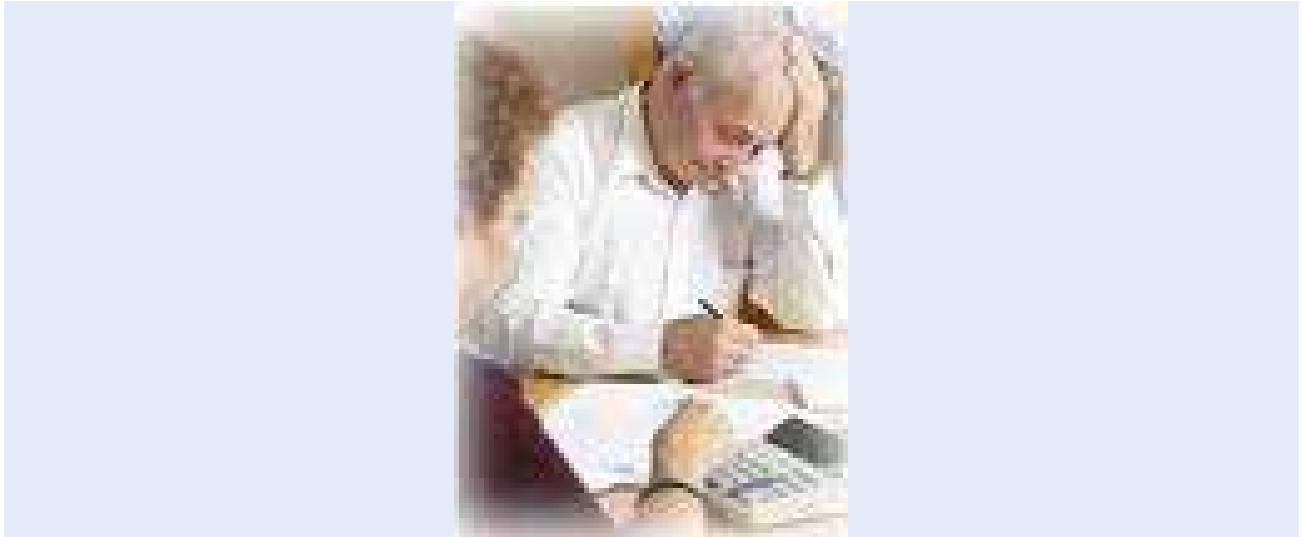


# A HELPFUL HINTS GUIDE



*When Dementia  
Begins to Cause  
Changes and Challenges  
For You and Your Loved Ones*

*By Mary Jo Gibbons, MPA, NHA  
January, 2007*



*Mary Jo Gibbons and her father,  
James Jackson Johnson Jr.  
Age: 76 years old  
Devoted Husband  
Proud Father of 6 Children  
Loving Grandpa of 15 Grandchildren  
Faithful Friend to Many  
Successful Business Owner  
Avid sports fan and former outstanding  
athlete  
Respected and admired by all who know  
him*

*I am a daughter blessed with a wonderful father who was unfortunately diagnosed with Alzheimer's disease in his early so called "Golden Years." I had already been working in the long term care field for many years when my professional passion of specializing in Alzheimer's care turned deeply personal. I had the privilege of having my father reside at a Specialized Alzheimer's Assisted Living facility that I had developed in Kalamazoo, Michigan. It was then, the concept of person-centered care became evidently clear and preserving "his" and other's "personhood" was very important to me. Like many of you traveling this ill-fated journey, I can relate to the rollercoaster of emotions that are experienced and want to serve as a support and advocate for you.*

*People encounter dementia in different ways, in different degrees, and to different extents. Some notice changes or peculiarities in behavior, some recognize increasing forgetfulness or repeating of oneself. Some experience it gradually while others may have a more sudden onset. In any case, it is cause for concern for the individual and their family which creates lots of questions.....  
What is happening? Why is this happening? What do we do?*

*People respond to dementia in different ways as well. Can you imagine the fear and frustration it must bring to realize something is happening to you and it's out of your control? Some try desperately hard to cover it up while others openly admit and painfully joke about it. Denial is also a common response which can bring about greater problems in prolonging appropriate treatment and care by refusing to accept the changes in one's mental capabilities.*

*My personal philosophy is to educate yourself, focus on your loved one's well-being and what really matters. Embrace each moment. Make the most of the good and try to minimize the bad. Work with professional caregivers in a unified way to share in the responsibilities together of caring for your loved one with a "we" approach instead of "us" and "them." Have realistic expectations so that contentment and satisfaction, which leads to greater peace, wins over disappointment and dissatisfaction.*

*You know your loved one's wants, needs, and desires better than anyone else, so by sharing this information with all who come in contact with him/her is extremely helpful. The caregivers are then given the knowledge and tools to provide more personalized service based on what is really important.*

*I have much to share in hopes of helping in some small way.*

*My purpose in providing you with this Helpful Hints Guide is to:*

- 1. Present information that enhances your understanding and acceptance of Alzheimer's disease and related dementias.*
- 2. Provide suggestions for strategies and techniques in responding to your loved one with Alzheimer's disease and/or related dementia.*
- 3. Provide resources on where to turn so you know that you are not alone on this journey.*

*May you always keep the faith and  
find the beauty in every moment*

*Mary Jo Gibbons,  
Daughter of Jim Johnson  
Executive Director of The Gilbert Residence*

*No longer do I lean on him  
Instead he leans on me.  
No longer does he make requests  
Yet still I feel his plea.  
No longer can he say my name  
Instead I hear his heart.  
No longer can I bear his pain  
Yet still I can't depart.  
No longer can he walk so tall  
Instead I watch him sleep.  
No longer does he joke a lot  
Yet still his laughter runs so deep.  
No longer are his eyes so sharp  
Instead I see his pain.  
No longer are the days so bright  
His smile's the rainbow in the rain.  
I feel his love; I feel his strength;  
I feel his sorrow too.  
I know my husband's deep inside  
Behind the eyes of greenish blue.*

*Poem written by Beverly Johnson,  
Wife of Jim Johnson  
Mother of Mary Jo Gibbons*

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## **HISTORY:**

The Gilbert Residence is a not-for-profit senior health care community with a long history of service to the Ypsilanti/Ann Arbor area. It was founded by Mr. William Gilbert, a banker in Grand Rapids, Michigan, as provided by his will upon his death in 1935. A substantial portion of his estate was left to begin “The Gilbert Old Peoples Home of Ypsilanti” in honor of his mother. A few years later, his sister, Alice Gilbert, passed away and also left a portion of her estate to the organization. These contributions allowed the organization to begin meeting the needs of elderly citizens of the area and eventually construct the current building in 1960.

The Gilbert Residence currently operates as a small continuing care retirement community. It has a 32 person licensed Nursing unit and a 40 person licensed Assisted Living unit. In the Assisted Living area, a 10 person specialized dementia care unit named “*Grace Hall*” has been added to meet the unique needs of persons with Alzheimer’s disease and related dementias.

## **MISSION:**

*“Our Mission is to continue a tradition of excellence by providing compassionate and dignified care for seniors in our community.”*

Providing quality care for which The Gilbert Residence have become so well known for is our goal. By providing for the welfare and happiness of those who reside here, we are serving as an extension of their families.

## **PERSON-CENTERED CARE CULTURE:**

- ❖ Recognizing men and woman in their full humanity
- ❖ Centrality of relationships
- ❖ Uniqueness of persons- their “very being”
- ❖ Recognition
- ❖ Respect
- ❖ Trust
- ❖ The use of abilities
- ❖ The expression of feelings
- ❖ Enabling the exercise of choice

Source: Tom Kitwood  
Dementia Reconsidered

**THE GOAL OF PERSON-CENTERED CARE:**

*To minimize Ill-Being and maximize Well-Being!*

**Ill-Being**

**Well-Being**

Loss.....	Fulfillment
Loneliness.....	Connectedness
Sadness.....	Cheerfulness
Confusion.....	Orientation
Worry/Anxiety.....	Contentment
Frustration.....	Peacefulness
Fear.....	Security
Paranoia.....	Trust
Anger.....	Calm
Embarrassment.....	Confidence

**PHILOSOPHY OF DEMENTIA CARE:**

Resident rights, dignity and choices are highly regarded with the utmost respect preserving the basic human right of “*personhood.*”

We advocate for a *specialized approach* to care for persons with cognitive deficits such as Alzheimer’s disease and related dementias. We accomplish this on *Grace Hall* through a carefully planned “Activity-Focused” program that is “Person-Centered.” Each area of life such as sleeping, eating, grooming, working, and playing makes up all of life’s components and becomes blended, not disconnected separate activities. Involvement in these activities will be simplified, broken down into steps and/or adapted to meet specific needs and functional abilities so that persons with dementia can be more involved in *active doing* rather than passively having tasks done for them. Dignity and the inner sense of worth arise from work or integrated occupations, including daily living activities and recreation.

The “activity” of life is a search for meaning and purpose. Each resident will have a strength-based service plan developed that is tailored to their individual abilities and challenges while striving to most closely replicate their previous lifestyle’s interests, familiarities and routines. Family members and authorized representatives play a vital and cooperative role with staff in the creation of this plan.

We believe that a stable, friendly, relatively simple environment, placing few demands on the resident will tend to minimize the likelihood of associated challenging behaviors often caused by rigid approaches to meet the demands of a dictating clock or by the environment itself. We must support persons where they are at cognitively instead of forcing them into our reality placing unrealistic expectations upon them.

Consistency and flexibility are both critical to balance. For example, allowing residents to gradually get up at a leisurely non-stressful pace instead of the traditional rush by a certain time promotes a more positive tone for the start of a day. Also, residents with altered sleep/awake

cycles will be supported during the night time hours when awake instead of being insisted upon returning to bed. Furthermore, residents who have a limited attention span and inability to sit for certain duration of time, such as for dining, will be assisted in eating finger foods while they walk and offered frequent nutritional snacks and hydration. Supportive and flexible staff approaches are the intervention methods which best reduces the frequency and intensity of behaviors that are associated with dementia. Success is often determined by the approach. Since persons with dementia are relatively well physically and most often ambulatory, they are often *not* in need of extensive medical intervention, rather more in need of social roles from a “social model” of care.

We recognize that the size of a residential living environment for persons with dementia is of utmost importance, both in terms of physical space and the number of other residents and staff. With an appropriate number of residents (10), staff can provide a far more therapeutic and non-stressful environment. A warm, cozy, home-like environment is preferred enabling staff and residents to develop a much closer relationship and activities of daily living are more easily organized and managed. We provide a therapeutic program that is sensitive to resident needs and responsive to their moods with an effort to constantly be creative and innovative in individual approaches and interventions. Each staff member is carefully selected based upon their interest level and demonstrated passion for persons with dementia. They receive comprehensive and continual training with emphasis placed upon how to “prevent and avoid” rather than “react and manage” challenging behaviors and situations.

Both social and physical environments can be significant factors in the care of persons with dementia. We strive to achieve a proper balance of stimulation so as to avoid “over-stimulation” which creates greater confusion and “under-stimulation” which creates greater apathy and loss of functioning. The environment is designed and programmed to help residents continue to function optimally and to support positive behaviors. Residents are able to continue the familiar tasks of everyday life such as washing and drying dishes, setting the table, dusting, vacuuming, folding clothes, planting flowers, singing, dancing, playing the piano, and caring for a pet to name just a few. Outside each resident room there is a life history frame complete with photos and personal information highlighting the resident’s life favorites and accomplishments. The individual rooms are personalized with their own furniture, wall décor, and special keepsakes to provide a sense of familiarity and identity. Grace Hall is a secured and safe environment with an enclosed outside patio preventing a person with dementia from leaving the building or grounds unsupervised.

Psychosocial well-being, peer support and communication are essential for loved ones and caregivers. The family is an integral part of the care giving team and works closely with the staff as well as receives educational and emotional support and assistance during visits. Grace Hall fosters a spirit where friendships and loving relationships are freely formed by all whom are connected giving it that family feel. Humor is a necessary ingredient to managing the associated stressors for residents, families and staff. Promoting lively, fun and meaningful moments while honoring choices are what really *matter*.

Philosophy Developed by  
Mary Jo Gibbons

## GOALS

1. Safety and Security
2. Support Functional Ability Through Meaningful Daily Activities
3. Maximize Well-Being and Awareness
4. Provide On-going Opportunities for Stimulation
5. Maximize Autonomy and Control
6. Adapt to Changing Needs
7. Establish Links to the Healthy and Familiar
8. Provide Daily Opportunities for Socialization
9. Protect Need for Privacy and Dignity

## Gilbert Residence Dementia Continuum of Care

CARE LEVEL	FUNCTIONAL LEVEL	NEEDS
Day Services Supportive Care and Assisted Living	Early Dementia – Mildly Confused	Verbal Cueing and Directing Initiating and Reminding Physical Prompting
<i>Specialized Dementia Unit            “Grace Hall”</i>	<i>Middle to Late Dementia            Highly Active            Wandering            Challenging Behaviors</i>	<i>Highly Trained Staff            Higher Staffing Ratio            Specially Designed Activity –            Focused, Person-Centered Program            Specially Designed Environment</i>
Nursing Care	Late to End Stages of Dementia Immobile, Bedridden	Medical Intervention Sensory Stimulation Hospice Care

## *What is Happening to My Family Member?*

### **What is Dementia?**

In most cases, it's a gradual loss of mental abilities. It is marked by changes in:

- Memory
- Personality
- Behavior
- Thinking Abilities

Signs may include:

- Forgetfulness- Trouble remembering names, dates, events, directions, the location of household objects.
- Confusion- It may be difficult to follow instructions or learn new skills. Judgment and reasoning may also slip.
- Withdrawal- This can be combined with low energy, hostility, mistrust of others, loss of interest in formerly enjoyable activities.

Signs can progress over years, or within weeks, depending upon the cause.

Dementia is *not* a disease – it's a condition that may occur along with certain medical and mental health problems.

Dementia is *not* a normal part of aging. Most older people do *not* develop dementia or dementia like symptoms. However, people over 65 are at greatest risk.

Dementia may be caused by **REVERSIBLE** conditions such as:

- Metabolic Disorders
- Alcoholism – treatable though not technically reversible
- Mental problems- such as anxiety, depression, etc.
- Poor Nutrition- resulting in vitamin and mineral deficiency
- Toxic Effects of Medications
- Other problems- such as head injuries, high fever, certain infections like urinary tract infection, and brain tumors

Dementia may be caused by **IRREVERSIBLE** conditions such as:

- Alzheimer's Disease
- Vascular or Multi-Infarct Dementia- Stroke
- Dementia with Lewy Bodies
- Frontotemporal Dementia
- Parkinson's Disease
- Rare Viruses and certain inherited diseases

# What is Alzheimer's Disease?

- The most common form of dementia
- A progressive, degenerative disease of the brain
- Its cause is unknown and there is no cure (*yet...keep hoping and supporting research*)
- It is a fatal disease that, from diagnosis to death, can last from 2-20 years
- There are no predictors for length or severity of the disease
- Symptoms may differ for each individual and vary from day to day
- Most often affects people over 65 but there have been cases in people much younger
- At this time, there is no one clinical test to diagnose Alzheimer's disease. A battery of test must be performed to rule out all other conditions which cause similar symptoms. With the help of standardized diagnostic criteria, physicians can now diagnose Alzheimer's disease with an accuracy of 90-98% once symptoms occur. However, a definitive diagnosis of Alzheimer's disease is possible only through a brain autopsy.

Upon examination of the brain, the three hallmark indicators of Alzheimer's disease are:

1. **Amyloid Plaques**- found in the spaces between the brain's nerve cells. They consist largely of insoluble (cannot be dissolved) deposits of a protein peptide or fragment, called beta-amyloid together with other proteins.
2. **Neurofibrillary Tangles** – consists of abnormal collection of twisted protein threads found inside the nerve cells.
3. **Brain Atrophy**- reduced brain mass from loss of connections between neurons.

Two kinds of changes are going on simultaneously:

1. **Neurological** – advancing failure of mental powers such as memory, reasoning, comprehension, judgment. The brain is less efficient; its function has declined and usually there is a degeneration in its actual structure.
2. **Social-Psychological** – changes in ability to interact with others, thus changes in relationships with others. This is a consequence of the neurological changes. This is often what is referred to as a person's behavior.

***WE DON'T HAVE CONTROL OVER THE NEUROLOGICAL CHANGES  
OCCURRING, BUT WE CAN HAVE AN EFFECT ON THE  
SOCIAL-PSYCHOLOGICAL CHANGES....***

***This is where good dementia care makes a difference!***

## **GETTING THE DIAGNOSIS:**

Clinicians use a range of tools to diagnose “*possible Alzheimer’s disease*” (dementia can also be due to another condition) or “*probable Alzheimer’s disease*” (no other cause of dementia can be found). These tools include a medical history; physical exam; tests that measure memory, language skills, and other abilities related to changes in brain function; and sometimes brain scans. The diagnostic process is crucial in identifying Alzheimer’s disease accurately as well as in ruling out other conditions that might be causing the cognitive problems or dementia such as stroke, tumors, Parkinson’s disease, or side effects of medications. In many older people, Alzheimer’s disease co-exists with other conditions, such as cerebrovascular disease, that may also cause dementia.

An early, accurate diagnosis is especially important to people with the disease and their families because it helps them plan for the future and pursue care options while the person with Alzheimer’s disease can still take part in making decisions.

## **PREVELANCE OF ALZHEIMER’S DISEASE:**

- 4.5 million Americans currently have the disease (the number of the people with the disease at any one time) doubles for every 5-year age group beyond age 65.
- Estimate that by 2050, 13.2 million Americans will have Alzheimer’s disease if current population trends continue and no preventative treatments become available.
- Approximately 4 million Americans are age 85 years or older, is one of the fastest growing segments of the population and the group with the highest risk of Alzheimer’s disease.
- As more and more people live longer, the number of people affected by diseases of aging, including Alzheimer’s disease, will continue to grow.
- One in 10 persons over 65 and nearly half of all people age 85 have Alzheimer’s disease. A small percentage of people as young as their 30’s and 40’s get the disease.

Source: Basic Facts and Statistics  
Alzheimer’s Association

## *What Should We Expect?*

### **PHASES OF ALZHEIMER'S DISEASE**

#### ***First Phase, Early Stage, Mild Impairment 2 to 4 years leading up to and including diagnosis***

Loss of energy and spontaneity  
More easily angered  
Slow to react  
Picks up new information slowly and with errors  
Less initiative and reluctance to try new things  
Sticks to familiar, predictable activities  
Takes longer with routine chores  
Unable to think of words, especially name of things  
Loses way to familiar places  
Trouble with finances  
Gets anxious or withdrawn

#### ***Second Phase, Middle Stage, Moderate Impairment 2 to 10 years after diagnosis (longest phase)***

Trouble recognizing familiar people  
Difficulty with decisions  
Makes up stories to fill in empty memory spaces  
Speech noticeably impaired  
Trouble comprehending that which is read  
Cannot write clearly  
More self-absorbed  
Late afternoon restlessness – “Sundowner’s Syndrome”  
Difficulty with perceptual motor coordination  
Emotional lability  
Loss of inhibitions  
Acts impulsively  
Loses ability to maintain physical independently  
Cannot monitor physical appearance appropriately  
Repetitive physical movements  
Delusions or hallucinations  
Overreaction to minor events  
Easily overloaded by stimuli  
Needs some supervision at beginning of phase and total supervision by the end of phase

***Third Phase, Late or End Stage, Severe Impairment  
1 to 3 years (terminal phase)***

Requires total care for activities of daily living such as dressing, grooming, hygiene, bathing  
Apathetic, remote  
Cannot recognize self or family  
Cannot find way around  
Incontinent  
May lose weight  
May put objects in mouth  
Unable to communicate with words  
Can understand emotion and tone  
May become immobile and unable to walk  
Responsive in small ways to physical care and sensory stimulation

Source: Basic Facts and Statistics  
Alzheimer's Association

*How Do We Prepare for the Journey?*

**Alzheimer's Disease  
Bill of Rights**

*Every person diagnosed with Alzheimer's disease or related dementia  
deserve the following rights:*

- ❖ *To be informed of one's diagnosis*
- ❖ *To have appropriate, ongoing medical care*
- ❖ *To be productive in work and play for as long as possible*
- ❖ *To be treated like an adult, not like a child*
- ❖ *To have expressed feelings taken seriously*
- ❖ *To be free from psychotropic medications, if possible*
- ❖ *To live in a safe, structured, and predictable environment*
- ❖ *To enjoy meaningful activities that fill each day*
- ❖ *To be outdoors on a regular basis*
- ❖ *To have physical contact, including hugging, caressing and hand-holding*
- ❖ *To be with individuals who know one's life story, including cultural and religious traditions*
- ❖ *To be cared for by individuals who are well trained in dementia care*

Best Friends Approach  
Virginia Bell & David Troxel

## **HOW IS ALZHEIMER'S TREATED TODAY?**

For those who already experience some of the effects of Alzheimer's disease, the most immediate need is for treatments to control cognitive loss as well as behaviors that become challenging, such as verbal and physical aggression, agitation, wandering, depression, sleep disturbances, and delusions. Treatments are needed that work on many people with Alzheimer's disease, remain effective for a long time, ease a broad range of symptoms, improve a person's cognitive function and ability to carry out activities of daily living, and have no serious side effects.

The U.S. Food and Drug Administration (FDA) have approved five (cognitive enhancing) medications to treat mild to moderate symptoms, though only four are used today:

1. Cognex (first drug to be approved, now replaced by the following three)
2. Aricept
3. Exelon
4. Razadyne (previously known as Reminyl)

These drugs will not stop or reverse the disease, but may help to slow progression. The newest medication, memantine (Namenda), is prescribed to treat moderate to severe symptoms. This medication is taken in combination with one of the cognitive enhancing drugs listed above. Results vary from person to person with any of these medications.

In addition to these medications, physicians use a number of drug and non-drug approaches to treat the behavioral and psychiatric challenges that occur frequently as Alzheimer's disease progresses. Specialized dementia care programs promote the use of therapeutic interventions that are individualized to meet the specific needs of a person, exhausting all other alternatives before a medication intervention is attempted.

Source: U.S. Department of Health and  
Human Services - Progress Report  
on Alzheimer's Disease 2004-2005

## **APPROACHES and RESPONSES THAT WORK**

Smile and approach slowly and calmly  
Speak slowly and in a calm and reassuring voice  
Introduce yourself and say what you are there to do  
Listen, really listen, to the person  
Have a minimum number of people interacting with the person at any one time  
Give immediate response to the person's identified needs  
Use touch as reassurance only if you know that the person responds positively to it  
Avoid disapproving or angry facial expressions and reactions  
Stay calm, take a deep breath, and be gentle in your manner  
Respect the person's space  
Be aware of the person's verbal and non-verbal behavior  
Decrease stimulation, noise and activity  
Give the person time to work through anger or anxiety and gently redirect  
If a person becomes resistant, back off and re-approach in a moment  
Remove the person from a stressful activity  
Acknowledge the person's feelings and allow time to cool off  
Always approach from the front and speak his/her name  
Break a task down into small steps to avoid asking to do too much

## **APPROACHES and RESPONSES THAT DO NOT WORK**

Using logic to try to talk the person into something  
Asking the person to "try harder"  
Telling the person "no" or "you are wrong"  
Scolding, mocking, or embarrassing the person  
Getting angry with the person because the behavior was assumed to be intentional  
Being "parental" or patronizing and talking to the person as if he/she is a child  
Talking too fast and asking questions that require memory  
Asking too many questions and not allowing the person time to respond  
Approaching the person from behind  
Touching someone when he/she is not expecting it  
Invading a person's "personal space"  
Pressuring a person to complete a task

Source: Gentlecare

## **\*\*\*HELPFUL HINTS\*\*\***

- ✚ It is okay to use “therapeutic fibs” because the truth may not always be what is best.
  - Example: Do not tell him/her that his/her mother is dead and can’t possibly be alive. This may be the first time they recall hearing this information and will experience unnecessary pain and grief with the news. Instead, ask him/her to tell you about their mother and what a wonderful person they must be and redirect to pleasant reminiscent stories.
  
- ✚ Balance over-stimulation with under-stimulation.
  - Example: Watch for signs of agitation or apathy as it relates to the environment and activities around the person. Some may enjoy a visit from one child, but a group of children singing music or a family gathering may be overwhelming. Some may refuse certain favorite activities but with one on one interaction, that person may respond positively to favorite music being played and a scrapbook to scan through as opposed to sitting idle.
  
- ✚ Do not force a person into our world of reality, we must enter their world and provide positive affirmation and validation.
  - Example: If a person insists that it is time to go to work, don’t argue that they are retired, find a productive task that has meaning for them to do so they feel a sense of purpose. One of their greatest needs is to feel useful.
  
- ✚ Protect his/her dignity when in public.
  - Example: The Alzheimer’s Association can provide you with small cards that you can discretely hand to a waitress, cashier, etc. when you are out that will inform them that the person with you has Alzheimer’s disease and asks for their patience and understanding.
  
- ✚ Don’t quiz him/her to test what they remember and don’t remember.
  - Example: Don’t ask “So, what did you have for lunch today?” or “Mom, tell me who this is.” Instead, you offer the information without difficult questioning of him/her, you must now act as their memory. “Remember when...” is a good way to evoke pleasant reminiscing from the past.

- ✚ If having the car keys or money is important for him/her to feel in control, let him/her have them.
  - Example: You may need to provide a “fake” set of keys and paper money that looks real, but to him/her it is gratifying to just still have possession of them and may never need to use. Or, if she wants to keep her purse and hoard many non-essentials (like lots of tissue) than let her.
  
- ✚ Mirrors may evoke a tendency to think someone else is present as a result of not recognizing themselves. This may cause them to talk to the person in the mirror and may even cause a source of distress.
  - Example: One person had horrible memories of their mother and would stand in front of the mirror arguing and yelling at this person. Easy solution, remove the mirrors or other items that cause distorted reflections.
  
- ✚ The toilet may become an object he/she does not understand its use and begin urinating in wastebaskets, drawers, or a corner instead; just as the tableware may become all blended and him/her not be able to recognize the objects; just as the chair and the floor that are the same color may become blended and not be able to distinguish where to sit.
  - Use contrasting colors for food, tableware or placemat, table, chair, floor, even toilet seat. This helps identify objects better. They say the aging eye yellows so look at your surroundings as though looking through yellow cellophane paper. What do you see? Basic colors are the most preferred to create contrast. Muted and mauve colors are more difficult to distinguish.
  
- ✚ It said that the last ability a person with dementia loses is the ability to read, therefore, it is recommended to label or place visual cues as to what objects are or the whereabouts of items. Research suggests black writing on white background with large, bold font.
  
- ✚ In the earlier stages of dementia, it is recommended to resort to various compensatory techniques to support memory loss and forgetfulness.
  - Example: Use calendars, lists, small notebook to write reminders down, etc. In the more advanced stages, it is helpful if families leave notes and reminders for caregivers to refer to in order to reassure a person with dementia when they become anxious or agitated because they are apart from their loved ones.

## Support for Caregivers

### Who are the AD Caregivers?

- Spouses – the largest group. Most are older with their own health problems.
- Daughters – the second largest group. Called the “sandwich generation,” many are married and raising children of their own. Children may need extra support if a parent’s attention is focused on caregiving.
- Grandchildren – may become major helpers.



- Daughters-in-law – the third largest group.
- Sons – often focus on the financial, legal, and business aspects of caregiving.
- Brothers and Sisters – many are older with their own health problems.
- Other – friends, neighbors, members of the faith community.

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If you are feeling frustrated, fatigued, angry and a sense of grief, loss and mourning.....know that these are natural responses to dealing with a progressive illness. You are not alone. There are numerous resources to turn to for support, education and assistance.

## Support for Caregivers

### Demands of Caregiving

AD takes a huge physical and emotional toll. Caregivers must deal with changes in a loved one’s personality and provide constant attention for years. Thus, caregivers are especially vulnerable to physical and emotional stress.



- Peer support programs can help link caregivers with trained volunteers. Other support programs can offer services geared to caregivers dealing with different stages of AD.



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## Support for Caregivers



### Technology and Caregiving

The NIA is studying how computers can provide information and support to family caregivers through:

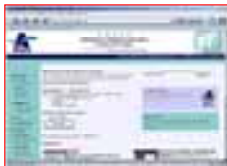
- computer-based bulletin boards
- chat rooms
- Q & A modules
- medical advice forums

These features have become very popular among users because they reach many people at once, are private and convenient, and are available around the clock.

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For more information on Alzheimer's disease and a list of the NIA-funded Alzheimer's Disease Centers, contact the Alzheimer's Disease Education and Referral (ADEAR) Center at:



**1-800-438-4380**  
***www.alzheimers.org***

The ADEAR Center is a service of:

■ ◆ ✦ ⚙ National Institute on Aging, part of the



National Institutes of Health (NIH), part of the



Department of Health and Human Services

*This PowerPoint slideshow is based on the publication **Alzheimer's Disease: Unraveling the Mystery**. Contact the ADEAR Center for free copies.*

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## *National Support for Caregivers*

### Alzheimer's Association

- Local chapters provide referrals to area resources and services, and sponsor the Safe Return Program, support groups, and educational programs:

**1-800-272-3900**

*[www.alz.org](http://www.alz.org)*



### Eldercare Locator

- Nationwide service of the Federal Government helps caregivers locate local support and resources:

**1-800-677-1116**

*[www.eldercare.gov](http://www.eldercare.gov)*



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## LOCAL RESOURCES

24/7 Helpline  
Alzheimer's Association  
1-800-272-3900

Alzheimer's Association  
Michigan Great Lakes Chapter  
107 April Drive, Suite 1  
Ann Arbor, MI 48103  
1-800-337-3827

Alzheimer's Association  
Greater Michigan Chapter  
20300 Civic Center Dr. #100  
Southfield, MI 48076  
1-800-337-3827

## **DEMENTIA/ALZHEIMER'S SPECIFIC WEB SITES**

### **Administration on Aging, Alzheimer's Resource Room <http://www.ao.gov/alz/>**

From the Department of Health & Human Services' Administration on Aging, this link goes directly to the department's resources for professionals and the public regarding Alzheimer's. The public can get information on care giving, health maintenance, working with physicians and more about the disease. Professionals can access assessment tools, disease management guidelines, training materials and more.

### **Alzheimer's Association <http://www.alz.org/>**

The Alzheimer's Association is a national volunteer health organization composed of a national network of chapters. It offers education, research grants and support for people with Alzheimer's, their caregivers and families. Its web site is devoted to the activities of its mission and offers information for professionals, caregivers, persons with the disease, families, and the media.

### **Alzheimer's Disease Education and Referral (ADEAR) <http://www.alzheimers.org/>**

ADEAR's Center web site is a service of the NIH's National Institute on Aging.

### **ALZwell, Caregiver Page <http://www.alzwell.com>**

A resource for caregivers, ALZwell offers news, frequently asked questions, bookshelf, eldercare topics, dementia care topics and more. Caregivers can access a learning education series, which include resource guides, a pharmacy discount program, and audio and videocassettes.

### **The Cognitive Neurology and Alzheimer's Disease Center <http://www.brain.nwu.edu/>**

CN-ADC is located in Chicago and conducts research to discover how the brain coordinates mental functions such as memory, language, attention and emotion. The web site describes the center's various projects, research and educational opportunities, and it offers information for patients, caregivers and professionals.

### **Dementia.com <http://www.dementia.com>**

A resource offering consumers and professionals more information about dementia and Alzheimer's disease.

### **Elder Care Online <http://www.ec-online.net>**

Provides a message board on elder care, a newsletter and separate sections on elder care issues such as Alzheimer's, home care and more. This web site also provides links to services and a bookstore.

### **Healing Well.com, Alzheimer's Disease Resource Center**

**<http://www.healingwell.com/alzheimers>**

This resource offers news and information culled from other web sites. It also features online chat groups, a bookstore, a video center and more.

### **Medline Plus <http://www.nlm.nih.gov/medlineplus/dementia.html>**

This link directs users to the National Library of Medicine and the National Institutes of Health reference site on dementia. It offers categories and links to other sites about dementia including clinical trials, news, coping and more.