now that you have found the Alzheimer's Aid Society's "Blue Book", you can begin to put together a plan of action. You will also need to also ask your physician or your pharmacist to explain the medications that may improve memory and slow the symptoms of the disease. Finally, find a support group near you and join. The support you get there will prove to be invaluable.

Remember, every person has their own journey through Alzheimer's / Dementia and so does every caregiver. It is our hope that this booklet will be an invaluable help to you on your journey through this disease.

Warmest Regards,
Sheryl Ashby

Do you wish to copy pages from this book?

To use or disseminate any article in this "BLUE BOOK" in any manner (such as handouts for a support group, caregiving classes, etc.) you are welcome to copy any of the pages from this 'BLUE BOOK" provided each page is used in its entirety with the top and bottom banners giving credit to the Author and to the Alzheimer's Aid Society of Northern California.

To better serve you, we would be delighted to know how this book is being put to good use! In duplicating any "BLUE BOOK" pages, we would be grateful to hear which articles are used and for what purpose. Please send a brief email to: info@AlzAid.org

For permission to place or quote any article or portion of this "BLUE BOOK" in another publication, please contact the Alzheimer's Aid Society at 1-916-483-2002. Thank you.

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916-483-2002

ABOUT THE "BLUE BOOK" CONTRIBUTORS

The Authors Who Have Donated Their Valuable Words and Advice

Max Perry, JD

Max Perry has been actively involved with senior issues since 1993 when he helped to found Respect Your Elders®, a senior referral resource for the greater Sacramento area. Prior to being asked to sit as one of the Directors for The Alzheimer's Aid Society, Max helped organize Adopt an Elder, a non-profit entity founded to assist indigent seniors with their costs of activities of daily living.

Max graduated from Chico State College with a B.A. in Political Science and later received a J.D. degree from Lincoln Law School in Sacramento, with two achievement awards for American Jurisprudence. Max has worked for local area attorneys. He brings to our seminars his many hours of experience regarding senior legal issues, including conservatorships, probates, trusts, wills, powers of attorney, advanced healthcare directives and other related topics.

Arturo Benavidez, ESQ

Arturo Benavidez has been practicing law in the Sacramento area since 2006. Art Benavidez runs a small general-practice law firm in downtown Sacramento. He has litigated in probate matters in various counties across Northern California including Sacramento, San Joaquin, Solano, Yolo and Butte.

Art Benavidez graduated from the Sandra Day O'Connor College of Law at Arizona Sate University in 2005. He is a dedicated attorney with a strong work ethic. Mr. Benavidez is a community oriented attorney with an emphasis on his clients. He currently lives with his wife and two small children in the Sacramento area.

Ulric N. Duverney, Esq.

Mr. Duverney earned his Bachelor of Science degree at Long Island University, New York in 1977 with a major in Accounting. In 1980 he was awarded a Juris Doctorate Degree from Western State University in Fullerton, California. He was admitted to the California Bar in 1980 and the Federal Bar in 1981.

During the last 35 years Mr. Duverney has represented large Insurance Companies, National Corporations, Municipalities and many individuals and families during litigation and mediation. He currently practices Probate, Civil Litigation and Bankruptcy and is a current Director for the Alzheimer's Aid Society where he provides free legal advice for caregivers and their loved ones dealing with dementia.

Cynthia Wilson MA, AT, MFTI

Cynthia Wilson MA, AT, MFTI received her Marriage and Family Therapy Masters Degree with an Art Therapy Certificate from Notre Dame de Namur University, her Psychology Bachelors of Art Degree from Sonoma State University with a Gerontology Minor and Certificate and Art Minor from Sonoma State University. Cynthia has Eight years' experience working with adults, older adults, caregivers and families in Art Therapy groups or individual settings.

MaryLee Moritz, RN, BA, MA

MaryLee Moritz received her nursing degree in 1961 from the University of North Dakota. She established the first female health counseling program at the University of Nebraska in 1970. In the 90's she returned to school at UCD, earning a Bachelor's degree in Art then a Master's degree in Art History. She has been a docent at the Crocker Art Museum since 1999.

When MaryLee's mother began her decent into Alzheimer's, the Alzheimer's Aid Society provided education and support. MaryLee has been a Peer Counselor for the Society since 2003.

ABOUT THE "BLUE BOOK" CONTRIBUTORS

The Authors Who Have Donated Their Valuable Words and Advice

Barbara Gillogly, PhD., LMFT, CPG

Dr. Gillogly has been the Chair of the Gerontology Department at American River College for the past 20 years. This program has been awarded the designation of Program of Merit by the Association for Gerontology in Higher Education in Washington, DC. American River College is one of only nine colleges and universities in the U.S. awarded this designation.

Dr. Gillogly also maintains a private therapy practice working with people of all ages, but especially with seniors and their families in challenges of aging within the family. She has both a BA and MA in psychology from CSUS and a Ph.D. in Human Development with an emphasis on aging from U.C. Davis.

Dr. Gillogly wrote The New Nursing Assistant 2000, a textbook published by Medcom, Inc. and widely used in C.N.A. training programs.

She facilitates educational support groups and is a member of the Advisory Boards for the UCD Center for Healthy Aging, CSUS Gerontology Program, UCD Extension Services, California Council on Gerontology and Geriatrics, and the National Association for Professional Gerontologists. In 2005 she was invited to participate with 33 other leaders in the field of aging in a week-long discussion of aging issues at Oxford University in England. She has taught at American River College, CSUS, and UC Davis in gerontology, psychology, and human development.

Kelly Rogers

Kelly Rogers is a certified gerontologist with experience in operating an In-Home-Care Agency. Kelly gained much insight over the years in understanding the needs of both patients and caregivers. Kelly has overseen the in-home care plans of hundreds of patients .

Clara Jackson, RN

Clara Jackson is the VP of Medical Information on the Board of Directors for the Alzheimer's Aid Society. She has been a registered nurse since 1959. She has volunteered her time and expertise to the AASNC for over 30 years. Clara and her family coped with her mother's Alzheimer's in the early 1980's when community support and knowledge were nearly non-existent. In 1982 Clara began attending the only support group for caregivers in Sacramento. It was offered by the Alzheimer's Aid Society. Clara has been instrumental in the expansion of services offered by the Alzheimer's Aid Society of Northern California.

Margie Eisenhower

Margie Eisenhower was involved with the Alzheimer's Aid Society from 1991 to 2012. Margie and her family did everything they could to ease her mother's decent into Alzheimer's. Margie stayed on with the Alzheimer's Society after her mother's death. She has been a volunteer, a peer counselor, a board member, and the Sacramento office manager. She is currently retired from these positions

Cynda Rennie

Cynda Rennie has been a resource specialist in the Sacramento area since 1985, working for Sutter Hospitals and later in private practice, specializing in dementia and Alzheimer's. She is a former licensed administrator for assisted living. Cynda has been involved with the Alzheimer's Society as a resource specialist, a support group facilitator for caregivers and patients, and as a presenter for seminars. Since 2010, she was the Program Director for the Alzheimer's Society and was the editor of the newsletter and Blue Book. Cynda has an adult daughter with Down's Syndrome who was also diagnosed with Alzheimer's Disease.

DESCRIPTIONS OF ALZHEIMER'S DISEASE

Compiled by Cynda Rennie

Mayo Clinic

www.mayoclinic.com/health/alzheimers

Alzheimer's disease is the most common cause of dementia — the loss of intellectual and social abilities severe enough to interfere with daily functioning. In Alzheimer's disease, healthy brain tissue degenerates, causing a steady decline in memory and mental abilities.

Alzheimer's disease is not a part of normal aging, but the risk of the disorder increases with age. About 5 percent of people between the ages of 65 and 74 have Alzheimer's disease, while nearly half the people over the age of 85 have Alzheimer's.

Although there's no cure, treatments may improve the quality of life for people with Alzheimer's disease. Those with Alzheimer's — as well as those who care for them — need support and affection from friends and family in order to cope.

UCDavis Alzheimer's Disease Center

www.ucdmc.edu/alzheimers

Alzheimer's disease is a progressive, irreversible neurological disorder that attacks the brain and results in memory loss, confusion, impaired judgment, and personality changes. It is the most common cause of severe intellectual impairment in older individuals and is a primary reason for the placement of the elderly in nursing homes.

More than 5,000,000 Californians are affected by this illness. At present it is not known what causes Alzheimer's disease or how to prevent or cure it. However, there is often much that can be done to reduce the symptoms, improve functioning, and aid the family in caring for the patient at home.

Harvard University Medical Center

www.neurodiscovery.harvard.edu

AD symptoms develop because brain cells (neurons) are decimated. Why are neurons dying? Part of the answer lies in brain changes observed in Alzheimer's patients, including the characteristic "plaques" and "tangles." Plaques are dense and toxic clumps of proteins that collect around neurons. Tangles occur when fibers inside neurons become twisted, also causing neurons to die.

Precisely why plaques and tangles develop or why some individuals but not others are predisposed to AD are largely unanswered questions. There are no cures for AD.

ALZHEIMER'S AND OTHER NON-REVERSIBLE DEMENTIAS

ALZHEIMER'S DISEASE (AD) is a progressive debilitating and eventually fatal neurological illness affecting an estimated 4-5 million Americans. It is the most common form of dementive illness, a major killer in America today, ranked as the fourth leading cause of death after heart disease, cancer and stroke. The disease can last up to 25 years.

CREUTSFELDT - JAKOB (CJD) is a rare, fatal brain disorder caused by an unknown organism, possibly a virus, that can be transmitted from patients to animals and from one animal to another. The disease causes mental deterioration and a variety of neurological symptoms, and usually leads to death within a year of onset. (Source: NIH Pamphlet, Scientific and Health Reports, Neurological and Communicative Disorders and Stroke.)

MULTI - INFARCT DEMENTIA (MID) Something clogs or blocks a small artery in the brain, causing a loss of circulation beyond the blocked area. When the blood supply is blocked off for a long time, the cells die, leaving a hole. Individuals with a history of arrhythmias, irregular heart rhythms, may be particularly vulnerable to this type of problem. (Source: The Loss of Self, Donna Cohen, Ph.D. and Carl Eisdorfer, Ph.D., M.D.)

PICKS DISEASE Clinically presents very similar symptoms to Alzheimer's Disease, rigidity and pronounced gasping and sucking release phenomenon. The disease lasts approximately 7 years. (Alzheimer's & Other Dementias, R. Murray, M.D.)

BINSWANGER'S DISEASE First described by Otto Binswanger in 1894. This is another rare disease. Clinically, Binswanger's appears as a dementia syndrome, a deterioration of intellectual capacity characterized by disturbances in memory, orientation, language, and performance of tasks, with loss of awareness that such changes are occurring. Such difficulties are never a part of normal aging, and always represent some type of disease process. (Source: Stolen Mind, Myrna Doemberg.)

PROGRESSIVE SUPRANUCLEAR PALSY (PSP) Problems that are common symptoms of PSP are unsteady gait, backwards falls because of poor balance, visual disturbances, slurred speech and forgetfulness. The average duration from onset to death is approximately 6 years. Bronchopneumonia is shown as the most usual cause of death recorded on death certificates. All patients with supranuclear palsy have a downgaze and often have a dementia. (Source: Neurology, July, 1986, E.R. Maher, BSC, MRCP, and A. J. Lees, MD, MRCP.)

PARKINSON'S DISEASE This is a chronic disorder of the central nervous system of variable progression and severity. Clinically, the disease is characterized by rigidity, a resting tremor, bradykinesia, and gait disorder. There can be speech impairment. There is a growing awareness of dementia among Parkinson's disease patients, however, other mental changes may also occur such as changes that consist of drug related episodic confusional states. Depression frequently accompanies Parkinson's disease. (Source: Alzheimer's Disease, The Standard Reference, Barry Reisberg, MD.)

WERNICKE'S SYNDROME Wernicke's is associated with chronic alcoholism. It also occurs as a complication of gastrointestinal tract disease and complications with malnutrition. This is a degenerative condition of the brain and is caused by a thiamine deficiency. There is a decreased mental function which may be mild or severe. (Source: Mosby's Medical & Nursing Dictionary.)

Diagnostic tools mentioned are MRI (Magnetic Resonance Imaging) and CT (Computed Tomography). These are often used with other tests to determine the clinical diagnosis. Social and Medical information is also considered.

WHAT IS SENILE DEMENTIA?

Cynda Rennie, Resource Specialist

The word, ***Senile***, is taken from the Latin “sen,” which means “old.” In medical terminology this usually refers to a person’s age being over 65. The word, “senile,” is an adjective usually linked to the word, “dementia.”

The word, ***Dementia,*** is taken from the Latin, “de,” which means “away,” and “mentia” which means, “mind.”

Dementia is defined as a group of symptoms including:

Memory loss and forgetfulness

Changes in language or problem-solving abilities

Disorientation

Possible personality changes

The existing symptoms have not been present since birth and do not relate to level of consciousness.

The existing symptoms are severe enough to interfere with the person’s ability to function independently.

Pre-senile Dementia refers to a presentation of these symptoms in a person below the age of 65.

Causes of dementia include:

Alzheimer’s Disease

Lewy Body Disease

Pick’s Disease

Huntington's Disease

Creutzfeldt-Jacob Disease

Parkinson’s

Brain Tumor

Head Trauma

Hydrocephalus

Multiple Sclerosis

Prolonged Abuse of Alcohol or other Drugs

Vitamin Deficiency : thiamin, niacin, B12

Hyp0thyroidism

Hypercalcemia

Vascular Dementia

Some of these conditions can be treated or reversed. Please see page 8 for more information about medical evaluation.

REFERENCES: The Farlex Medical Dictionary 2010; Miriam Webster Dictionary www.miriamwebster.com: UC Davis Alzheimer’s Disease Center www.alzheimer.ucdavis.edu

THE IMPORTANCE OF A PROPER DIAGNOSIS
IN ALL FORMS OF DEMENTIA

Cynda Rennie, Resource Specialist

When someone exhibits the symptoms of dementia (memory loss, changes in language and math skills, disorientation) it is essential to have a thorough medical evaluation to determine the cause. Alzheimer's Disease is diagnosed through the process of ruling out other conditions which can cause similar symptoms of dementia.

Some of these conditions, unlike Alzheimer's, can be cured or reversed. Examples of these conditions include:

- Thyroid Disorder
- Low Blood Sugar
- Low or High Sodium
- Low or High Calcium
- B-12 Deficiency
- Dehydration
- Low Thiamin (B-1)
- Interaction of Medications
- Meningitis / Encephalitis
- Lyme Disease
- Untreated Syphilis
- Untreated Infection
- Depression
- Brain Tumor
- Alcohol or Substance Abuse
- Normal Pressure Hydrocephalus

The evaluation for the cause of dementia symptoms, including Alzheimer's, should include:

A complete history – To evaluate the person's lifestyle and history of head injury (even as a child), military service, visits to foreign countries, and family health history.

A thorough exam by a neurologist – which should include:

- Physical and neurological evaluation.
- Complete review of all medications; prescribed, herbal, and over-the-counter.
- Neuropsychological testing, to assess thinking and memory skills
- Complete Blood Count.
- Screening Metabolic Panel.
- Thyroid function tests.
- Levels of Vitamins B-12, B-1, B-6.
- Urinalysis.
- Electrocardiogram, to assess heart function.
- Brain Scan –
    - Magnetic Resonance Imaging (MRI)
    - Computerized Tomography (CT)
    - Positron Emission Tomography (PET)
    - Single-Proton Emission Computerized Topography (SPECT)

NOTE: Usually, one Brain Scan is sufficient. Discuss with your neurologist which of these scans would be best, what is available, insurance coverage, and costs.

REFERENCES: Mayo Clinic Alzheimer's Disease Center www.mayoclinic.com; American Academy of Family Physicians www.aafp.org; University of California at San Francisco www.ucsf.edu

CAREGIVING

Barbara Gillogly, Ph.D., LMFT, CPG

Care of the Caregiver

In the partnership between caregiver and care receiver, the more important partner is the caregiver—***the caregiver is the foundation of this partnership***.

Caring for yourself is legitimate and of first priority. It is not being selfish. Remember, one-third of caregivers die before the person they are caring for because they have not taken care of themselves first.

Boundaries

We all have limits, both physical and emotional, and we all must function within the confines of reality.

Consider carefully each task and where your physical and emotional boundaries lie.

Then accept that you have the right and obligation to set realistic boundaries and the right and obligation to maintain them.

If you do not do this, you will eventually resent the person you care for, become angry with yourself, and then feel guilty. This destroys your effectiveness**.** ***In the interest of yourself and others, boundaries must be set and maintained.***

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Steps in Establishing/Maintaining Boundaries

Set realistic goals for yourself and your loved one. Much stress is self-induced—especially when you feel you "should" be able to do this or you "ought" to do it. You feel guilty when you can't be perfect and expectations are not met. "Should" and "ought" have no basis in reality—allow yourself to be human. This is what your loved one needs most of all.

Learn to say "no" to others and to yourself. "No" is a life-saving word—it literally can preserve you and your loved one. It is OK to say, "No, I can't do that"—good people say "no", too.

Accept the fact that you cannot and should not do, or solve, everything. It is often difficult to accept that we can't fix everything or do everything. Many things have no solutions or explanations. The world if full of unexplainable things. You're not expected to have all the answers.

Talk to yourself using positive statements. Remind yourself of all the things you are doing—if you can't do anything about a situation, remind yourself that it's a waste of energy to get upset about it. Tell yourself it's OK not to be able to do everything. Let go of things you really cannot do and refer them to someone who can. Let go of those that really don't matter—decide what's really important, do that, and let the rest go.

Have someone to talk to. It helps to talk with someone who will listen and not judge you. Be each other's support system—the benefit is in talking about it.

Accept the fact that all emotions are OK. Emotions are part of being human and are meant to be felt and expressed. Saying how you feel is satisfying and reduces stress. Talking about your feelings is OK—how you act on them can be OK or not OK.

Take care of yourself. Many people depend on you and need you. If you give everything you have without replenishing yourself, soon you'll have nothing left to give. By taking care of yourself, you're taking care of those who depend on you. Taking care of yourself is not selfish, it is essential

THE CAREGIVER

Margie Eisenhower

There is a wonderful saying that goes like this (anonymous):

"***Today I bent the truth to be kind, and I have no regrets, for I am more sure of what is kind, than I am of what is true."***

As caregivers of a patient with Alzheimer's Disease or other dementia, there will be times when the patient imagines things that aren't real. Because of their confused and jangled minds, they become frightened or stressed by these things. You can try to relieve them of the worry from these things if they can't let it go. For instance, one woman in a care home 'imagined' there were two children coming in and out of her room, and she was afraid they'd be hurt. She called her husband, very agitated; she didn't know what to do. He told her, "not to worry," -- the police department knew about them and was sending someone right out to take them to their parents. She was *so* relieved.

My own mother told me the neighbor boys were coming into her home and stealing money. She lived a great distance from me but I knew the neighbors well, and knew this couldn't be so. Contradicting her and trying to reason with her about the impossibility of this would have been futile. Instead, I said, "Yes, I know about that, Mom, it's terrible! However, I've talked with the parents and they will make sure it doesn't happen again." That truly appeased her. When it came up again another time, I said the same thing, and again she was relieved. Eventually, I moved my mom closer to me, and when I packed up her home, I found several rolls of twenty-dollar bills – one roll inside a cereal box, one inside a roll of paper towels, one hidden in a secret drawer in an old trunk, and rolls in a couple of other places. It was a "Catch-22." She'd go to the bank and draw out money. She'd worry about the neighbor boys stealing it, so she'd "hide it," from them. When she needed money she couldn't remember hiding it; hence, the neighbor boys took it!

One daughter told me her mother was very frightened, as she thought a burglar had entered her home and she feared he'd be returning. The daughter told her mom she had called the police and they'd already caught and arrested the burglar, so she needn't worry any more. That's all it took.

As a Peer Counselor for Alzheimer's Aid Society, I've had both men and women tell me that they can't imagine lying to their own mothers. But, that's where the quote above comes in. This 'white lie" you're telling is a way to bring comfort to that mom (dad, sibling or friend) whom you love, respect and want to protect.

I had someone explain to me once, that having Alzheimer's or dementia, is like having someone fly you to a foreign country, set you down on a bench in the city and just leave you! You can't speak the language, you don't know where you are, you don't know where to go, you don't know anyone around you. Can you imagine the fear and anxiety this would bring? Many patients deal with confusion and stress on a regular basis. They forget they have Alzheimer's but they know *something* is very wrong with them and it is always frightening.

A simple rule when dealing with loved ones: Be Kind. Don't argue with them. Don't tell them they are wrong. Don't tell them they don't make sense. Don't say, "You already asked me that!" Don't say, "You've told me that five times!" They can't help it that their brain is off balance and mixed up. Ask yourself, "How would I want to be treated if that were *me?"*

When your loved one is gone, you will be happy that you treated them with kindness, love and respect. But don't be hard on yourself either. Joe Frazier, the great boxer once said, "If I lose [a fight], I'll walk away and never feel bad, because I did the best I could, and that's all I can do."

This job isn't easy! Caregiving is probably the toughest occupation out there right now. Call our office for help. P-l-e-a-s-e take yourself to a Support Group. Not only can you visit with people who are going through the same thing you are, but you will pick up ideas and suggestions that will make your job much easier. No one knows how difficult this job is unless they've done it themselves. And sometimes other family members make it tougher instead of easier because they simply 'don't get it.' What they don't know is that unless they spend two full days with the patient, they have no idea how bad the disease is or how hard it is for you, the caregiver.

I salute you! I admire you! I wish you well!

COMMUNICATION AND DEMENTIA

Barbara Gillogly, Ph.D., LMFT, CPG

Understanding Communication Problems

Communication problems with dementia are caused by damaged nerve cells and the decrease in neurotransmitter activity.

Symptoms

- Trouble with naming, word-finding, fluency, comprehension and repetition. In some cases, difficulties with reading and writing.
- Body language may be impaired.
- Don't assume the person's communication tools have the same meaning as before.
- May only be able to use a limited number of words.
- The person with dementia may be dealing with one or more of the following:

Confusion
Fear
Depression
Inability to learn new things
Loss of self-esteem
Anxiety
Irritability
Short attention span
Loss of inhibition

Your Response

The caregiver's response needs to be:

Calm
Accepting
Kind, patient and respectful
Listening more than talking
Reassuring
Connecting, not correcting
Flexible

General Techniques

- Approach from the front.
- Proceed slowly.
- Maintain a routine and structure.
- Have realistic expectations.
- Be involved in their daily tasks.
- Break down tasks into simple steps.

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Remember:

- Disorientation may be greater at specific times of the day.
- The patient needs a quiet, non-distracting environment.
- When you think you understand what's being communicated, try to help finish the sentence or complete the task.
- Be alert to signs that you have misunderstood the message and try again.
- Try to find a word you recognize and then repeat that word with inflection while mirroring the person's facial expression.
- If you cannot understand their verbal input, respond to their feelings or emotions.
- Patients may revert to original language in the later stages. Try to learn some simple adaptive words and phrases to help during this time.
- Every behavior has a reason.
- The patient is doing the best they can at the moment.
- Don't overreact.
- Don't embarrass, scold, shame, moralize or punish.
- Correct, if possible, any hearing or vision deficit.

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Verbal Communication

- ◊ Speak slowly.
- ◊ Construct communication to match the person's ability.
- ◊ Use simple words and short sentences.
- ◊ Use words frequently used by the person in the past.
- ◊ Use nouns rather than pronouns.
- ◊ Don't use two-part questions.
- ◊ Address the person by name .
- ◊ Make one request or ask one question at a time.
- ◊ Give the impaired person time to respond.
- ◊ If you need to repeat, use the same words.
- ◊ Change topics slowly.
- ◊ Use humor.
- ◊ When questions are repeated, answer once and then use reassurance.
- ◊ If necessary, speak louder or lower your tone of voice.

Nonverbal Communication

Nonverbal Cues

- ◊ Nonverbal communication ultimately becomes more important than verbal.
- ◊ More is communicated through nonverbal means.
- ◊ Your body language expressed while talking with someone other than the person with dementia will be interpreted by him/her as pertaining to him/her.

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Remember:

- ◊ The tone of our voices can be colored by the history of a relationship.
- ◊ The person needs to feel that his/her dignity and self-esteem remain intact, even if their mental condition is declining.

Techniques:

- ◊ Maintain eye contact.
- ◊ Your verbal message should match your body language.
- ◊ Listen and pay attention.
- ◊ Use gestures.
- ◊ Show love and affection.
- ◊ Touching can enhance attention and listening.
- ◊ Be alert to the feelings being communicated.

Non-verbal Messages from Person with Dementia

Be alert to physical signals -

- ◊ Pale or flushed face, perspiration, etc. may mean the person is receiving too much sensory stimuli.
- ◊ Averting the eyes, looking down and increasing use of hand gestures may mean the person does not understand.
- ◊ Feelings of hostility may be expressed by an increase in motor activity (pacing), frowning, speaking loudly, pursed lips, and tight facial muscles and jaw.
- ◊ Non-listening behavior may be exhibited by a lack of direct eye contact, failing to nod or affirm.
- ◊ Being receptive is often indicated by decreased or absent body motion, relaxed facial muscles, smiling, extending hands.
- ◊ Anxiety may be exhibited by hand wringing, crossing and uncrossing legs, stepping toward you, increased body movement.

ALZHEIMER'S AND DEPRESSION

MaryLee Moritz, RN

Alzheimer's disease and depression are among the most common disorders of the elderly and both can have a major impact on quality of life for patients and caregivers alike. In fact, experts believe that two out of every five people with Alzheimer's will eventually suffer from depression.

We all feel low or down from time to time but this isn't the same as being depressed. Depression is a more persistent condition in which a number of feelings, such as sadness and hopelessness, dominate a person's life and make it difficult for the person to cope.

However, many people with moderate to severe Alzheimer's don't have the insight or the words to express how they feel and they may have trouble realizing where their sadness comes from. Older people with depression may also experience physical symptoms, such as loss of energy and appetite changes.

People with both Alzheimer's and depression will be struggling with two sets of difficulties, and they may find it even harder to remember things and may be more confused or withdrawn. Depression may also worsen behavioral symptoms in people with Alzheimer's, causing aggression, problems sleeping or refusal to eat. These upsetting behaviors can lead to earlier placement in care facilities if not properly treated.

SIMILAR SYMPTOMS

Some of the symptoms common to both Alzheimer's and depression include:

- Depressed mood (sad, hopeless, discouraged, feelings of guilt)
- Social withdrawal and isolation.
- Memory problems and impaired thinking, inability to concentrate.
- Loss of interest and pleasure in hobbies or activities once enjoyed.
- Sleeping too little or too much, tiredness or loss of energy.
- Irritability, mood changes

DIAGNOSIS AND TREATMENT

The most common treatment for depression in Alzheimer's involves a combination of medicine, counseling, support at home and gradual reconnection to activities and people that bring happiness. Simply telling the person to "cheer up" is seldom helpful. Depressed persons with or without Alzheimer's are rarely able to make themselves feel better just because they want to, or without professional help, lots of support and reassurance. Proper treatment relies on the education and patience of caregivers and physicians and can greatly improve a person's quality of life.

Many of the depressive symptoms shared by Alzheimer's and depressed persons are so similar that even doctors may have trouble deciding which one it is. Because these symptoms often overlap when depression and Alzheimer's occur together, thorough physical, mental and psychological exams are helpful in diagnosing the two disorders.

Much of the diagnoses may rely on the observations of caregivers since they have daily contact with their loved ones. Fortunately, symptoms and behaviors are often treatable with medications and change. Successful treatment requires easing anxiety through a combination of treatments, including medications and improving situations at home. Support groups and counseling may help persons with depression in the early stages of Alzheimer's, before their ability to communicate deteriorates.

Caregivers can help ease anxiety by:

- Creating a calm environment. Try to get rid of the triggers that could set off anxiety, such as machines that make loud or unusual noises, bright lights and other distractions.
- Simplifying frustrating tasks and routines. Take over some chores that the person may have trouble with, such as bathing and dressing.
- Making sure the person is comfortable. Is your loved one feeling any pain, hunger or thirst? Is the home at a comfortable temperature and is the bathroom easy to find and use when needed.
- Giving the person chances to burn off excess energy, especially in the morning. Take daily walks with your loved one and encourage them in other forms of exercises, such as gardening or taking care of pets.

Anti-anxiety medications are also available. SSRIs (Selective Serotonin Reuptake Inhibitors) such as citalopran (Celexa) and Sertraline (Zoloft) are antidepressants used for people who have depression and Alzheimer's because of the low risk of side effects and drug interactions. Making the right diagnosis and getting treatment can help make life easier and more enjoyable for the person with Alzheimer's and depression as well as his or her caregivers.

If you are caring for a person who is suffering from depression or anxiety related to Alzheimer's, don't let them endure the pain any longer than necessary. Remember that everyone is unique and depression symptoms can vary greatly among people. Always contact your loved one's doctor to answer your questions about any unusual symptoms or concerns. Try the tips mentioned here and take steps to handle situations in positive ways. Proper treatment of both diseases can greatly improve quality of life for patients as well as those who care for them.

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APPOINTMENTS AND COMMUNICATION WITH THE DOCTOR

Clara Jackson, RN

Medical appointments can be very stressful for caregivers and patients alike. Here are some tips to help ensure a successful visit to the doctor.

Try to get an appointment for the time of day the confused person is at his or her best to gain better cooperation. This is a good rule to follow whenever any medical problems arise in the future.

Allow enough time for getting the impaired person ready, the trip and getting into the office. If bathing before the appointment is likely to create another battle, skip that step. You should not feel rushed or exhibit stressfulness as this can agitate the impaired person.

When arriving for the appointment let the receptionist know that the person is memory impaired and confused. If the waiting room is crowded and noisy, ask for a quiet room in which to wait. Take items from home to keep the person occupied while waiting, such as you would do for a small child. At the same time remember to respect the person as an adult. If the patient is restless, ask the receptionist if you can be paged or called on your cell phone when it is nearly time for the patient to be seen by the doctor. Take a walk with the person. Most medical centers have art displayed on walls and a nice landscaped area outdoors. Stay with the impaired person at all times to minimize fright in a strange place. It is helpful to take a friend with you.

Provide written information and questions for the doctor. Make a copy for yourself. In this way important information and questions are not forgotten and efficient use of time is made. State the person's name and reason for the appointment. List all medications such as prescription drugs, over the counter medications and any herbal products. List the reason for taking these medications and products. If you have questions or concerns you feel uncomfortable saying in front of the patient, list these in "bullet fashion" so they are easy and efficient for the doctor to review.

If the person does not have a medical power-of-attorney, learn more about this. Contact the Alzheimer's Aid Society for more information. Without power-of-attorney or conservatorship, the doctor may decline sharing information with you. Remember though, even if the doctor will not give you information, YOU can give information to the doctor.

Learn more tips by attending a support group or talk with a peer counselor at the Alzheimer's Aid Society.

BATHING

Barbara Gillogly, Ph.D., LMFT, CPG

- Persons with dementia often exhibit a fear of undressing and of water.
- A handheld showerhead can be less threatening.
- A shower chair with arms can be reassuring.
- Give the person his/her own washcloth while you are helping with the washing.
- Consider showering with the person.
- Allow the person to enter the tub or shower wearing underwear or a robe and then when wet, suggest the person take it off.
- Older people do not have to shower daily - 2-3 times per week is sufficient. Alternate with sponge baths.

DEMENTIA AND INTIMACY

Barbara Gillogly, Ph.D., LMFT, CPG

Introduction:

- Sexual behavior is seldom discussed as it is considered very personal.
- We tend to accept the myths we are raised with.
- Little is written on the topic of sexuality and dementia.
- Due to a lack of understanding of the sexual needs of older adults, the sexual interests of the individual with dementia are often viewed as behavior problems rather than a need for love and intimacy.

Sexual Behavior:

- It is a human to need to be touched and held and to express sexual feelings.
- All of us are sexual beings from birth throughout our life span. Even impaired, dependent people with dementia retain adult feelings.
- We may not always be sexually active, but we are still sexual beings.
- Most people with dementia respond to the opportunity to give and receive affection.
- People with dementia may express inappropriate sexual behaviors because they cannot remember or understand the consequences or meaning of such behaviors.
- Persons with dementia lose impulse control. They lose the ability to make appropriate judgments about when, how, and with whom sexual activity is appropriate.
- Older men who feel their physical strength and abilities waning, may feel the need to reassure themselves they are still men by flirting and making inappropriate sexual comments and behavior. Today's elderly men grew up in a society that expected men to make sexual advances to prove their manhood.

Affection and Sexual Intimacy:

- Sexuality involves expressions of affection as well as sexual intimacy.
- Affection: kissing, touching lovingly, caressing, holding hands, placing arm around, sleeping in the same bed.
- Sexual intimacy: sexual intercourse.

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DEMENTIA AND INTIMACY

Barbara Gillogly, Ph.D., LMFT, CPG

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Problems and Coping:

The issues are as different as the couples involved.

- Both can be very affectionate with sexual activity.
- Both can be very affectionate without sexual activity.
- For some, sexual activity becomes more physical and less emotional.
- There may be little affection, but one or both partners may still be interested in sexual activity. If it is the caregiver, he/she may seek it elsewhere.
- Hypersexuality may be exhibited on the part of the person with dementia. The caregiver may be reluctant to show affection as he/she fears it may lead to unwanted sexual activity.
- Confronting the impaired person or trying to reason with him/her is useless.
- Gently guiding the person to a private place where the behavior (masturbation) may be more appropriate.
- Distraction works better than confrontation. Asking the individual to hold something for you will keep his/her hands busy.
- Shaming or demeaning is counterproductive. The individual is expressing normal adult feelings, but he/she has lost the ability to judge appropriateness.

Effect on Relationship:

Many factors influence the relationship between the spouse who is the caregiver and the spouse with dementia.

- Belief in what is perceived as “normal” or “abnormal.” Belief that diminished sexual desire is expected with age.
- Quality of the past relationship is a factor in present feelings.
- Pattern of life over time.
- How important sex was in the past.
- Conflict in roles: caregiver/lover.
- Increase in responsibility leaves less energy, physical and emotional, for sexual intimacy.
- Afflicted spouse may believe he/she is still sexually active when that is not the case—the mind’s eye is in the past.

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DEMENTIA AND INTIMACY

Barbara Gillogly, Ph.D., LMFT, CPG

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Summary:

- **There is no one right way to feel or deal with the issue of intimacy in the presence of dementia.**
- **You have a right to feel whatever you feel and the right to say "no" when you want .**
- **The one constant is that the individual with dementia needs to be treated as an adult with respect and caring. He/she is suffering with a disease that changes how the person reacts.**
- **It is important to talk with someone about this issue, so that you know you are not alone and that all your feelings are valid.**

HOPE: Art Therapy For Those With Dementia

Cynthia Wilson MA, MFTI, AT

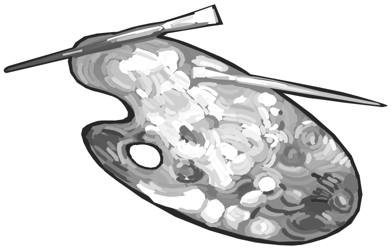
Hilda Goldblatt Gorenstein was a painter in the Chicago area in the mid 1900's. During her later years she developed dementia. Yet she was able to live a long and fulfilling life in a nursing home, thanks to her daughter's persistence Her daughter, Berna Huebner, hired the art students from the School of the Art Institute of Chicago to come and work with her mother in painting again. "Her mother had said to Berna when asked if she wanted to paint again, 'I remember better when I paint.'"(*Whitcomb 2010*) Hilda had not painted in several years. She had a history of being withdrawn and sometimes agitated to the point where staff would give her mild tranquilizers to help calm her in her dementia. (*Whitcomb 2010*)

Jenny Shepard, the first art student to work with Hilda, received little results and equally poor support from facility staff. "One told Shepard, 'You're wasting your time. The lights are either on or they are off, and with Hilda, they are definitely off.'" (*Whitcomb 2010*) I have many years of managing and observing caregivers of those with dementia and this statement can be very discouraging. This staff member was most likely uneducated about the disease or closed-minded due to being overworked. Whatever the motive for her statement, don't be discouraged by statements like this one. There's always something for which to be hopeful. For instance, it took some time, but the art students got Hilda painting again. They got her back to doing something she had always loved.

There used to be the idea that if you are artistic you are "right brained". However, it has since been discovered that the creative aspects of the human mind are located all over the brain. (*Lusebrink 2004*) There is no one special place for creativity, allowing the mind to always have creative capacity. Even those with dementia, whose brains are being taken over by a devastating disease that gradually inhibits their ability to remember and physically function, still have the potential to be creative. There is no prior artistic skill or desire needed in order to do this in an Art Therapy setting.

> "As Samuel Gandy, associate director of the Mount Sinai Medical Center Alzheimer's Research Center in New York, puts it: 'Alzheimer's typically hits memory areas of the brain early, while sparing areas responsible for creativity. Art and music are perfect modalities for stimulating these creativity areas.'" (*Whitcomb 2010*)

As an Art Therapist who has worked with several groups and individuals with various forms of dementia, I have witnessed amazing things coming from them. The act of creating allows them to still have self-expression when they can no longer make sense of their world. The creation of the artwork gives vision to their voice when they can no longer speak. It can also give a voice to those who are capable, but normally wouldn't talk anymore. The process of making art in a therapeutic environment helps them to be themselves again by expressing their emotions in a non-judgmental environment.



I have also discovered that art is a great way to spark creativity, individuality and self-confidence in those with dementia. I have seen group Art Therapy sessions help people reconnect and find their place in the world as well as find their voice again.

Sometimes I have to put a brush in their hand to get them going. At other times, once I have set up the paints and brushes, they start by themselves. One gentleman I'll call Ebert (pseudonym), when using water colors, would not wait for me to pour the water. He would spit in his paints and just get to painting. As soon as he was finished with his painting he would ask, "So teacher, did I get an A?" I would always reply, "You get two thumbs up," as I held my thumbs up for him. He would laugh and the group would laugh with him.

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HOPE: Art Therapy For Those With Dementia

Cynthia Wilson MA, MFTI, AT

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As an Art Therapist I know that if I told Ebert he got an 'A' like he wanted, then the others in the group could feel that they were being judged on quality of work and not process. Giving the "Two thumbs up" was a fun and playful response that pulled on his personality allowing him to feel as though he did well and yet not give a direct judgment. No judgment is a key component to an Art Therapy session. The artwork created in an Art Therapy session is a form of self-expression however the artists need to express themselves in that moment.

The goal of every group I do with those with dementia is to get them feeling comfortable, relaxed and confident in what they are doing and who they are. There are so many things going on around them that they no longer understand or remember. Feelings of anxiety, fear, disorientation, sadness or anger can be very overwhelming for one with dementia. Giving them at least 1 hour a week to regain that confidence, control and self-confidence can carry on throughout the rest of the week.

With some of the clients I have worked with, staff has reported to me that it has helped prevent the need for tranquillizing medications for at least a few hours if not days. The clients socialize and laugh and know that whatever they create is the right thing for them to create that day. They talk about old memories and bond over this art process. I find that some of them actually remember me when I come back again. They even tell me how great the art makes them feel and that they were just waiting for me to come back.

I had one client say that her mind was feeling all fuzzy that day and she just couldn't get things figured out, but that after she completed a painting in my group she finally felt relaxed, her headache was gone and she wasn't worried anymore. "I don't know what I painted for sure, but it doesn't matter because I feel happy now," she said with a smile. Another time this same woman entered the group complaining of her loss of eye-sight and that it seemed worse this day than others. I brought in another group member who had never been there before, but also had the same eye condition, and sat them next to each other. The new member stated she could not do the art because she couldn't see well as she had this special eye condition. The regular attending client said she couldn't see either, but painted anyway because it was fun to let go and just do whatever. She further explained, "At first the loss of my eyesight was horrible, but now I realize that it allows me to relax and do whatever I want. I can't see what I'm doing so it doesn't matter anymore. I'm free. I'm free to imagine whatever I want to and just paint." She used to be very meticulous and precise in everything she did as a seamstress. She says coming to the art class has taught her to be otherwise and she very much enjoys it.

During the art process, I get to see the most wonderful thing ever. These individuals--who spend day in and day out, often feeling isolated, scared, frustrated, confused and disoriented--relax their shoulders, giggle to themselves and visually lighten up. It's as if the shell of the disease breaks open and the person who is hidden inside is freed. Their eyes, face and whole being, change as they create art. People who haven't talked in months hold conversations with others in the group. People who haven't done anything for themselves and have a 24hour caregiver taking care of all their needs, pick up a brush and paint a picture on their own.

So, I say to that staff member at Hilda's nursing home who said, "Hilda's lights were definitely off": **No one should ever be discounted in their abilities to create beauty. Those with dementia have their light on at all times.** It's breaking through the shell of Alzheimer's that allows us to see them in their light once more.

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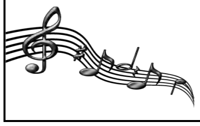
INCORPORATING MUSIC IN CAREGIVING

Clara Jackson, RN

Dr. Oliver Sacks, Professor of Clinical Neurology and Psychiatry at Columbia University, in his current best-selling book, ***Musicophilia***, writes about the amazing therapeutic effects of music on people with Alzheimer's disease and other dementias. Dr. Sacks describes how familiar music is the key to eliciting emotions and unlocking words that have been silent.

The parts of the brain where we make memories, the medial temporal lobes like the hippocampus, are the first areas to be attacked by Alzheimer's. The cortical and subcortical areas of the brain are the "music areas" and have less damage. Studies have been done on the effects of music therapy on the five brain chemicals of melatonin, serotonin, norephedrine, ephedrine, and prolactin in Alzheimer's patients. Melatonin is associated with mood regulation. With music therapy, aggression and depression were reduced and sleep was enhanced. The brain chemicals of epinephrine and norepinephrine rose immediately but did not last long after the music was stopped. Serotonin and prolactin were not affected by music therapy.



Listening to music that is personally enjoyable to the patient has positive effects on cognition as well as decreasing problem behavior. Researchers from Boston School of Medicine have shown that patients with Alzheimer's are better able to remember new verbal information when it is provided in the context of music (can remember new information if it is sung to them.)

For both the patient and the caregiver, music can bring relaxation, feelings of peacefulness and a sense of calm. Music can also bring energy and feelings of happiness. Music floods our brains with memories and emotions. Music brings joy!

Activities to consider:

Look for music on CD's, DVD's and sing along videos containing music from the 1930's through the 1950's familiar to your loved one. Selections from their teen years through young adult years are most likely to have the best responses. Also try music of Mozart, Chopin, Gershwin and show tunes.

Live music such as acoustical guitar, piano, etc.

Soothing music on the radio.

Singing and humming while doing your daily activities. Encouraging your loved one to sing along.

Encouraging clapping hands, swaying or dancing to music.

Keep musical activities to no more than 30-40 minutes.

Use stimulating music with quick tempos to rouse those who tend to fall asleep at meals or other activities of daily living.

Ballads and lullabies with slow tempos are best at bed time or for any change that might cause agitation.

In late stage dementia, music from their childhood works well such as lullabies, folk songs and favorite hymns. If your loved one spoke another language in childhood, be sure to sing in that language.

Avoid:

Music that is loud or inharmonious. This may confuse, agitate, or increase disorientation.

Videos of ocean waves and roar of surf as this can be disturbing.

Song books showing notes. Musical notes are often seen as confusing figures.

CAREGIVING TIP:

Some patients enjoy music more when they are doing something else at the same time. Folding towels, sorting silverware or nuts and bolts. During a bath, grooming rituals or meals music can provide a bridge to feeling more "at home."

DEMENTIA AND HOME SAFETY

Barbara Gillogly, Ph.D., LMFT, CPG

INTRODUCTION

Dementia affects the brain and its ability to process information. Each person goes through the stages of dementia in his/her own way, so what works today may not work tomorrow. The caregiver's job is to watch, listen and constantly adjust to any changes. The goal of home modification is to provide safety and comfort to all family members.

SAFETY

- The person with dementia loses the ability to think rationally, so it helps to think of this as "child-proofing" your home. For example, an electrical plug may appear to be a curious hole to explore.
- Cleaning supplies and other potentially dangerous products if consumed in excess, including alcoholic beverages, need to be kept in locked containers or cupboards. Lock up matches, lighters, and cigarettes. Childproof latches on cupboard doors are often effective.
- The garbage disposal is a potential danger. You can have it rewired to a hidden switch (inside a cabinet) that the person with dementia cannot find or access.
- Electric stoves can also be rewired to a hidden switch that controls the on/off function. Gas can be turned off at the valve for gas stoves. Control knobs can be removed so the stove cannot be turned on.
- Doorways leading to stairwells, balconies, garage, and pool areas need to be blocked to prevent access.
- The person with dementia can often be diverted from a door by placing small scenic posters on the door, placing removable gates, a curtain, or brightly colored streamers across the door. The door can also be wallpapered to match the adjoining walls. Place *STOP, DO NOT ENTER, or CLOSED* signs in strategic areas on doors.
- Stairways should have at least one handrail that extends beyond the first and last steps. If possible, stairways should be carpeted or have safety grip strips. Check the carpet to see that it is not frayed or torn which could pose a tripping hazard.
- Yards need to be enclosed by a fence that is not easily climbed, and gates need to be locked to prevent the person with dementia from getting outside the yard. Slide locks can be installed on gates at the very bottom where the person would not think to look.

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DEMENTIA AND HOME SAFETY

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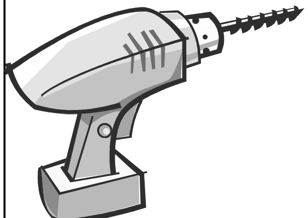
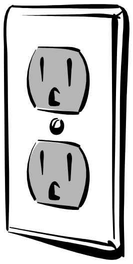
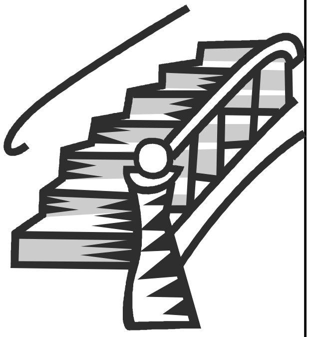
SAFETY continued...

- Exit doors can be alarmed to alert the caregiver when they are opened, or additional locks can be installed either higher or lower than the normal lock position.
- For doors that lock from the inside, such as a bathroom, either remove the lock or keep an emergency key nearby.
- Lower the thermostat on your hot water heater to its lowest setting or no higher than 120 degrees to prevent accidental burns.
- Grab bars beside the toilet and at the bathtub can provide safe access. A non-slip mat in the tub or shower can prevent falls.
- Hide a spare key outside in case the person with dementia locks you out of the house.
- Avoid the use of extension cords where possible. If extension cords have to be used, tack them to the baseboards to avoid tripping.
- Cover unused outlets with childproof plugs.
- Make sure smoke alarms are functioning
- Get rid of clutter which can create confusion and danger. Keep all walk areas free of furniture. Get rid of throw rugs which can pose a tripping hazard.
- Keep plastic bags out of reach as these can be a choking hazard.
- Lock up or store elsewhere all firearms and power tools.







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DEMENTIA AND HOME SAFETY

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SAFETY continued…

- Remove all poisonous plants from the home and yard. Check with local nurseries or poison control centers for a list of poisonous plants.
- Keep fish tanks out of reach. The combination of glass, water, electrical pumps, and potentially poisonous aquatic life could be harmful to a curious person with dementia.
- Provide adequate lighting that does not produce glare or shadows by using soft light or frosted bulbs. Use nightlights in bedroom, bathroom, and hallways to orient person at night.
- Remove artificial fruits and vegetables or food-shaped kitchen magnets—all of which might appear to be edible.
- Avoid the use of electric mattress pads, blankets, sheets, or heating pads as they can cause burns.
- Move the bed against the wall for increased security, or place the mattress on the floor if falling is an issue.
- Remove small electrical appliances from the bathroom.
- Remove or cover mirrors if they cause the person with dementia to become confused or frightened.

COMFORT AND EASE OF FUNCTION

- Vary the home environment as little as possible to minimize the potential for visual confusion. Keep furniture in the same place.
- Use dishes and placemats in contrasting colors for easier identification.
- Place brightly colored signs or simple pictures on important rooms (the bathroom) for easier identification.
- Remove all unnecessary clothing from the closets and drawers to avoid confusion.

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DEMENTIA AND HOME SAFETY

Barbara Gillogly, Ph.D., LMFT, CPG

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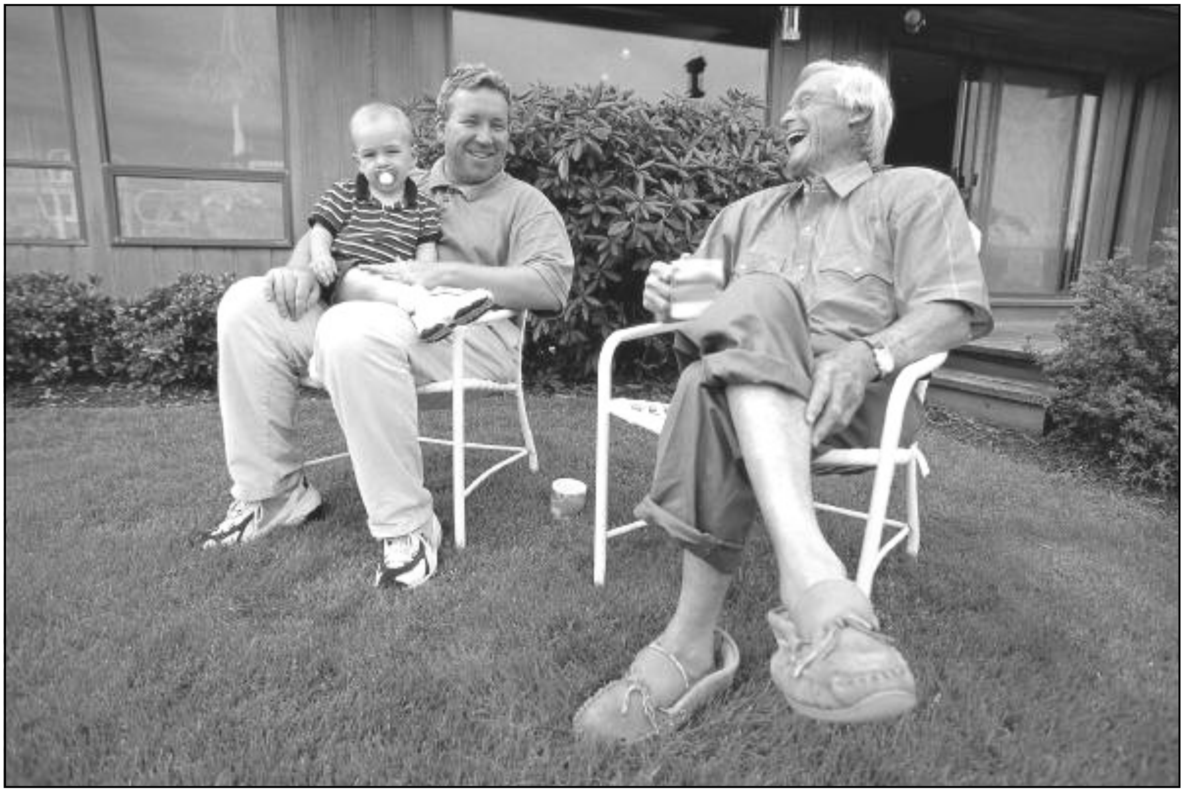
SUMMARY

Changing and adapting the home environment can promote better functioning while increasing safety. If the person with dementia is doing better, the caregiver will do better. There are many items available to help you provide safety and function for someone with dementia. One source is "The Alzheimer's Store" which can be accessed online at www.alzstore.com or by phone at 800-752-3238.



END STAGE OF ALZHEIMER'S AND HOSPICE

Clara Jackson, RN

As abilities fade it becomes more difficult to figure out how to stay in touch with the person with Alzheimer's disease. The person may no longer recognize you or understand speech. However the sound of your voice and holding your hand can be comforting. Massaging hands and feet with scented lotion helps to stimulate the senses. Music is stimulating and comforting, especially if it is music your loved one grew up with. Visitors and laughter may provide comfort and stimulation even if the visitors may not be recognized. Flowers, plants and the outdoors are stimulating if the person can be in a wheel chair. This is enjoyment for the care giver as well.

End stages are stressful for family members including children. Explain events in a kindly way to children in terms they can understand. There may be family conflicts and differences concerning care, treatment and placement. A professional advisor can help the family in coming to agreement and preparing for the inevitable loss. Hospice services, bereavement experts and spiritual advisors can help you work through your feelings.

In spite of the best of care the disease wins and your loved one approaches the end of life. Health declines as body systems begin to shut down. Swallowing is impaired, speech is lost and walking is no longer possible. Communication, if at all, is through moans or cries. The brain is no longer able to interpret sensory input. Sleeping is increased. There is no bowel or bladder control. The person is bedridden and requires total care around the clock for all functions of living. The person may develop an intermittent fever. Average length of life in this stage is a matter of days to a few weeks. Although all physical and cognitive functions are depleted the capacity to feel frightened, lonely, sad, secure, or loved is still there. The emotions remain.

Hospice care is considered when someone with a terminal illness no longer responds to medical intervention and has a life expectancy of six months or less. Hospice care is usually available around the clock every day of the week. It is provided in the home, hospital, private care facility or nursing home. Nurses, doctors, social workers, home health aides, volunteers and clergy are just a few who make up the hospice team. Hospice does not provide direct caregivers but does assist by training caregivers and offering support to them, whether family members or professionals. Hospice workers focus on the family as well as the patient. Hospice always provides palliative (comfort) and compassionate care specialized for the dying patient. Palliative care does not hasten or delay death. It means taking care of the whole person in body, mind and soul, helping the patient to live out his/her life in a comfortable way by relieving symptoms and pain. A reputable hospice supports their client's faith by encouraging contact with their own clergy, offer chaplain assistance if needed, provide volunteers to read spiritual resources as requested. They do not take the place of the family's spiritual mentor.

Hospices can be funded in many ways but usually Medicare covers the cost of care. Most hospices belong to the National Hospice and Palliative Care Organization (www.nho.org) but each hospice is its own entity and runs itself accordingly.

Professor Mark Braun in the journal **Clearly Caring**, Second Quarter 2010, Vol. 30 / Number 2 writes about a movie he saw 40 years ago based on a 1930's novel, "They Shoot Horses...". In the movie Robert shoots his girl friend, Gloria, who wishes to die. Questioned by the police, he responds, "They shoot horses, don't they?" He implied that he was acting from an ethic of compassion. Isn't it more merciful to end a hopeless or pain filled life than to force people in such straits to go on living? But Brian Pollard, retired anesthetist and palliative care physician, has called such termination of life a "form of abandonment." *Compassion*, he notes, derives from Latin and means "to suffer with." In reference to dying patients, it translates as walking the rest of life's journey beside them, offering comfort and support at every stage. To end their lives is an act of abandonment, not compassion. It does not address the best interests of the patient but is often done because the journey is too difficult on the others. (Used by permission from **Clearly Caring**.)

BEHAVIOR MANAGEMENT: DEMENTIA

Barbara Gillogly, Ph.D., LMFT, CPG

INTRODUCTION

- Problem behaviors need understanding and managing.
- All problem behaviors have an underlying cause—anger, frustration, pain—physical or psychological, effects of medication, or lack of understanding.
- Determine if this is a lifelong pattern of behavior or behavior developed to cope with late-life changes. Some lifelong patterns are depression, negativity, suspiciousness, bullying, manipulation, bipolar disorder, personality disorders.

  NOTE: medication for lifelong problems needs to be continued but closely monitored for changes in metabolism and interactions with other drugs.
- Those with dementia don't perceive the world in the same way you do. Nevertheless, their perceptions are very real to them.
- If they see and understand the world differently, it follows that your line of logic and explanation probably won't be accepted.
- In trying to cope with their perception of the world and their diminishing control over it, Their behavior may become strange, disturbing, and/or irritating.
- You need to understand the behavior, why it's occurring, and how you can change the environment and/or your own behavior in order to minimize the problem.

WHAT IS PROBLEM BEHAVIOR?

- Does it interfere with daily functioning? Does it have the potential to harm the person or someone else? Does it bother the person exhibiting the behavior?
- Sometimes it is difficult to differentiate the person's behavior from your reaction to it. **EXAMPLE:** Is eating with fingers really a problem, or is the problem that it really bothers you?
- There is a need to evaluate the circumstances in which the behavior occurs.
- What was happening before the problem occurred?
  1. This helps you define the context of the problem and yields clues to finding a solution.
  2. What makes something abnormal is often defined by the context in which it occurs.

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PROBLEM SOLVING

- Identify the problem behavior being sure that it is not just your problem. You can work on only one behavior at a time.

- Try to identify the trigger for the behavior—where does it occur? What happens just before it occurs? What time of day does it occur? With whom does it occur?

- What purpose or need does the behavior fulfill? Need for attention, need to be left alone, need to feel a sense of power, need to be heard, need for reassurance, need to communicate?

- Define what you want to happen. Remember goals have to be considered in terms of both what is optimal and what is possible.

- The best approach to a problem is prevention--anticipating reactions, planning ahead, being aware.

    1. Preventing incontinence may involve a program of being taken to the toilet every two hours.

    2. Be aware of potential explosive situations and defuse them before they happen.

- Replace problem behavior with a suitable activity.

    1. People with dementia cannot perform as well as they once did; however, they often still have a desire to participate in activities.

    2. Suitable activities can make the person with dementia more satisfied, less apt to be anxious, and easier to look after.

    3. A suitable activity must keep the person involved and not cause frustration and anger.

- Change the environment

    1. Remove items - obstacles, clutter, confusion, distractions.

    2. Add items - signs pointing to the bathroom, a chair with armrests, warm colors.

    3. Modify the environment - Velcro instead of buttons, large spoon instead of fork, fencing for safety.

    4. Maintain a calm environment.

- Reassure the person continually that he/she is safe.

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BEHAVIOR MANAGEMENT: DEMENTIA

Barbara Gillogly, Ph.D., LMFT, CPG

Continued from page 32...

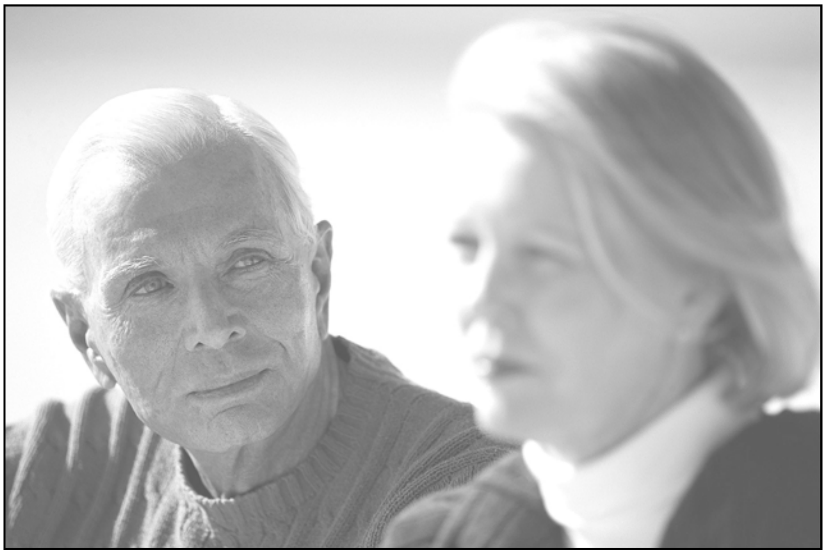
CHANGE YOURSELF

- Nothing is a "problem" until it is perceived and defined that way.
- Some behaviors are problems only because they are defined that way. Is hallucinating *really* a problem? Only if it interferes with the participant's functioning, produces fear or threatens someone.
- Otherwise, they're quirks, interesting behaviors, or differences in opinion about how things should be done.
- Problems that arise because of the way behavior is perceived and judged rather than because the behavior is truly harmful are usually due to one of two things:

  1. Limited knowledge or misinterpretation about the behavior or

  2. Extreme standards and expectations regarding how people should act.

  NOTE: If either or both of these are changed, behavior that was once a problem may suddenly become a non-problem.



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GENERAL PRINCIPLES

- Approach the person slowly from the front and stand within the person's field of vision—don't startle.
- Remain calm—speak in a calm and reassuring voice.
- Smile.
- Avoid confrontations and power struggles—don't argue or challenge.
- Never yell, scold or strike back at the person.
- Never make fun of or laugh at a confused person's behavior.
- Remember the confused person is frightened and needs to feel safe. Reassure the person that you will take care of the situation.
- Improve your communication:
    1. Stand where you can be seen and maintain eye contact.
    2. Gentle touch helps focus attention on the conversation.
    3. Don't expect a quick response.
    4. Look for visual clues of misunderstanding.
    5. Use simple, short sentences and avoid abstractions.
    6. Most sentences are too complex for the impaired person to understand:

       NOT: "Come here, Bill, it's time for you to eat your lunch."

       INSTEAD: "Bill, come here" "Here's lunch."

       Avoid sentences phrased in the negative:

       NOT: "Don't go outside."

       INSTEAD: "Stay inside"

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BEHAVIOR MANAGEMENT: DEMENTIA

Barbara Gillogly, Ph.D., LMFT, CPG

Continued from page 34...

GENERAL PRINCIPLES (continued from page 33)

7. Avoid offering difficult choices or decisions.

   EXAMPLE: "Bill, do you want to go to exercise group with Mary and Joe like you did yesterday, or would you rather try the new craft project with yarn and pictures that I bought yesterday at the store?"

   NOTE: This sentence is ten times too long to be understood.

8. Monitor your own tone of voice and body language – nonverbal cues speak louder than words.

9. Try using gestures, pantomime or pictures.

10. Don't speak "down" to the person with dementia. The person may act "childlike", but is still an adult and deserves respect.

11. Avoid topics that cause anxiety – don't say "don't you remember?" Talk about pleasant, easily accessed topics and memory.

- **Distraction** - one advantage of dementia is that the person is more easily distracted.

  1. You can often turn the person's attention to something else and the problem will be forgotten.

  2. This has to be done slowly and calmly so as not to add more frustration to the situation.

SUNDOWNING

Barbara Gillogly, Ph.D., LMFT, CPG

WHAT IS IT?

Approximately one quarter of patients with Alzheimer's-type dementia exhibit disruptive, restless, and/or confused behavior that tends to be more apparent in late afternoon or early evening.

The person may pace more, display increased anxiety, repeatedly ask questions, become more confused as to person and place.

WHY IT OCCURS

No one knows for sure why sundowning occurs, but there are several hypotheses:

- Being tired toward the end of the day.
- Disturbance in the circadian rhythms of a patient.
- In a darker setting, people and objects may become less distinct which can lead to anxiety, fear, and/or paranoia.
- Late afternoon is also a period of a natural drop in blood sugar that could lead to agitated behavior.

WHAT CAN YOU DO ABOUT IT?

- Exposure to bright light during the day.
- Playing quiet, soothing music during the sundowning period—music previously enjoyed by the individual.
- Increasing the light in the environment.
- Offering a late afternoon snack containing some protein.
- Minimizing sensory input—creating a calm, soothing environment.
- Minimizing expectations of the person with dementia.
- Low doses of anti-anxiety medication may be helpful.

SPECIFIC BEHAVIOR PROBLEMS: DEMENTIA

Barbara Gillogly, Ph.D., LMFT, CPG

WANDERING

Memory impaired individuals tend to stray away when they are agitated or angry. Wandering is more likely to occur when the patient is in an unfamiliar situation or the caregiver is distracted.

- Wandering is 0ften a response to a need to move or to find something or someplace. The impaired person may have excess energy, or a need for stimulation.
- Walk along with the person and then gently guide them back to safe area.
- Do not reprimand.
- Provide them freedom to walk within safe areas.
    - Use fences or hedges to secure areas.
    - Place latches and locks on gates either higher or lower than normal – but, insure ease of exit in emergencies –a sliding bolt at floor level.
    - Block or lock exits to balconies.
    - Ponds, pools, creeks need to be fenced off.
    - Place secure gates at the top and bottom of stairs.
    - Camouflage exits to areas that are unsafe, use child-proof door knobs.
    - Securely lock outside exits. Install an alarm that sounds when a door is opened.
    - Place large "STOP" signs on doors you do not want opened. Also, try a barrier such as a curtain or colored streamers to mask the door.
    - A black mat in front of the door may appear to be an impassable hole the dementia patient will not try to cross.
    - Put away items that the person will not leave without such as coat, purse, keys, glasses.
- Use nightlights in the person's bedroom, bathroom, and hallways to decrease nighttime confusion.
- Have the person wear ID bracelet. Keep current photos in case you need it for the police.
- Alert neighbors and police/sheriff to the possibility of the person wandering – make sure they have your phone number.
- Provide regular exercise to dissipate excess energy.
- Never restrain - this just escalates the situation.

AGITATION

- Maintain your own calm.
- Take the person to a quiet area.
- Assess for any physical discomfort: thirst, hunger, pain, need for toileting, overstimulation.
- Use validation: respond to the person's emotions, ask non-threatening questions about whatever is upsetting the person, help him/her to talk about it.
- Listen without rationalizing, explaining or denying.
- Listen to quiet music.
- Talk soothingly about familiar things.

DENIAL OF THE NEED FOR HELP

- Explanations are useless and only increase resistance.
- Normalize the situation and emphasize how we all need help.
- Have their doctor "prescribe" the help or level of care.
- Speak of the help in terms of your help being temporary—until the person "gets better".

VIOLENCE

- Combativeness is a response to either external or internal stimuli - it is a response to fear and/or frustration.
- Stop whatever activity that is going on.
- Take five steps back.
- Stay calm and then offer your hands, palms up.
- Apologize—even if you think you did nothing wrong—this is about the impaired individual, not about you.
- Never strike back or use force unless the person is in immediate danger.
- Reaffirm your caring for the person—let him/her know you will keep him/her safe.
- Move to a quiet place, if possible.
- Encourage the person to talk about what is happening and listen without judging.
- Evaluate the underlying cause of the combativeness:
  - ◊ Is the person overtired?
  - ◊ Is it due to medication side effects?
  - ◊ Is the person in pain?
  - ◊ Was the person over stimulated?
  - ◊ Was the person in an unfamiliar environment?
- Try not to take it personally.
- Try not to act afraid—the person will sense your fear.
- Sometimes pets or stuffed animals can soothe the person.
- Request that the doctor re-evaluate medications.

SUSPICIOUSNESS

- May be due to loss of control, insecurity, being threatened or a need to preserve self-esteem.
- Don't argue, but ask factual questions regarding the problem.
    - "What color was your purse?" "How big is it?" "Do you always carry it?"
    - "I'll help you look for it."
- Reassure the person of your love and caring.
- Check the trash routinely.
- Don't argue or rationalize – respond to the emotion and provide reassurance.
- Don't take accusations personally—remember it is the disease talking, not the person.

INAPPROPRIATE SEXUAL BEHAVIOR

- All individuals, regardless of age, have a need for love, touch, companionship and intimacy.
- Due to a lack of understanding of the sexual needs of older adults, the impaired person's sexual interests are often viewed as behavior problems rather than a need for love and intimacy.
- Distinguish between inappropriate sexual behavior and just normal sexual desire.
- With dementia there is a loss of inhibitions, but not a loss of normal sexual urges. Care givers need to understand that this loss of judgment and inability to control impulses or judge what is socially appropriate are due to the dementia.
- Confronting the impaired person or trying to reason with him/her is useless.
- Gently guide the person to a private place where the behavior may be more appropriate.
- Distract rather than confront.
- Don't shame or demean.
- Adjust clothing for comfort and to make inappropriate undressing more difficult. Put their trousers or dress on backwards or use pull-on pants with a drawstring at the waist.
- Give the person plenty of physical contact in the form of stroking, patting, hugging to satisfy the need for physical contact and reassurance.

BEHAVIOR MANAGEMENT: CONCLUSION

Barbara Gillogly, Ph.D., LMFT, CPG

CONCLUSION

- Similar to young children, people with dementia have difficulty differentiating between what is factual and what they are thinking about.
- The person is not willfully forgetful, rude, or combative, but cannot control his/her behavior.
- Don't waste time and energy fretting over what cannot be changed.
- Praise and support the abilities that are left; find tasks the person can do reasonably well, and try to avoid frustrating situations.
- Remember, all behavior has a reason, even though you don't understand it.
- Remember what works today may not work tomorrow. What works for someone else may not work for you. Tomorrow it may all be different.
- "Tips for Responding to Challenging Behaviors" *
  - Stay calm and be understanding.
  - Be patient and flexible.
  - Look for reasons for each particular behavior.
  - Respond to the emotion, not the behavior.
  - Don't argue or try to convince.
  - Acknowledge requests and respond to them.
  - Accept the behavior as a reality of the disease and try to work through it.
  - Explore various solutions.
  - Find other outlets for the behaviors.
  - Use memory aids.
  - Try not to take behaviors personally.
  - Talk to others about your situation.
  - Find time for yourself.

**Alzheimer's Association*

Distinguishing Between an Advance Health Care Directive (AHCD) and a Power of Attorney for Health Care (PAHC)

Ulric N. Duverney, Esq.

Often when I'm preparing or reviewing an estate plan for a client I am asked if there is any difference between a living will, advance health care directive and a power of attorney for health care. I give the usual attorney answer "it depends on what's contained in the document."

Traditionally, a living will is a quality of life/end-of-life statement. Typically the person creating the living will with indicate that if their physical condition deteriorates to the point where machines are necessary to keep them alive they do not want to be "hooked up" or if they are in a vegetative state, that they are not to be revived should their heart stop beating.

As people became more proactive in their health care, advance health care directives became more common. In the advance health care directive you could make an end of life/quality of life statement plus you could indicate whether or not you would agree to undergo certain types of medical treatment if the need arose.

With a power of attorney for healthcare you are authorizing someone to make your health care decisions for you when you are incapable of doing so on your own. In the health care power of attorney you can also include quality of life/end of life terms as well as state if there are certain medical procedures you would or would not be willing to undergo.

In California, there are two primary types of health care documents executed by a person when planning for future health care decisions: and advance health care directive (AHCD) and a power of attorney for health care (PAHC).

A PAHC is defined as "a written instrument designating an agent to make health care decisions for the principal." In comparison, an AHCD means "either an individual health care instruction or a power of attorney for health care." Thus, an AHCD usually includes both designation of an agent and health care instructions, but may be only a written health care instruction that indicates a preference for a type of health care without designating an agent.

Under the Health Care Decisions Law, there are two basic types of AHCDs: a statutory form and any other writing such as attorney-drafted forms. This law authorizes an adult having capacity to make an oral or written "individual health care instruction" that provides direction for future health care decisions or for the patient to appoint an agent under a power of attorney for health care. The PAHC is durable when the principal provides that is shall not be affected by the subsequent incapacity of the principal; in other words, it "endures" incapacity.

An AHCD may grant authority to the agent to make personal care decisions for the principal. These decisions include determining where the principal will live. Thus it may be helpful to include specific provisions in the AHCD that address personal care concerns.

Under California law there is a rebuttable presumption that a patient has capacity to make a health care decision and to give or revoke an AHCD. Unless otherwise provided in an AHCD or PAHC, the authority of the agent becomes effective only on a determination that the principal lacks capacity. Capacity is defined as "a person's ability to understand the nature and consequences of a decision and to make and communicate a decision, and includes in the case of proposed health care, the ability to understand its significant benefits, risks, and alternatives."

Unless the AHCD states otherwise, a determination of capacity or a determination of the authority of the agent shall be made by the primary physician. The 'primary physician" is generally defined as a physician designated by the patient or the patient's agent, conservator to have primary responsibility for the patient's health care.

The agent has a duty to act consistently with the principal's desires as expressed in the PAHC or otherwise made known to the agent at any time or, If the principal's desires are not know, to act in the principal's best interest, and the law requires the agent to consider the principal's personal values when determining what would be in the principal's best interest.

When you appoint an agent under a health care power of attorney you are making that person your eyes, ears and voice with respect to your health care when you are incapable of making these decisions on your own. It is very important that you discuss with your agent your philosophy and feelings with respect to types of medical care you are willing to undergo, and your quality of life and end-of-life decisions. It is important to select an agent who is not in conflict with your philosophy and feelings on these subject matters.

One final note, after you execute your power of attorney for health care, make sure your loved ones are 1.) Aware that it exists and 2.) they know where it is. Without knowledge of your power of attorney or possession of it, it is very likely that your wishes may not be carried out.

WILLS AND TRUSTS

Arturo Benavidez, Esq.

Benavidez Law Firm

Wills and Trusts are devices which can be used to provide for the distribution of your estate upon your death. In deciding whether a Will or a Trust best fits your needs you must look to your own unique set of circumstances.

What does a Will do?

A Will is the legal document that, upon your death, allows you to distribute your property to beneficiaries of your choice. Beneficiaries can receive specific items from your estate or receive everything in your estate. You might give your two children, for example, all of your estate, to share equally, but reserve the antique coin collection as a specific bequest to your nephew, Sam.

To ensure that your wishes are carried through, you would appoint an executor of your estate. That person/entity will be in charge of your estate during the distribution of your assets, pay your bills and/or initiate probate proceedings. In California (as of 2015) an estate worth $150,000.00, or more, will have to go through the probate process, even with a valid Will.

A Will can give the parents of minor children the opportunity to nominate a guardian. Ultimately, the court will make the final decision as to who will be the guardian for your children after your death, but the court will try to honor your nomination.

A Will can be as simple as a statement in your own handwriting (holographic will), dated and signed by you, declaring who will be executor and who will receive property upon your death.

What does a Trust do?

As stated above, a Will comes into effect only after you die. However, a trust can benefit you while you are still alive. Trusts can be revocable or irrevocable. A living trust is a revocable trust established during your lifetime. You are both, the Grantor (person creating the trust) and the Trustee (person managing the trust). You are also the beneficiary of the trust during your lifetime. Therefore, all of the assets in a revocable trust are still under your control, used for your benefit and the trust is changeable (by amendment). Living Trusts become irrevocable (unchangeable) only upon the Grantor's death.

A Living Trust is used as a device to manage your property before and after your death. Should you become incapacitated, or disabled, the trust is in place to manage your financial affairs through a successor trustee that you have previously nominated. Upon your death the distribution of the assets of the trust are a private affair as a trust avoids the publicity of probate.

Trusts can be as simple or as complex as your estate demands. The most common trust today is the Living Trust, a revocable trust as described above. There are Marital Deduction trusts that allow a doubling of the Federal Estate Tax exemption for a husband and wife. There are irrevocable Special Needs Trusts, Medicaid Trusts and Intentionally Defective Irrevocable Grantor Trusts. These trusts offer more than just probate avoidance, they can offer tax avoidance and asset preservation as well.

In essence, a Trust should be made like a good suit, tailored to your needs and desires.

VETERANS AFFAIRS AID AND ATTENDANCE BENEFITS

Compiled by Max Perry, JD

ELIGIBILITY CRITERIA

1. Age 65 or older or disabled
2. Have an honorable or general discharge from the military
3. Served at least 90 days active duty with at least 1 day during any of the following:
    - WWII – December 7, 1941 thru Dec 31, 1946
    - Korea – June 27, 1950 thru January 31, 1955
    - Vietnam Conflict – August 5, 1964 thru May 7, 1975
    - Persian Gulf – August 2, 1990 to a date to be determined
4. Have a medical diagnosis that requires daily assistance with at least one or two of the following ADL's:

Bathing	Personal hygiene	Feeding
Dressing	Toileting	Meal preparation
Grooming	Ambulation	The need to live in a protected environment.

5. Have limited income and net worth that does not provide adequate maintenance. Whether a veteran or a claimant has excessive net worth is determined on a case-by-case basis.

Maximum Monthly V.A. Benefits for 2016

Veteran with Spouse	$2120.00
Single Veteran	$1788.00
Surviving Spouse	$1149.00
Veteran's Spouse	$1406.00

MEDI-CAL BENEFITS
AND LONG TERM CARE FOR THE ELDERLY

Compiled by Max Perry, JD

What is Medi-Cal?

Medi-Cal is a combination of federal and California funds for public assistance recipients and other low-income persons. Unlike Medicare, an entitlement, Medi-Cal is a needs-based program. Once eligible, Medi-Cal covers medically necessary services that Medicare does not fund.

Eligibility

Eligibility is based upon the applicant's assets. In 2016 the property limit is $2000.00. That is in addition to exempt, or non-countable assets such as the home, other real property subject to value to income standards, household goods and personal effects, one automobile, IRAs, a prepaid irrevocable burial plan, term life insurance, (whole life insurance if the value does not exceed $1500) and other assets subject to certain limitations and conditions.

Share of Cost

The Share of Cost for a Medi-Cal recipient in a skilled nursing facility is the amount of income the recipient receives less any monthly medical premiums (such as the Medicare Part B premium) and $35 (the Long Term Care person's maintenance need). The balance of the recipient's income will be designated as the recipient's share of cost for skilled nursing care.

The Non-institutionalized Spouse

The community spouse can retain a Community Spouse Resource Allowance of up to $119,220 (as of 2016) as well as other exempt assets such as pensions, retirement funds and IRAs. The community spouse can also retain a minimum monthly maintenance needs allowance of up to $2,981 per month (in 2016) allowing the community spouse the opportunity to keep some, or all, of the institutionalized spouse's income.

The amount of income to the community over the minimum monthly maintenance needs allowance will be considered as the share of cost obligation for the institutionalized spouse's care.

Spending Down

Excess property owned by the Medi-Cal recipient can be spent down until the property is reduced to the Medi-Cal resource limit of $2000. If excess property is given away 30 months prior to an application for Medi-Cal there may be an ineligibility period established from the time of the gift. Gifting exempt property will not trigger an ineligibility period even if gifted during the 30 month look back period. Non-exempt property can be transferred without creating an ineligibility period provided that the gift does not exceed the average private pay rate for a skilled nursing facility as determined yearly by Medi-Cal ($8,092 as of 2016).

Medi-Cal Recovery

Medi-Cal can recover its expenditures from the recipient's estate after the Medi-Cal recipient dies. The Medi-Cal recipient's home is exempt from lien while the spouse, child or sibling is living there provided the beneficiary indicated an intention to return to the home on the Medi-Cal Application. If Medi-Cal is used for long term care it is important that prudent estate planning be implemented to avoid a Medi-Cal recovery lien on estate assets.

RESOURCES FOR PROVIDING CARE

Cynda Rennie, Resource Specialist

As Alzheimer's progresses the caregiver's burden increases. No caregiver can do it alone; many try but the price they pay is often exhaustion resulting in health problems of their own. Family members and dear friends rarely are able to relieve the caregiver sufficiently. In most cases family and friends just don't have enough available time.

The options available include hiring a caregiver yourself, hiring an agency to provide a caregiver, utilizing a day-care program, or placement of your loved one in a long-term-care facility for respite or full-time care. Here and in the pages that follow, are a review of these options. Also, please be sure to see the pages in the **Legal Issues** section of this book to learn more about public and veteran benefits which may defer some of the costs of care.

Hiring A Caregiver

Advertising for, and hiring a caregiver for your loved one, without help from an agency, can save money but is not recommended for most people. There are cautionary tales as you can well imagine. It is an option for the individual who has expertise in checking backgrounds and references; interviewing and writing job descriptions. It is also important to check with a tax professional since you, or your loved-one, will be the employer.

Agencies for In-Home Care

Home Health Agencies

These agencies are licensed by the state to provide in-home care. They are a medical-model of care, meaning the primary care focus is health care. The Home Health Agency can provide a Home Health Aide to care for your loved one. Care is monitored by a registered nurse. Physical therapy, speech therapy and dietary consultation are also available. Some care requires a physician's referral, and Medicare or private insurance may pay for some services which are medically indicated. General care, including help with grooming, bathing, meal preparation and supervision are not covered by Medicare or private insurances. Some Long-Term-Care policies may cover care in all the categories mentioned on this page.

Home Care Agencies

These agencies hold a general business license, but have no specific licensure and are not regulated. They are a social-model of care, meaning the primary care focus is on the safety and well-being of the clients they serve. The staff is generally able to provide personal care and assistance, help with meals, errands, household chores and companionship. Some are able to provide incontinence care. Home Care Agencies are less expensive than Home Health Agencies.

While these agencies are not regulated by the state, there are many out there with good reputations for reliable care. Be sure to do your own homework: How long have they been in business? Is the agency bonded? Registered with the Better Business Bureau? How much caregiver training is offered? Is there training specifically for Alzheimer's Disease? How are the employees screened? Costs can vary from $20 to $26 per hour. There is usually a four-hour minimum.

IN-HOME CARE AGENCIES

Kelly Rogers, Gerontologist

In-Home Assessment is the first step when you have tentatively selected an agency.

Each agency has their own policies and procedures, however it is reasonable to expect the agency to send a representative who is knowledgeable of the philosophy and operations of its company. You should be able to get answers to any and all questions you may have. Prepare your list of questions and concerns before your interview. A few questions to include are **Does your agency:**

- **Specialize in dementia and Alzheimer's care? If so, how?**
- **Have caregiver requirements? (i.e.: min years of exp, state or national background checks, specific training)**
- **Have any upfront costs or deposits?**
- **Have Worker's Compensation and a Bond?**
- **Follow up and reassess periodically?**
- **Have any hourly or weekly rate and minimums?**
- **Have any testimonials and/or references?**

The agency should have experienced staff in Alzheimer's disease and memory loss.

The assessment should be approximately an hour long. It should generally consist of observing the person with Alzheimer's behaviors, mannerisms and ADL's (Activity of Daily Living). An assessment of the home is essential too. A proper assessment of the needs and personality is essential for a good plan of care.

Have the representative go over all of their written materials, policies and procedures with you at this time. Make sure you understand the entire working relationship prior to signing any agreements. Note: There should never be a "Contract" that forces you to use the agency for any period of time.

Go over the care needs, care plan, and consistent schedule with the set days and times to expect the caregiver's services. A set schedule will not only provide a helpful routine for the person's with Alzheimer's, but will also ensure the same caregiver providing services (A consistent caregiver and care plan routine is key).

The focus should always be on how the agency can maximize and personalize the quality of care. If the representative is focused on the "sale" and you feel any pressure, it would be wise to shop around until you find the perfect fit.

How to Maximize Your Caregiving Services

1st priority: Caring for all ADL's, while maintaining the person's dignity and safety at all times.

2nd priority (during up/awake time): Activities and hobbies that will trigger their long term memory (watering the lawn, gardening, music, crafts, etc...) This will increase their mental stimulation, neurotransmitter activity, circulation, and possibly the biggest reward of all.....self worth.

3rd priority (during down/nap time): Basic housekeeping (dishes, laundry, vacuum, dusting, bathrooms, sweeping, etc...). This is a great way to not only increase your quality time with loved ones by eliminating some of the household chores; it is also a great way to maximize the services you are paying for.

Remember...an In Home Caregiver becomes an extended family member to the person in need of assistance. Keep exploring until you find a good match.

WHEN YOU HIRE AN AGENCY CAREGIVER

Kelly Rogers, Gerontologist

Introducing a caregiver for the first time requires teamwork and communication between the family and the agency. Working together is essential in making the first connection to a "Stranger".

Here are some steps that will improve the initial contact:

Meet with the agency prior to the first day of care to go over the plan of care, life story, caregiver personality and skill level.

Make sure the agency and caregiver are fully informed about your loved one's likes, dislikes, pet peeves, preferences, interests, behaviors, etc...

Stay positive and optimistic. Always communicate in a nonthreatening, relaxed tone and body language.

Allow time for the caregiver and your loved one to develop a bond together. Keep in mind; if you act comfortable with the caregiver in their home then they will often follow/mirror.

If they are resistant to the idea of a "Caregiver":

The word "Caregiver" can create anxiety, fear and sometimes depression. We can avoid this by replacing it with: "Homemaker, Housekeeper, Attendant, Personal Assistant, or Friend."

Having a long term family member present that they know, recognize and trust for the first introduction can be very helpful and reassuring.

Ask your loved one for their help. Even a person with Alzheimer's likes to feel needed. Tell them that it's "You" that needs the "Homemaker" or "Friend" to come help with day to day needs.

Reassure them: "We will just give it a try." Take it one day at a time.

Although it might be challenging when introducing a new caregiver at first, over time it will get easier as the relationship and routine develop. The person with Alzheimer's might not always remember the new caregiver's name, but they will get familiar and respond to their touch, routine, voice, and personality which will develop their own trusting relationship with one another.

ADULT DAY CARE PROGRAMS

Cynda Rennie, Resource Specialist

Adult Day Care

Adult Day Care facilities are licensed under the State Department of Social Services. Some are able to provide supervision and care for Alzheimer's and dementia patients who may wander or need special attention.

In an Adult Day Care, you can expect appropriate supervision, a noon meal, a diverse activity program, and opportunities for socialization. Most centers do not provide transportation.

Generally, individuals sign-up for the schedule that best suits the needs of the patient and family. That may be one half-day per week, five full-days per week, or anything in-between.

Adult Day Care is not covered by MediCal, Medicare or private insurance. Some long-term-care insurance policies may include day care. Private pay costs vary and are usually lower than in-home care.

Adult Day Health Care

Adult Day Health Care facilities are licensed by the State Department of Health. Some can provide supervision and care for Alzheimer's and dementia patients who may wander or who need special attention.

Adult Day Health Care will offer the same services as the Adult Day Care centers. A hot meal, socialization and activities are comparable to what is offered at the Adult Day Care program.

The only real difference is, because of the Health Care designation, there are added optional/MD ordered services or therapies. Physical therapy, speech therapy, diabetes care and consultation with a registered dietician are some of the additional services available at this type of day care. Transportation is provided, door to door, within a determined number of miles surrounding the center.

Medicare and private insurance may pay for MD ordered therapies but will not pay for care and supervision. MediCal will pay in some circumstances. Some long-term-care insurance policies may include Adult Day Health Care.

Socialization and activities for the patient and a bit of a break for the caregiver.

The individual with Alzheimer's or dementia may be resistant to going to a day care setting. Changes in routine are often met with negative feelings. As you can imagine, it is very difficult to be in new surroundings when you have memory problems.

Your loved one may never learn the names of people at the center. They may not remember what type of a place it is at all. But, amazingly, people with Alzheimer's and dementia DO develop familiarity and a sense of belonging if given time to do so.

If you decide to enroll your loved one in a day care program, there are steps you can take to ensure the transition from resistance to enjoyment is as smooth as possible.

Consider going together for the first few visits. "We are signed-up at the Senior Center. We'll give it a try, if we don't like it, we'll quit." On the second or third day, tell your loved one you have to help someone with an errand, "I'll be back soon." As soon as he/she feels fairly comfortable you will be able to leave at the start of the program.

Do not call it what it is! If your loved one would be angry, frightened or insulted by the thought they may need supervision, then just refer to it as the Senior Center or The Club or any name which may be less intimidating

In the first weeks, your loved one may continue to be oppositional to going. Communicate well with the center's staff and give it several weeks at least. Most families find that, quite suddenly, the loved one begins to look forward to going. And, comes home with a smile.

CHOOSING A FACILITY

Cynda Rennie, Resource Specialist

There are only two categories for care in a facility. Within those two categories, or licensures, there is a huge variance in the type of care, level of care, and quality of services and living arrangements.

Assisted Living, Residential Care or Board and Care.

These facilities can vary in size from four beds to over one hundred. Regardless of what they are called, they all have the same license. They are licensed by the state Department of Social Services as

"Residential Care Facility-Elderly (RCF-E)"

These facilities ***must provide*** housekeeping, laundry, medication management, all meals and snacks, activities, and at least minimal assistance with daily dressing, grooming and bathing. They must monitor the resident and notify family and the doctor of changes.

RCF-E's ***may also provide*** a much higher level of care and supervision which may include incontinence care, supervision and safety for wandering, higher staff ratio and training for the behavior problems of Alzheimer's, assistance with all hygiene, dressing and grooming, lifting and transferring for non-ambulatory, hands-on assist with walking, and help with feeding. Some ***may provide, with a special waiver,*** care for insulin dependent diabetics, catheter care, or hospice care. Generally a Home Health Care Agency or Hospice Agency works with the facility and family for these special health care needs.

When you visit each facility, observe the peer group, view the menu and inquire about activities. Look at the available room and see if you can envision this room and bath fitting the needs of your loved one. Is the room close to common rooms and activity areas? Observe the cleanliness of the home and the interactions between staff and residents. If you have used a referral agency, homes that are unclean or have had poor reviews by the state should not be on your list.

Be brutally honest in describing the caregiving challenges your loved one presents. A good care home will tell you if that behavior or condition can be managed in their home. Protecting your loved one by omitting issues or by minimizing the challenges can result in a placement that fails.

Costs will vary widely in residential facilities and are usually based on the level of care and supervision needed by the individual. The small facilities which are typical homes in a residential neighborhood are usually lower in cost. Some people do better in small homes; others thrive in the large facilities because of a greater variety of social activities and more room to walk about.

Continued on page 52...

CHOOSING A FACILITY

Cynda Rennie, Resource Specialist

Continued from page 51…

Nursing Homes or Convalescent Hospitals

These large facilities are licensed by the state Department of Health as

"Skilled Nursing Facility (SNF)" or "Intermediate Care Facility (ICF)."

These facilities are "medical models," meaning the license focuses on health care needs. A person who has certain continuous nursing care needs such as bed sores or tube feeding must choose this category of care.

Since these facilities are licensed by the Department of Health, most are able to provide care through MediCal. Personal finances may limit placement options to those which accept MediCal.

Some SNF's have specific Alzheimer's units which are secured for patients' safety. A few specialize in providing dementia care throughout the facility. Some have "wander guards" and can care for mildly confused individuals. Some cannot, or will not, care for a person with any behavioral issues. Before you even visit a nursing home, make sure the facility is able to care for the particular needs your loved one has.

All ICF's and SNF's have physicians who visit each resident at least once monthly. Physical therapy, special diets, and speech therapy are all provided on-site if ordered by the physician.

There are several good websites that rate Nursing Homes and track complaints and other problems. One such site is: www.cnhs.org.

Closing Thoughts

Nursing Homes and Residential Care Facilities both provide care to seniors who cannot live alone. For Alzheimer's patients, Residential Care homes are often the best choice when finances permit.

For those on MediCal or who will deplete their funds in the next few months, a Nursing Home may be the only option. Contact the Alzheimer's Aid Society as you begin to consider placement.

A Resource Specialist can answer questions about long-term-care insurance coverage you may have and about the current California programs which may help cover costs. Our legal consultant can answer questions about Veterans Benefits and Medi-Cal eligibility.

Alzheimer's Aid Society of Northern California

Visit our Office.

Browse through our educational material and meet with a peer counselor. There are hand outs on many of the subjects in this blue book as well as other topics. There is a lending library. All of these services are free of charge.

Sacramento Area Office
2641 Cottage Way, #4
Sacramento, CA. 95825
916-483-2002

Toll Free: 800-540-3340

Phone us.

A peer counselor or resource specialist is available to talk with you. We will mail an information packet to you. These services are free of charge.

Attend a Support Group.

The Alzheimer's Aid Society offers caregiver support groups throughout Northern California. Support groups for persons with memory loss are offered in several sites. Phone us or visit our website to locate a group near you.

Sign up to receive our bi-monthly newsletter, either by mail or electronically via email.

Learn about up-coming events and new support group listings. Read an array of articles dealing with the stress of caregiving, understanding dementia, and other helpful information. We do not charge a membership fee or subscription fee for our mailed materials.

Attend a Mini-Seminar.

These are held throughout the year in a variety of locations in the northern state. Mini-seminars are usually held on Saturdays and feature two to three topics and speakers They are free of charge.

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Make an Appointment for Legal Help

Ulric N. Duverney, Attorney at Law donates one day per month to the Alzheimer's Aid Society to provide legal counseling free of charge.

Visit our website.

www.AlzAid.org

You can find past issues of our newsletter and links to our office websites. Learn about events. See support group listings. Contact us via email at:

info@AlzAid.org

Alzheimer's Aid Society

OF NORTHERN CALIFORNIA

Meet our Board of Directors!

SEATED, Left to Right:

Christina Ness, Treasurer

Sheryl Ashby, President

Clara Jackson, VP of Medical Information

Ashley Young, Executive Assistant

STANDING, Left to Right:

Steve Gianandrea, VP of Finance

Max Perry, VP of Development

Ulric N. Duverney Esq.

The seven members of our Board of Directors, combined, have over 100 years of experience and dedication to the patients and caregivers of Alzheimer's Disease. Four current board members have also been caregivers to a loved one.

OUR MISSION STATEMENT

Alzheimer's Aid Society

OF NORTHERN CALIFORNIA

We exist to provide support, education and compassion
to patients and caregivers
throughout the journey of Alzheimer's Disease,
to support medical research, and to promote public awareness.

The Alzheimer's Aid Society of Northern California
is a Non-Profit, Tax-Deductible 501 (c)(3) Corporation
Federal ID Number: 94-2721961

Thousands of these "BLUE BOOKS" are distributed annually, without charge, to new callers, support groups, health fairs, health agencies and Alzheimer's programs.

The printing of the "BLUE BOOK"
is done by the
A. Warren McClaskey Adult Center,
which offers job training and employment
to developmentally disabled workers
in the Sacramento area.
Their reasonable rates
and excellent service allow us to make
maximum use of donated funds.

Can You Help?

Your tax-deductible donation of **just $10.00** will cover the cost to print and distribute three "BLUE BOOKS" to caregivers right here in your community.

Your tax-deductible donation in **any amount** will assist in maintaining and expanding services in Northern California such as support groups, peer counseling, seminars, newsletters, respite care, and more.

Please use the donation envelope in the center section of this book or mail your donation to:

Alzheimer's Aid Society of Northern California
P.O. Box 60095
Sacramento, CA. 95860

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Since 1981

Every donation, in any amount, provides help LOCALLY!
THANK YOU!