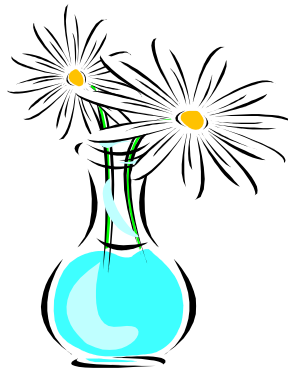


**alzheimer's  association™**

the compassion to care, the leadership to conquer

# **Especially for Caregivers: MIDDLE STAGE CARE**

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# *Especially for Caregivers:* **Middle Stage Care**

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# Especially for Caregivers: Middle Stage Care

## Alzheimer's Association Services

Alzheimer's disease (pronounced Alz'-hi-merz) continues to affect the lives of millions of families. In the United States more than 4 million people live with AD, and an estimated 100,000 live in Washington State. Yet there is a lack of public awareness about AD, and in general only a vague understanding of what it does to the individuals affected, and to their families and loved ones. For all families, meeting the care needs of a loved one with Alzheimer's is a tremendous challenge.

***Our mission is to educate, support and advocate for individuals, families, and communities affected by Alzheimer's disease and related disorders.***

The Western and Central Washington State Chapter of the Alzheimer's Association serves 23 Washington counties, helping individuals and their families, as well as other service providers in the community who need information about Alzheimer's disease and related disorders. Alzheimer's HELPLINE Services are available to assist with a variety of needs, and can help from the beginning for those suspecting Alzheimer's who need information on its warning signs, how it is diagnosed, and referrals to physicians for diagnosis and treatment of the disease. Once a diagnosis is made, there is information available on Caregiver Support Groups and other community resources that can help, as well as educational information and advice for caregivers on some of the specific challenges of caring for a loved one with Alzheimer's or a related disorder.

The Alzheimer's Association is a privately funded, non-profit organization. Services are provided without cost, although donations are always gratefully accepted. **Memberships are available that include such benefits as:**

- A quarterly newsletter to keep informed about the latest information on Alzheimer's and Alzheimer's care
- Free use of educational videos from our resource library
- Discounts on the purchase of books and other educational publications
- Information about training conferences
- Notification of special programs and events
- Discounts on events and programs (e.g. Education Conference)

## Getting the Support You Need to Care for a Loved One at Home

When providing care at home, it is important to know about community resources that can help you to provide the best possible care, and to prevent the caregiver from "burning out".

**Programs available through the Alzheimer's Association:**

HELPLINE is staffed by trained professionals who are knowledgeable and experienced in issues related to Alzheimer's disease and related disorders. Through HELPLINE, a variety of articles are available for caregivers, as well as information about the range of available local community resources that can help you.

SUPPORT GROUPS for caregivers and family members that provide a safe, non-judgmental group setting to talk about the challenges of caring for a loved one with Alzheimer's.

CARE COORDINATION through the *Connections* program to assess the care needs of your loved one, and to recommend programs and services that will support you.

The RESOURCE LIBRARY, providing books, pamphlets and videos on a wide variety of topics related to Alzheimer's care.



**CONTACT HELPLINE**

**206-363-5500 or 1-800-848-7097**

The HELPLINE is available 24 hours a day, seven days a week. Whether you need information on community resources for patients and families, support groups and classes, articles on a wide variety of topics related to caring for someone with Alzheimer's or a related disorder, or information on coping with the challenges of caregiving, the Alzheimer's HELPLINE is available to assist you.

**Contact HELPLINE for information about:**

- **Warning Signs of Alzheimer's**
- **Related Disorders**
- **Diagnosis & Treatment**
- **Physician Referrals**
- **Current Research**
- **Stages of Alzheimer's Care**
- **Caregiver Support**
- **Resources & Services**
- **Respite Care Options**
- **Case Management Services**
- **Counseling Services**
- **Home Safety Concerns**
- **Driving & Alzheimer's**
- **Long Term Care Options**
- **Residential Care Options**
- **Financial & Legal Concerns**
- **Education & Training**
- **Safe Return Program**

**...and other questions related to  
Alzheimer's & related disorders**

## **FAMILY SERVICES & SUPPORT GROUPS**

*Coping with Alzheimer's disease does not have to be a lonely experience.* The Family Services Program provides support to family and friends from the beginning through the Early Stage Memory Loss Seminar, as well as ongoing support through more than 100 caregiver support groups in Western & Central Washington. In addition to support, practical information about caregiving and community resources is provided. Contact HELPLINE to connect with a support group.

## **THE CONNECTIONS PROGRAM: ALZHEIMER'S CARE COORDINATION**

### **PROGRAM GOAL:**

The Connections Program provides direct assistance to families and individuals throughout the course of the disease through an interactive process. It helps caregivers to implement the actions necessary to improve the health of the family and its members.

The Care Consultant is available by phone or in person to meet with families at home, in a care facility, or at the Alzheimer's Association office. She will discuss your needs, provide individualized information and connect you to services and resources. She will also set a plan for follow-up on a regular basis so that you can be assured of getting the help you need.

This service is confidential and there is no charge (although contributions are always gratefully accepted).

## **ALZHEIMER'S RESOURCE CENTER**

Books, pamphlets, newsletters and videos are available through our Resource Center. These materials cover a wide range of topics to inform families, health professional and individuals diagnosed with Alzheimer's or a related disorder.

Books can be reviewed and purchased through the Resource Center. As mentioned previously, books are offered at a discount for chapter members.

Videos can be rented for a week for \$5.00 each. You may rent two videos at a time. Video rental is free of charge for chapter members.

## **EDUCATION & OUTREACH**

Keeping health care professionals, families and friends informed is accomplished by such events as our **Annual Education Conference** and through a series of classes throughout the year for families and friends of Alzheimer's patients.

**Dementia Care Trainings** can be arranged for professional groups; public education forums enhance caregiving skills and keep health care professionals, families and friends informed.

Our **Speaker's Bureau** provides presentations on a variety of topics related to Alzheimer's to inform and educate families, professionals and community groups.

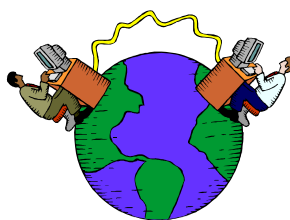
## PUBLIC POLICY & ADVOCACY

The Alzheimer's Association, Western and Central Washington State Chapter, supports state and national policies that promote respite care, long-term care, research funding and other issues affecting the well-being of people with Alzheimer's and their families.

An **Annual Legislative Outreach Day** provides families and others impacted by Alzheimer's disease an opportunity to meet with legislators and advocate for legislation that addresses the needs of people with Alzheimer's.

If you or someone you know would like to join us in this effort to make a difference locally and nationally, call us at 1-800-848-7097 for more information!

## VISIT OUR WEBSITE



Our chapter's website can be visited at [www.alzwa.org](http://www.alzwa.org). You will find several articles available, as well as additional information on our many programs and services.

## WAYS YOU CAN HELP

### Care Partners

Make a difference in the lives of people living with AD and their families through a *Care Partners* monthly pledge. It's simple: you pledge a monthly amount that is automatically deducted from your checking account or charged to your credit card. It's an easy way to touch the lives of so many, every month of the year.

### Membership

Your annual membership helps provide financial support for **critically needed services**. You can play a vital role in helping families impacted by Alzheimer's disease. Benefits include our quarterly newsletter, discounts on trainings, conferences, books and materials, and free access to our video library.

### Bequests, Memorials & Other Gifts

Your gift of a memorial, honorarium or special occasion tribute is a wonderful way to mark to mark a special date or event. Bequests through your estate have a lasting impact. You can also designate the local Alzheimer's Association through your employee giving programs such as United Way, Employee Combined Fund Drive, or if your employer has a matching gift program.

## **Consider Volunteering!**

Volunteer your time and talents in many ways:

- To assist callers on the HELPLINE
- In the Resource Center
- Providing clerical support or computer skills
- Helping with Memory Walk, the Annual Auction or other special events
- Participating in the Annual Legislative Outreach Day
- Serving on committees

**We have several interesting volunteer opportunities.** Call (206) 363-5500 or 1-800-848-9707 for information.

## **CAREGIVING AT HOME**

The onset of Alzheimer's disease is so subtle that only in retrospect do most families put the pieces together. Forgetfulness is the primary symptom of the early stage, but other signs include:

1. Short term memory loss
2. Trouble finding the right word or substituting inappropriate words
3. Poor judgment
4. Misplacing things
5. Difficulty performing familiar tasks

### **Examples of these symptoms include:**

- Forgets what he/she has just been told
- Arrives for an appointment on the wrong day, or at the wrong time or place
- Pays bills more than once, or not at all. Forgets which bills have been paid
- Asks the same question over and over again
- Has difficulty making decisions and planning; seems easily overwhelmed

Because its onset is so gradual, it is common for even close family members to be unaware of the disease process for some time. In the early stage, persons with dementia are able to cover up their forgetfulness. Some days their memory may seem to be perfectly normal. They are able to make an extra effort to "keep it together" for family gatherings or brief doctor visits. This contributes to confusion and denial of the problem among family members. It is normal for families to try to

rationalize the memory loss by blaming it on a recent death in the family, adjustment to retirement, or just getting older. Eventually, the bad days begin to outnumber the good days, or a crisis occurs which brings the problem to the family's attention, resulting in a visit to the doctor.

## MIDDLE STAGE CARE

### The Middle Stage: Staying a Step Ahead

The middle stage of Alzheimer's disease is the longest, lasting 2 to 10 years, and is characterized by worsening mental function, increased confusion, and often-disruptive behaviors. The person in this stage cannot live alone and the caregiver(s) must assume more responsibility for their financial and physical well-being. A person in the middle stage of Alzheimer's disease requires full-time supervision.

- **During this phase, the person with dementia may start to have delusions (false beliefs) and hallucinations (seeing and hearing things that are not there).** Understandably, this can be very frightening to them, and they may respond by being very argumentative and accusatory, acting out, or even striking out! The disease is making it increasingly difficult for them to control their impulses.
- **Also, in the middle stage, persons with dementia commonly resist bathing and other aspects of personal grooming.** They may have trouble finding their way to the bathroom, or knowing what to do once they get there. Toileting accidents may occur.
- **Social isolation becomes a real concern for both the caregiver and the person with Alzheimer's disease.** The "odd" appearance of the person with dementia becomes noticeable to most people, and may make being with others who do not understand the disease very uncomfortable.
- **Persons with dementia may experience tremendous swings in their appetite.** The caregiver will need to be more diligent to ensure proper nutrition, particularly if the person has other medical conditions.
- **Sleeping problems are common in the middle stage.** The person with dementia may sleep at odd times of the day and often disrupts the household at night. They are frequently restless and do repetitive things such as pacing the floor or rummaging through drawers and closets.
- **Problems with balance and an unsteady gait become a concern.** At the same time, because of a loss in their physical coordination from the disease, persons with dementia may have difficulty with balance and are at risk for falls.
- **Wandering becomes a concern.** They may not recognize familiar surroundings and preventive measures to prohibit wandering and getting lost need to be in place.
- **A simple and supportive daily routine is helpful.** Persons in the middle stage need a simple and supportive daily routine that provides them with exercise and meaningful activities.

- **Effective communication skills make a difference.** It is suggested that everyone interacting with your family member with dementia learn how to communicate with him effectively. As the disease progresses, persons with dementia lose the ability to organize their thoughts, or to remember the meaning or usage of words. Using some simple techniques to communicate with them can reduce anxiety, improve self-esteem, and decrease problematic behavior.
- **To better cope with the difficult behaviors that characterize this phase,** it is important for caregivers to remember that the person's behavior may be "normal" for the disease. We need to remind ourselves that the person's brain is being affected with a horrible affliction, and that the behavior is not directed at us.
- **It is helpful to reminisce and remember the good times.** Looking at a memory book, old photos or videos may help to care for the person who is increasingly difficult to love.

### **During the Middle Stage Respite, Support & Knowledge are Important!**

*The middle stage, often referred to as the confusion phase, becomes obvious when the person can no longer hide the illness from others. At this stage, the person with Alzheimer's disease becomes easily confused and cannot be safely left alone. As the caregiver of a person in the middle stage, you will need ongoing help and support.*

#### ***Support Groups***

Support Groups help by giving you a chance to meet others who are facing similar challenges and issues. Ideas are exchanged, problems are discussed, and solutions are explored. It will not take long to become comfortable sharing your problems with such a group.

#### ***Respite Services***

It is wise to consider some respite services. You may choose an Adult Day Care facility or have someone come into your home to relieve you for a few hours on a regular basis. Some nursing homes and assisted living facilities offer monthly, weekly, or weekend respite care. These options are especially helpful if you become ill, if you need to take a short trip, or if you need a longer break.

**IT IS IMPERATIVE FOR YOU TO RECOGNIZE THAT YOU CANNOT DO THE JOB OF CAREGIVING ALL ALONE WITHOUT RELIEF!**

*Contact our HELPLINE for information about support groups and respite care services.*

#### ***Future Planning***

The middle stage is a time when you may want to start thinking about future housing options, even if you feel you may never move your family member to a nursing home. Many people try to keep the person with Alzheimer's at home as long as they can, but in some cases the care demands may become impossible to meet at home. It is helpful to begin planning before a crisis occurs. This will allow you time to visit a number of facilities and to decide what will best meet your needs as opposed to making a hurried decision while under pressure and stress.

### ***On-going Support***

The Western and Central Washington State Chapter of the Alzheimer's Association is here to help you learn to cope with the increased confusion, difficult behaviors and decisions facing you during this stage. We understand what you are experiencing and urge you to call us as problems present themselves. We have a variety of brochures, books, videos, and other resources that you may find very helpful. For more information about these informational materials, contact our **HELPLINE** at **206-363-5500** or **1-800-848-7097**.

*Adapted from "Stages of Care", Alzheimer's Association, Greater Pittsburgh Chapter; revised 12/99*

## **HOME SAFETY**

There are three basic principles to remember when evaluating the safety of your home for an adult with Alzheimer's or another related form of dementia:

1. **Think prevention!** It is very difficult to predict what a person with Alzheimer's disease will do. Often hazards that arise are not foreseen in advance. Even with careful planning, accidents can happen. However, checking the safety of the home helps the caregiver to take control of some of the potential problems that may create hazardous situations.
2. **Changing the environment is more effective than trying to change most behaviors.** While some behaviors can be managed with medication, others cannot. It is possible to make changes in your environment to decrease the hazards and stresses that accompany the behavioral and functional changes of Alzheimer's.
3. **When you minimize the danger, you will maximize independence.** A safe environment can be less restrictive allowing the person with Alzheimer's increased security and more mobility.

### ***How do I know if it is safe to leave the person I'm caring for alone?***

This is one of the primary safety concerns for family members and caregivers. Ask yourself the following questions:

- Does he become confused or unpredictable under stress?
- Does he recognize a dangerous situation, for example, a fire?
- Does he know how to use the phone in an emergency?
- Does he know how to get help?
- Will he stay content within the home?
- Does he wander and become disoriented?

- Does he show signs of agitation, depression or withdrawal when left alone for any period of time?
- Does he attempt to pursue former interests or hobbies that might now warrant supervision? (cooking or woodworking?)

## **Home Safety Tips**

- Display emergency phone numbers and the home address near all phones.
- Consider a phone answering machine when the caregiver is unable to answer calls. The person may be unable to take messages and may become a target for telephone exploitation by solicitors. When the answering machine is on, consider turning down the phone bell to avoid disruptive ringing.
- Provide smoke alarms and carbon monoxide alarms near all bedrooms; check frequently to make sure they are functioning properly.
- Use “baby monitors” or motion sensor alarms to let you know if the person gets up in the night.
- Avoid the use of flammable and volatile compounds near gas water heaters or other sources of open flame.
- Have secure locks on all outside doors and windows.
- Have a spare key outside in case the person locks you out of the house.
- Avoid the use of extension cords if possible by placing lamps and appliances close to electrical outlets. Unused outlets should be covered with childproof plugs.
- Have adequate lighting in all rooms.
- Stairways should have at least one handrail that extends beyond the first and last steps. Light switches should be placed at the top and bottom of stairs.
- Keep all medications (prescription and over the counter) locked up. Each bottle of prescription medicine needs to be clearly labeled with the person’s name, name of the drug, drug strength, dosage frequency, and expiration date. Do not accept a prescription with “as directed” typed on the label. Use child resistant caps if needed.
- Keep all alcohol locked in a cabinet or out of reach of the person. Alcohol consumption may increase confusion.
- Monitor closely while the person is smoking. Remove matches, cigarettes and ashtrays when not in use. Often by not having these things in sight the person may forget the desire to smoke.
- Avoid clutter that can create confusion and danger. Dispose of newspapers and magazines regularly. Keep all walk areas free of clutter, throw rugs and furniture.

- Remove all guns or other weapons from the home, or accident proof them by removing ammunition, firing pins, or installing safety locks.
- Keep all power tools and machinery locked in the garage, workshop or basement.
- Eliminate all poisonous plants from the home. Check with a local nursery or the Poison Control Center for a list of poisonous plants.

## **Creating A Supportive Environment**

While it is important to make the environment safe, it is equally important to create an atmosphere that supports the changing needs of the individual with Alzheimer's.

### ***Encourage independent movement.***

Eliminate hazardous objects, limit access to danger-points such as stairwells, kitchens, and outside doors so the person can move safely and independently. If necessary, make room to accommodate walkers and wheelchairs.

### ***Involve the person in activities.***

Let her participate in preparing meals, rinsing the dishes, folding clothes, raking leaves and other activities with your supervision. These activities enhance self-esteem and make her feel more valued around the home.

### ***Use surroundings to initiate activities.***

Leave out scrapbooks, photo albums or old magazines that help the person to reminisce and encourage conversation. Try playing music the person once enjoyed in the past to prompt activities such as dancing, clapping, or other types of exercises. It is important, however, to keep the noise level to a minimum since loud distracting sounds may cause agitation.

### ***Create access to the outdoors.***

Encourage the person to enjoy supervised outdoor activities such as gardening or walking. A backyard with a fence allows her to go outside on her own. If she is unable to go outdoors, consider doing indoor activities in a room with many windows or on an enclosed porch.

### ***Be prepared for the possibility of wandering.***

If the person has a tendency to wander, enroll her in the Alzheimer's *Safe Return* program. The program is a nation-wide system designed to identify, locate and return to safety persons who are lost and memory impaired. A *Safe Return* brochure/ registration packet is enclosed for your consideration. Contact our chapter HELPLINE for more information about *Safe Return*.

Adapted from: 1) *Everybody Needs A FRIENDD\*: A Caregiver's Resource Manual*, Alzheimer's Association, Southern Arizona Chapter and 2) *Steps to Enhancing Your Home: Modifying the Environment*, Alzheimer's Association.

## CHALLENGING BEHAVIORS

- **Wandering, Shadowing, Restlessness**
- **Sleep Disturbances, Sundowning**
- **Hallucinations, Suspiciousness, Paranoia**
- **Resistance, Anger, Combativeness**

The brain impairment of Alzheimer's disease and related dementia causing illnesses reduces the person's ability to recognize and interpret the sights and sounds of his or her surroundings. Suspiciousness is a normal reaction to this feeling that more and more is slipping out of control.

Frustration builds quickly to anger as tasks that once seemed simple become complex and confusing. Shadows, reflections in windows and mirrors, noises, normal room clutter, even the passage of time become mysterious, indecipherable, and very frightening. It is hard to identify such internal causes of agitation as pain, hunger, thirst, the need to go to the bathroom, disturbing dreams, being too hot or too cold, depression, or feeling lost or abandoned. It is even more difficult for a person in the middle stage of Alzheimer's disease to communicate about the causes of discomfort and anxiety.

Sometimes medications intended to help can have unpredictable and adverse side effects in a person with dementia. The medication as well as the dementia itself can affect the person's internal clock so that the perception of time is distorted, and there is sleep reversal with the person wide awake at night and sleeping during the day.

Often there is a compulsion to try to "find" something familiar to mitigate the feeling of being lost. There is an effort to keep the caregiver in constant view, or to follow them continuously throughout the day.

### **Wandering, Shadowing, Restlessness**

#### **1. Check to see if the person needs something:**

A snack? Something to drink? To use the bathroom?  
Is he or she warm enough? Too warm? Clothes uncomfortable or binding?

#### **2. Try to interest him or her in an activity.**

Perhaps there is something he or she can do near you—folding clothes, for instance—that will allow you to continue getting your own activity or chore done.

#### **3. Check your home for items that may accidentally "cue" the person to go outside.**

Sometimes the sight of outdoor clothing will trigger a desire to go out. Keep boots, coats, etc., put away until you are ready to go out.

#### **4. Be prepared for potential hazards.**

Even if the person is now able to go outside by herself or wander through the house while you are in a different room, remember that her judgment is affected and she may not recognize the dangers of traffic, kids on bicycles, or may forget she has turned on the stove or the water faucet.

#### **5. Register your loved one with the *Safe Return* program or buy an ID bracelet.**

The Alzheimer's Association *Safe Return* program is highly recommended. It includes an ID bracelet or a necklace, a wallet card, clothing labels, readily retrievable identifying information provided at the time of registration, and a photo that can be faxed to local authorities in the event that your loved one should wander and become lost. Place identification labels on clothing, shoes, and glasses. It's also a good idea to keep a piece of worn, unwashed clothing put away in a special place in case it is needed for a search.

#### **6. Alert neighbors, shops, and other business your loved one may visit should she wander, and inform them about the disease.**

Some early stage Alzheimer's patients like to carry a card with their address, phone number, and simple instructions for getting back home. Others carry the card, but forget they have it, or cannot understand the directions.

#### **7. Include a brisk walk or a car ride together into your routine.**

Making time for a regular, brisk walk or two each day or some other regular exercise is often enough to eliminate restless wandering.

#### **8. Secure your home.**

Put a simple slide-type lock on the doors, placed very high or very low. Place child-proof devices on door knobs. Or, consider putting chimes or buzzers on the doors to alert you. If possible, fence and gate an outdoor area. Remove the person's shoes when indoors and substitute slippers, and keep "outdoor" clothing put away. This will help to "cue" the person to remain inside.

#### **9. Wandering is a coping mechanism for dealing with the stresses and fears that accompany the disease.**

Many caregivers learn to tolerate and work around it, as long as it doesn't endanger the person.

#### **10. In general, maintain a simple, predictable, reassuring routine.**

Provide interesting activities that the person can enjoy without frustration, adequate exercise to reduce agitation and "nervous energy", and enough structure to calm and comfort your loved one, and to reduce confusion.

### **Sleep Disturbances, Sundowning**

#### **Check for possible causes:**

- Caffeine
- Alcohol
- Daytime napping or lack of activity
- Pain or discomfort
- Hunger
- Room temperature: too hot or too cold

### **Try making a few changes:**

- Soft, relaxing music
- A night light
- Place the commode near the bed
- Place a comfortable rocking chair in the bedroom
- Maintain a regular routine with meals and activities
- Avoid talking about or anticipating the next day's plans
- Do stressful activities early in the day

### **Make sure that you get enough rest:**

- When he dozes during the day, you try to rest then, too.
- Make the house safe for wandering at night.
- If you have not installed a "kill switch" on the back of your stove, shut down its circuit breaker.
- Block off the stairs.
- You may need separate beds or bedrooms.
- Be flexible about allowing the person to sleep in a chair if she tends to fall asleep there.
- Consider using bedrails. Some people find them comforting.

## **Hallucinations, Suspiciousness**

### **Check for possible causes:**

- Problems with eyesight or hearing
- Infections
- Pain or discomfort
- Dehydration
- Reaction to medications

### **Try making a few changes:**

- Check for glare or shadows
- Add better lighting
- Close curtains and cover or remove mirrors to prevent reflections that can be frightening to a person with dementia.
- Avoid arguing or disagreeing. Instead, reassure, comfort, and use familiar distractions.
- Establish a regular routine to establish a sense of security.

## **Resistance, Anger, Combativeness**

- Keep room layouts the same. Keep things in well-established, predictable places to prevent frustration and emotional upset.
- Avoid surprises.
- Eliminate clutter. Even “normal clutter” can be unsettling for a person with dementia.
- Give information simply, providing instructions one step at a time, and allow plenty of time for each step. Avoid using a “teaching” tone of voice, or talking down to the person.

### **Check the person’s comfort level:**

- Rule out medical causes
- Alternate quiet and active periods
- Try exercise, calming music, gentle touch

### **Communicate clearly:**

- Don’t offer a choice when there is no choice. For example, when it’s time to go to daycare, state, “It’s time to go to daycare”, rather than “Do you want to go to daycare?”
- Give limited choices instead of asking open-ended questions. Instead of asking, “What would you like for lunch?” try, “Would you like tuna casserole or spaghetti for lunch?”
- If you encounter resistance, try backing off of the subject, using distraction, and trying again in a few minutes.

Prepared by Linda Schreiner for the Port Angeles and Sequim Support Groups

## **PROVIDING STRUCTURE: THE KEY TO PLANNING ACTIVITIES AT HOME**

A person with Alzheimer’s disease or a related disorder needs help organizing the day. Conscientious planning of activities is vital to providing care for the Alzheimer’s patient.

Activities are the “things that we do.” These include getting dressed, doing chores, playing cards and even paying bills. They can represent who we are and what we are about.

Activities can be active or passive, done alone or in the company of others. They can enhance a person’s sense of dignity and self-esteem by giving purpose and meaning to life.

Activities can help to lessen undesirable behavior such as wandering or agitation. Activities provide the person with dementia and the caregiver a sense of security, stability, fun and togetherness.

**Activities take on many forms and represent different facets of our lives.**

## DAILY ROUTINES

- **Personal Care Activities:** bathing, shaving and dressing
- **Mealtime Activities:** preparing food, cooking and eating
- **Chores:** dusting, sweeping and doing laundry

## OTHER ACTIVITIES

- **Physical:** taking a walk or playing catch
- **Social:** having coffee, talking or playing cards
- **Intellectual:** Reading a book or doing a crossword puzzle.
- **Spiritual:** praying or singing a hymn
- **Creative:** painting or playing the piano
- **Work Related:** making notes, typing or fixing something
- **Spontaneous:** going out to dinner or visiting friends

## When planning activities, think about:

- **The person**
- **The activity**
- **Your approach**
- **The environment**

## The Person

Planning Activities for the person with Alzheimer's disease involves continual exploration, experimentation and adjustment. Consider the person's likes, dislikes, strengths and abilities and past interests. As the disease progresses, keep activities flexible and be prepared to make adjustments. Consider the following:

### **What skills and abilities does the person still have?**

The person with Alzheimer's may be able to play simple songs learned on the piano years ago. Incorporate maintained skills into daily activities.

### **What does the person enjoy?**

Note when the person seems happy, anxious, distracted or irritable. Some people with Alzheimer's may enjoy watching sports, while others may be frightened by the fast pace or noise.

**Does the person begin activities without direction?**

Does the person set the table before dinner or begin sweeping the kitchen floor mid-morning? If so, you may wish to draw upon these types of activities at other times of the day.

**Does the person have physical problems?**

Does she tire quickly, have difficulty seeing, hearing or performing simple movements? If so, you may want to avoid certain activities.

**The Activity**

**Make activities a part of your daily routine.**

Asking the person with Alzheimer's to help you complete a task – like folding towels – may provide him with a sense of purpose and importance.

**Focus on enjoyment, not achievement.**

Find activities that build on remaining skills and talents. A professional artist might become frustrated over the declining quality of work, but an amateur might enjoy a new opportunity for self-expression.

**Stress involvement.**

Activities that help the individual to feel like a valued part of the household – like setting the table, wiping countertops or emptying wastebaskets – provide a sense of success and accomplishment.

**Relate the activity to work life.**

A businessperson might enjoy organizing activities such as putting coins into a holder, helping to assemble a mailing, or making a "to do" list. A farmer or gardener would probably enjoy working in the yard.

**Look for favorites.**

The person who always enjoyed drinking coffee and reading the newspaper may still find that activity enjoyable, even if he's not able to completely comprehend what he's reading.

**Modify activities as needed.**

Try to be flexible and acknowledge the person's changing interests and abilities.

**Consider the time of day.**

Many caregivers find that they have more success with certain activities such as bathing and dressing in the morning. Whatever the case, your typical daily routine may need to change somewhat.

**Adjust activities to stages of the disease.**

As the disease progresses, you may want to introduce more repetitive tasks or even expect the person to take a less active role in activities.

**Your Approach**

**Offer support and supervision.**

You may need to show the person how to perform an activity and provide simple step-by-step instructions.

**Concentrate on the process, not the product.**

Does it really matter if the towels are folded properly? Not really. What matters is that you were able to spend time together and the person with Alzheimer's feels useful.

**Be flexible.**

When she insists that she doesn't want to do something, she might be telling you she can't do it or fears doing it.

**Be realistic and relaxed.**

Don't be concerned about filling every minute of the day with an activity. The person with Alzheimer's needs a balance of activity and rest, and may need more frequent breaks and varied tasks.

**Help to get the activity started.**

Most people with Alzheimer's still have the energy and desire to do things, but lack the ability to organize, plan, initiate and successfully complete the task.

**Break activities into simple, easy to follow steps.**

Too many directions at once often overwhelm a person with dementia. Focus on one task at a time.

**Assist with difficult parts of a task.**

If you're cooking and the person can't measure the ingredients, finish the measuring and say, "Would you please stir this for me?"

**Let him know he's needed.**

Ask, "Could you please help me?" Be careful, however, not to place too many demands upon the person.

**Stress a sense of purpose.**

If you ask him to make a card, he may not respond. But, if you tell him that you're sending a special get-well card to a friend, he may enjoy working on this task with you.

**Avoid criticizing or correcting him.**

If he finds a harmless activity that seems significant or meaningful, encourage him to continue.

**Encourage self-expression.**

Include activities that allow the person a chance to express himself. These types of activities could include painting, drawing, music or conversation.

**Involve her through conversation.**

While you're polishing shoes, washing the car, or cooking dinner, talk to her about what you're doing. Even if she cannot respond, she is likely to benefit from your communication.

**Substitute an activity for a behavior.**

If she rubs her hand on the table, place a cloth in her hand and encourage her to wipe the table. Or if she's moving her feet on the floor, play some music so she can tap to the beat.

**Try again later.**

If something isn't working, it may be the wrong time of day for the activity, or it may be too complicated. Try again later or adapt the activity so that it is less complicated.

**The Environment****Make activities safe.**

Remove toxic materials and dangerous tools from a workshop. Activities like sanding a piece of wood can be safe and pleasurable.

**Change your surroundings to encourage activities.**

Leave out scrapbooks, photo albums or old magazines that help him to reminisce.

**Minimize distractions that frighten or confuse.**

She may not be able to recall familiar sounds and places, or may feel uncomfortable in certain settings.

**Making a Plan:****Structuring the Day**

When you plan the day for her, think about how you plan your own day. There are times when you want variety and other times when you welcome routine. The challenge for caregivers is to find activities that provide meaning and purpose, as well as pleasure.

Begin thinking about the past week. Make notes about activities and experiences that worked and didn't work. Try keeping a daily journal and ask yourself the following questions:

- **Which activities worked best and which didn't work? Why?/Why not?**
- **Were there times when there was too much going on or too little to do?**
- **Were spontaneous activities enjoyable and easily completed?**

Set up a written schedule based on your journal. A patterned day allows you to spend less time and energy trying to figure out what to do from moment to moment. Allow yourself and your loved one some flexibility for spontaneous activities.

*When structuring the day, consider the following examples of activities:*

### **Morning Activities:**

- Wash, brush teeth, get dressed
- Prepare and eat breakfast
- Coffee and conversation
- Discuss newspaper, make a craft or reminisce about old photos
- Take a break or have some quiet time
- Do some chores together
- Take a walk or play an active game

### **Afternoon Activities:**

- Prepare and eat lunch, read mail, clear and wash dishes
- Listen to music, do a crossword puzzle or watch television
- Do some gardening, take a walk or visit a neighbor
- Take a short break or nap.

### **Evening Activities:**

- Prepare and eat dinner, and clean up the kitchen
- Reminisce over coffee and dessert
- Play cards, watch a movie or give a massage
- Take a bath, get ready for bed, read a book or look through a magazine

### **Evaluating Your Plan: Determining Which Activities Work**

In evaluating the success of an activity, look at how well the person with Alzheimer's responds and how well the activity meets your needs.

The success of an activity can vary from day to day. In general, if the person seems bored, distracted or irritable, it may be time to introduce another activity or to take time out for rest.

In most cases, structured, pleasant activities decrease agitation and improve mood. The nature of an activity and the degree to which the person completes it successfully are not as important as the pleasure and sense of accomplishment the person derives from it.

### **Tips for Planning Activities**

- Choose activities that bring meaning, purpose, joy and hope to his life
- Select activities that use the retained skills and abilities of the person with dementia
- Pick activities that help to normalize his life
- Choose activities that involve family and friends
- Look for activities that are dignified and appropriate for adults
- Focus on activities that are enjoyable
- Select activities where the process is more important than the final product

### **Tips for Your Approach to Activities**

- Be flexible
- Avoid correcting her
- Stress involvement
- Be patient
- Help him to remain as independent as possible
- Offer opportunities for choice
- Simplify instructions
- Establish a familiar routine
- Respond to the person's feelings
- Provide encouragement and praise
- Simplify, structure and supervise

You *will need* breaks periodically as you care for your loved one with Alzheimer's disease. The one unchanging fact is that nothing stays the same for long.

Routines and behaviors that may now be manageable will inevitably change. ***The stamina and creativity you will need to cope with the progressive nature of Alzheimer's disease depends on your good health.***

## EXPLORING RESPITE CARE OPTIONS

**RESPITE CARE** refers to a short time of rest or relief. It allows caregivers a break from day to day duties and provides the person with Alzheimer's opportunities to interact with others.

Three types of respite care most commonly available are:

- ◆ **DAY SERVICES** Programs in adult day centers can give the person with Alzheimer's opportunities to socialize with others, exercise and engage in simple activities. Adult day care is a great way to maximize an Alzheimer's patient's functioning.
- ◆ **HOME CARE** Visiting nurses, home health aides, homemakers and volunteers can provide services at home such as bathing, dressing, or companionship while you go out for awhile.
- ◆ **RESIDENTIAL RESPITE** Some hospitals, nursing homes and other residential facilities offer short-term stays of a few days or a few weeks.

However annoying it is to hear people say "take care of yourself", try not to react obstinately. "Proving your strength" is not helpful to anyone, least of all for your loved one. The unseen emotional burdens add to the physical demands of caregiving. The only way you will be able to keep going and to make wise decisions is by making sure you get regular, adequate relief, rest and replenishing.

The most important factor in your success at finding respite care could very well be your **ATTITUDE**. Try to accept these facts:

- 1. None of the respite options will be ideal.** It will probably be the case that no day care program, drop-in care facility, or hired helper will be able to provide care to your standards. No arrangement of care-sharing will fit perfectly into your routine. Use the mode of care that is available. The greater the demand for respite care, the more options we will ultimately have.
- 2. You will have to make a lot of phone calls,** spend time on hold, have to call back several times, etc. Be patient and persistent.
- 3. Having a life of your own apart from Alzheimer's disease is not a selfish act.** It is wise and healthy to maintain other interests and relationships, and to have fun.

## TIPS FOR A SUCCESSFUL SEARCH FOR RESPITE CARE

- **Resist the temptation to compare respite care options with what your loved one might have preferred in earlier life.** That was then; this is now. Instead, compare today's choices with the person's *current* state.
- **Make 2 long-range plans:** one which assumes you will stay in good health; the other plan in case you become incapacitated yourself.
- **Become familiar with local information sources,** which include Senior Information & Assistance, senior centers, and social service agencies that serve your community. Keep a notebook with as many resources as you can find, and get acquainted with them even if you don't think you'll need them.
- **Hold a family meeting,** away from your loved one, of all family members living in your area. Inform them of your respite needs and put together a plan. If someone cannot personally provide respite, she or he may help to pay for professional respite care.
- **Give your friends information about the disease.** Help them to feel comfortable with your loved one by spending time together, all three of you, before you ask for respite time. Think of ways they can be helpful that won't scare them off. Freeze-ahead meals, shopping, errands, vacuuming, dusting, etc., are easy, non-threatening things you can ask for that will free up some time for yourself. Even though you will still need to arrange for a respite caregiver, at least you will not be using that precious time to do chores. Learn to respond quickly to every offer of help no matter how off-hand or insincere you think it is, with a positive suggestion, a time and a date. It is always harder to call someone back later to set something up.
- **Expect your loved one to reject the respite caregiver at first.** Just don't give up too quickly. Make sure your helper understands about dementia. Try different things, such as a few prior visits with you staying there. Help your respite caregiver to interact effectively with your loved one. Eventually you will adjust. If not, don't assume your loved one will reject everyone. Keep trying!
- **Use the same approach with Adult Day Care Services.** Work with the program to help your loved one to adjust. If she initially is unable to adjust to the program, wait a few weeks and try again.
- **Piece together a plan when there are no easy or affordable solutions.** Two or three families can sometimes share one full-time worker. Or you might start an informal "co-op" such as a Tuesday/Thursday coffeeklatch of four persons with Alzheimer's and two rotating pairs of caregivers. If there are scheduling problems with a day care program, there may be a neighbor willing to fill in the gap time or to provide transportation.
- **Remember, keeping you, the caregiver going is of higher importance** than "not pleasing" your loved one or compromising your standards for a short period of time. Consider this: If you burn out, what will the care be like?

Respite Care Options	Possible Resources for Respite Care/Other Household Help.
Adult Day Care	Senior Information & Assistance
Home Care Agencies	Social Workers
Brief stay at a Nursing Home or Assisted Living Facility providing respite care.	Bulletin Boards at senior centers
Family members	Ads in senior newsletters
Friends & Neighbors	Notices in church, synagogue, temple or mosque bulletins or newsletters
High School or College students	Chore Services
Nursing Students	Homesharing programs

Prepared by Linda Schreiner, Revised February 2001

## ADULT DAY CENTERS

For many family caregivers adult day care offers both a respite from caregiving responsibilities, and a care option that can provide several benefits for the loved one with dementia. Adult day care can provide opportunities for socialization, enjoyable activities, nutritious meals and snacks, and in some cases, a number of health care services.

Day care programs can vary, and you will want to consider the key components that will optimize this experience for your family. Such considerations may include:

- **What is the profile of clients attending the adult day center?** – Does the program provide services for people with a variety of impairments, as well as for those in good physical health? Be informed about any service limitations or restrictions beforehand.
- **Does the program provide an assessment?** – Will individual care needs be evaluated? How is the evaluation done, and how often is there a re-evaluation of needs? Will it cover medical needs, social and family history, cognitive functioning and social skills? Some adult day centers will perform assessments in the home.
- **What services are available to support both your family member and you?** – Few programs offer all of the following services, and not all of these services need be available to ensure a quality experience. When evaluating your needs, consider whether there is:

### ***Counseling***

Will the center provide support for clients and families? For example, can they offer guidance on outside resources and arrange for supportive care in the home?

### ***Health Services***

Will the center provide blood pressure checks and physical, dental, foot, eye and ear examinations? Can it dispense medications and/or offer medication reminders?

### ***Nutrition***

Does the center provide nutritious meals and snacks? Can the center accommodate special dietary needs or provide a culturally specific menu? Is there a nutritional education program?

### ***Personal Care***

Does the staff help with toileting, eating, showering, hair care and other appearance-related tasks?

### ***Recreation***

Is there an activities program that a person with dementia can participate in and enjoy?

### ***Behavior Management***

Has the staff been trained to handle wandering, incontinence, hallucinations, sexually inappropriate behavior, or speech difficulties? Is the environment secure and designed with special needs in mind?

### ***Therapy***

Will the center help arrange for needed physical, occupational or speech therapy? Are there therapists on site or on call?

### ***Special Needs***

Can the center meet the needs of someone who is wheelchair restricted, hearing or visually impaired?

- **How accessible is the program?** – Days and hours adult day programs are available vary. Many centers are open from early morning to early afternoon. Some programs are available one or two days per week. Many are available Monday through Friday. There are a few programs that are able to offer extended weekday hours (e.g. 7:00 AM to 6:30 PM), or may have weekend services. Find out what the minimum attendance requirements, and the notification policy for absences.
- **Consider the costs.** – Some centers offer services on a sliding scale, based on income. The Medicaid COPES Program may cover expenses for those who qualify. Ask about basic fees, financial assistance, and additional fees for transportation, crafts or field trips.
- **Are there transportation services available?** - Some centers offer transportation services. Centers may have their own van and driver, or have pre-arranged services available through public transportation that will provide door-to-door service for those attending the center.

- **Make certain you understand center policies.** – Center policies should be explained in advance and in writing. Know beforehand about minimum attendance requirements, absences, late arrivals or pick-ups.
- **Observe the environment of the center.** – Is the overall appearance warm, inviting, clean and free of clutter? Is the space adequate for activities and furnishings? Is there a safe, secure outdoor area for outdoor activities and for walking?
- **Consider the qualifications of the staff.** – Has the staff been provided specific dementia care training? Is there adequate staff available to provide quality care? Are there a physician, nurse or other health care professionals on staff or on call? If the program has volunteers, are they adequately trained and supervised? How well does staff cope with behavioral problems? Is staff warm, friendly and communicative with family members and caregivers?
- **Make sure the center director or intake coordinator understand Alzheimer’s disease.** – Be open about specific concerns or adjustment problems you anticipate your loved one experience. Determine how staff will assist in the transition to adult day care.

### **Tips for Adjusting to Adult Day Care**

- Take it slow. Allow 70 to 90 minutes to help her to get ready
- Have clothes ready in advance to avoid decisions about what to wear
- Ignore statements of refusal to get up or to go to the day care center
- Talk and move in an enthusiastic manner noting how good it will feel to get up and get some movement and exercise
- Continue your positive movements in getting her ready to go
- Use touch to calm her. Try a light, soothing neck massage. Apply moisturizing cream to legs and arms, and help her to apply makeup
- Serve her favorite breakfast as soon as she sits down. If it helps, sit down and eat with her

Once you’ve gotten past the resistance, you will find that adult day care will not only maximize your loved one’s overall functioning, it is a source of fun and enjoyment.

## **KEEPING PERSONAL CARE PLEASANT**

Having to rely on others to do these routine activities can be difficult for a person with Alzheimer’s disease. It may signal a loss of independence and dignity.

It’s difficult for caregivers as well, especially when one is learning to assist with personal care activities that seem invasive to a person’s privacy.

## BATHING

Bathing is usually the most difficult personal care activity that caregivers face. It is a very intimate experience, and the person with Alzheimer's may perceive it as unpleasant, threatening or painful. It can result in such disruptive behaviors as resisting, screaming, and even hitting. These behaviors occur because the person doesn't understand the process of bathing anymore, or doesn't have the ability to understand and endure some of the unpleasant aspects of the process.

Consider the following:

- **Be prepared.** Get everything set up in the bathroom in advance before mentioning the bath. Have towels ready, the room warm, clothes laid out, etc.
- **Create a safe atmosphere.** Place non-slip adhesives on the floor surface. Use grab bars and a bath bench if needed. Test the water temperature in advance to prevent burns and assure comfort.
- **Help him to feel in control.** Instead of asking "Do you want to take a bath?" say, as matter-of-factly as possible, "Your bath is ready". Have him do as much as he can on his own. Hand him the washcloth to wash himself. Think of this an activity you are doing together, rather than something you are doing to or for him. Offer a choice of soap or shampoo.
- **Respect his dignity.** Be sensitive to his self-consciousness about nudity. Allowing him to hold a towel in front of him both in and out of the shower may ease anxiety.
- **Don't worry too much about the frequency of bathing.** It is not necessary to bathe every day. Sponge baths can be effective between showers or baths.
- **Be gentle.** Avoid scrubbing sensitive skin. Use gentle patting dry instead of rubbing. Explain in a quiet, reassuring tone each step of what you are doing.
- **Be flexible.** If shampooing hair is uncomfortable or frightening, try using a washcloth to soap and rinse hair to reduce the amount of water on his face.
- **Try to make the bath enjoyable.** Play relaxing music, run a bubble bath, sing, give a foot massage, laugh, reminisce, use pleasantly scented products that are easy on the skin, and talk about the different aromas.
- **Keep a journal.** This will help you to know what has worked, and what hasn't. Record such things as the time of day, bath vs. shower, background sounds or noises that seemed either soothing or disturbing.

## TOILETING

Loss of bladder and or bowel control is common. Many factors can cause incontinence including medications, stress, a physical condition, the environment, and even the person's clothing. If incontinence is a new problem, consult the doctor to rule out a urinary tract infection, weak pelvic muscles or medications.

If the problem persists:

- **Provide visual cues.** Signs or other visual cues can help her to find the bathroom. Placing colorful rugs on the floors (use adhesive to secure and to ensure these don't cause a trip or falling accident) and lid covers on the toilet may help the bathroom to stand out. Avoid having items nearby that can be mistaken for a toilet (trash can, bucket, etc.)
- **Monitor incontinence.** Identify when accidents tend to occur, and make a toileting reminder schedule accordingly. For example, if you notice that accidents occur about every two hours, get her to the bathroom before that time.
- **Avoid dehydration.** Make sure she has at least 8 glasses of water each day. It's okay to restrict fluids in the evening, *if you make sure she has had 8 glasses of water earlier in the day.*
- **Remove obstacles.** Make sure clothing is easy to remove.
- **Provide reminders.** A person with Alzheimer's often forgets she has to use the bathroom periodically. Encourage her to use familiar words. Ask her to go along when you go. (This tends to work better with women.) Be aware of visible cues like restlessness or facial expressions that may indicate a need to go to the bathroom. When there is significant confusion, use step-by-step verbal instructions.
- **Be supportive.** Help him to retain a sense of dignity despite problems with incontinence. Reassurance will help to lessen feelings of embarrassment. Never scold or belittle him.

## DENTAL CARE

Good oral hygiene can be a challenge for individuals with Alzheimer's. Brushing their teeth is sometimes difficult due to the individual's inability to understand and resistance to assistance from others.

To help the person with Alzheimer's disease:

- **Provide short, simple instructions.** "Brush your teeth" may just be too little information about what exactly to do, and involve too many steps to think through, so instead, try: "Hold your toothbrush", "Put paste on the brush", "Rub the brush on your top teeth", etc.
- **Use mirroring technique.** Hold brush and show the individual how to brush his or her teeth. Get them started and instinct might take over.
- **Monitor daily oral care.** Brush teeth or dentures after each meal and floss daily. Remove and clean dentures every night, and brush the person's gums and roof of mouth. If the person refuses to open his or her mouth, try using aids available from your dentist to prop the mouth open. Facial expressions during dinner or refusal to eat may indicate oral discomfort.
- **Be creative.** If brushing the person's teeth is too difficult, offer carrot or celery sticks which will clean the teeth while they are chewing. Use their favorite style toothbrush. Make it a fun activity.

## DRESSING

Physical appearance contributes to everyone's sense of self-esteem. Clothing can be a form of self-expression, so it's important to consider his likes and dislikes.

To help the person to dress:

- **Simplify choices.** Each morning, offer no more than two choices of shirts and pants for the individual. Keep the closet free of excess clothing. Keep only seasonally appropriate clothes in the closet.
- **Organize.** Lay out clothing in the order it needs to be put on or hand each piece while giving short, simple instructions. Don't rush him as this will create anxiety.
- **Choose comfortable and simple clothing.** Shirts that button in front are sometimes easier to work with than pullovers. Substitute Velcro for buttons, snaps or zippers that may be too difficult to handle. Make sure that shoes are comfortable and not slippery.
- **Think of the environment.** Make sure the room is not cold. Make sure the lighting is adequate. Eliminate distractions.
- **Be flexible.** If you can only get a clean shirt on, save the pants for later. What is the harm in sleeping in the clothes they wore that day? If they have a favorite outfit, buy duplicates.

With all personal care activities it is important to incorporate past routine whenever possible. As you assist the person, be patient and creative. If she is getting too upset, walk away from the situation and try again later. An approach that works one day may not work the next, so be flexible and try it again another time.

Adapted from "Keeping Personal Care Pleasant", *Oregon Trail Chapter Newsletter*

## ENHANCING COMMUNICATION

A person with Alzheimer's disease often experiences changes in the way he expresses himself and the way he understands others. Communication is a vital part of our personal relationships. Through communication we convey our ideas, wishes and feelings. It helps us express who we are. It can be very troubling to experience difficulty verbalizing our thoughts, our understanding what has been said to us. However, communication is more than talking and listening. It involves attitude, tone of voice, facial expressions and body language.

### Changes In Communication

The way in which Alzheimer's disease affects communication will vary with each person. The person with dementia may find it increasingly difficult to express himself in words, and have trouble understanding what has been said. Those who interact with the person may recognize some of the following changes:

- Difficulty finding the right words
- Using familiar words repeatedly
- Inventing new words to describe familiar objects

- Easily losing train of thought
- Difficulty organizing words logically
- Reverting to speaking in a native language
- Using curse words
- Speaking less often
- Relying on nonverbal gestures more often

Keep in mind that a variety of physical conditions and medications can also affect a person's communication. Be sure to check with a physician when you notice significant changes.

### **Helping the Person With Alzheimer's to Communicate: Your Approach To Listening**

Have patience and understanding. You must be a *good listener*. When helping the person with Alzheimer's to communicate:

- **Be patient and supportive.** Let her know you are listening and trying to understand what he's saying.
- **Show your interest.** Maintain eye contact and show her that you care about what she's saying.
- **Offer comfort and reassurance.** If the person is having difficulty expressing himself, let him know it's alright. Encourage him to continue to explain his thoughts.
- **Give him time.** Let him think about and describe what he wants. Be careful not to interrupt.
- **Avoid criticizing or correcting.** Don't tell her what she's saying is incorrect. Rather, listen and try to find meaning in what is being said. Repeat what was said if clarification is needed.
- **Don't argue.** If the person says something you don't agree with, let it be. Arguing often only makes things worse.
- **Offer a guess.** If he uses the wrong word or cannot find a word, try helping him out. If you understand what he means, it may not be necessary to provide the correct word. In either case, be careful not to cause unnecessary frustration.
- **Focus on feelings, not facts.** Sometimes, the emotions being expressed are more important than what is being said. Look for the feelings behind the words. At times, tone of voice and other actions may help you to understand how the person is really feeling.
- **Limit your distractions.** Find a place that is quiet, so you won't be interrupted and he can focus on his thoughts.
- **Encourage her to communicate nonverbally.** If you don't understand what she is trying to say, ask her to point or gesture.

## Helping the person With Alzheimer's to Understand: Your Approach to Communication

As Alzheimer's disease progresses, communication can become increasingly challenging. Sensitive, ongoing communication is important, no matter how difficult it may become or how confused the person may appear. Although he may not always respond, he still requires and benefits from continued communication.

When communicating with a person with Alzheimer's, *words* must be chosen carefully. To enhance your interactions, try some of the following techniques.

- **Identify yourself.** Approach him from the front and tell him who you are.
- **Address the person by name.** This is not only courteous, but also helps to orient him and to get his attention.
- **Use short, simple, familiar words and sentences.** Don't overwhelm him with lengthy requests or stories. Speak concisely and keep to the point. In some cases, using slang words may be helpful.
- **Talk slowly and clearly.** Be aware of speed and clarity when speaking.
- **Give one-step directions.** Break tasks and instructions into clear, simple steps, giving one step at a time.
- **Ask one question at a time.** Don't overwhelm or confuse her with too many questions at once.
- **Patiently wait for a response.** She may need some extra time to process your request. Give her the time and encouragement she needs to respond.
- **Repeat information or questions.** If she doesn't respond, wait a moment and ask again. Use the same phrasing and words as before.
- **Turn questions into answers.** Try providing the solution rather than the question. For example, say "The bathroom is right here" instead of asking "Do you need to use the bathroom?"
- **Avoid literal expressions.** Directions such as, "Hop in!" may be taken literally and cause unnecessary confusion.
- **Avoid pronouns.** Instead of saying "Here it is," try "Here is your hat."
- **Emphasize key words.** Stress words that are most important such as "Here is your *coffee*."
- **Make negatives more positive.** Instead of saying, "Don't go there," try saying, "Let's go here."
- **Give visual clues.** Demonstrate your request by pointing, touching or beginning the task for the person.

- **Avoid quizzing.** Some reminiscence can be healthy, but avoid asking “do you remember when...?” or using statements like, “you should know who that is.”
- **Provide simple explanations.** Avoid using logic and reason at great length. Provide responses in a clear and concise way.
- **Write things down.** Try using written explanations for reminders when verbal ones are too confusing.
- **Try again later.** If she looks like she’s not paying attention, try to communicate again a few moments later.
- **Treat her with dignity and respect.** Avoid talking down to her or talking as if she isn’t there.

**Also, be aware of the *tone* you use:**

- Speak slowly and distinctly.
- Use a gentle and relaxed tone of voice. A lower voice pitch is more calming.
- Convey an easy-going, non-demanding manner of speaking.
- Be aware of your feelings and attitude. They are often communicated unintentionally through your tone of voice.

**Pay special attention to your *body language*:**

- Always approach the person from the front and avoid sudden movements.
- Maintain eye contact.
- Be aware of your stance to avoid sending a negative message.
- Use positive and friendly facial expressions.
- Use non-verbal forms of communicating such as pointing, gesturing and touching.

**Tips for Better Communication**

- Be calm and supportive
- Focus on feelings not facts
- Pay attention to tone of voice.

- Identify yourself and address the person by name.
- Speak slowly and clearly.
- Use short, simple and familiar words.
- Ask one question at a time.
- Allow enough time for a response.
- Avoid the use of pronouns, negative statements and quizzing.
- Use nonverbal communication such as pointing and touching.
- Offer assistance as needed.
- Don't talk about the person as if she wasn't there.
- Have patience, flexibility and understanding.

### ***Special Considerations***

#### **For the Hearing Impaired:**

*When communicating with someone who is hearing impaired:*

- Approach her from the front.
- Stand directly in front of the person when speaking to her.
- Get her attention by saying her name and gently touching her.
- Speak slowly and clearly, and use a lower tone of voice.
- Use nonverbal communication such as pointing or gesturing.
- Write things down if needed.
- If he has a hearing aid, encourage him to wear it and check the battery often.

#### **For the Visually Impaired**

*When communicating with someone who is visually impaired:*

- Avoid startling him.
- Identify yourself as you approach him.
- Inform him of your intentions before you proceed.

- Use large print or audiotape materials if available.
- Avoid loud noises or sudden movements.
- If she has glasses, encourage her to wear them, keep them clean and check the prescription regularly.

Adapted from: "Steps to enhancing communication: Interacting with Persons with Alzheimer's Disease", Alzheimer's Association publication, 1997.

## **LONG TERM CARE PLANNING**

Now that you have a diagnosis of Alzheimer's or a related disorder that causes dementia, it's important to develop a long-term care (or to review your plan to determine whether it is adequate to meet your projected needs. If you have not already received a copy, you may wish to call HELPLINE to request a copy of "Understanding Long-Term Care Options". The booklet contains information about **financial and legal options**, community resources that can help families caring for a loved one at home, and important considerations if you are seeking residential care.

### **WHEN STAYING AT HOME IS NO LONGER AN OPTION: FINDING A NEW HOME FOR SOMEONE WITH ALZHEIMER'S**

There are many reasons why a person may need residential care. Although many families may be able to provide care themselves or to hire 24-hour care when the time comes, this is not possible in all situations. Often families feel tremendous guilt when they realize they can no longer manage without finding an assisted living facility or a nursing home that can care for their Alzheimer's patient.

Promises that a loved one will never have to go to a nursing home should be avoided! Instead, reassure your loved one that you will make certain that she or he will always receive the best possible care.

When the time comes that a person with Alzheimer's disease requires 24-hour care, and those needs cannot be met with either family and supportive community services and resources (such as adult day care), or through paid homecare services, it is time to find a new home.

Appropriate residential long-term care options include:

- Assisted Living Retirement Homes
- Skilled Nursing

Assisted Living Retirement Homes are State-licensed boarding homes that combine housing, personalized care services and health care. More services are provided in an assisted living setting than in an independent retirement setting, but fewer services than a skilled nursing facility.

Skilled Nursing, also known as nursing home care, provides an intermediate or skilled nursing setting for those who require more assistance than an assisted living facility can provide.

There are both Assisted Living Facilities and Skilled Nursing Homes that can provide specialized care for persons with Alzheimer's or related disorders.

Many families prefer to move a loved one to a Continuing Care Facility (also known as Life Care or Continuum Care Retirement Communities). These facilities can provide independent retirement living, assisted living and skilled nursing care. As an individual's health declines, she is guaranteed continuing care in the nursing home section of the facility.

There are many factors to consider in choosing residential care. A booklet entitled ***Residential Care: A Guide For Choosing A New Home*** is available upon request. If you would like a copy of this guide, contact the HELPLINE, and a copy will be mailed to you.

It is a good idea even if think you'll never need residential care, to familiarize yourself with the options available in your community. Remember that many long-term care residences have long waiting lists. It is better to have a plan and not need it than to urgently need residential care and not know where to turn. Examine all of your available options well ahead of time. Do all of your information gathering early on to be as prepared as possible.

## **“A ROOM IS AVAILABLE” HOW TO MAKE THE MOVE TO RESIDENTIAL CARE**

*What do I tell Mother? How can I make it easier for us all?*

### **Gain Consensus**

Try to involve all concerned family members in making the decision. If the family is not in agreement, it can hinder the person's adjustment to the facility.

### **Keep It Brief, Simple**

When you tell your family member about the move, the simple facts work best. "It's not safe for you to live alone anymore; we've found the best place we could for you." Long explanations or trying to convince the person, only increase their resistance. It is usually best to tell the person only a few days in advance of the move.

### **Acknowledge Feelings**

It is crucial to acknowledge whatever feelings the person expresses. Anger and/or sadness are normal reactions to anticipation of a move and loss of independence. If the person expresses sadness, perhaps crying, join them in sorrow; allow your own tears and give your family member a hug. You may not need to do anything else.

If the person expresses anger, e.g. "I don't want to move; I want to stay in my own home," acknowledge these feelings by saying, "I know you don't want to move" or "I know you wish you could stay in your own home." This will help neutralize the anger, because the person feels understood. Then add, "We don't have a choice."

It is difficult to listen to feelings of anger, especially if they seem directed at you. Remember that sadness and anger are normal and healthy responses. The more your family member is able to

express these feelings, the easier their adjustment will be to the move. Your allowing and listening to these feelings may help avoid depression after the move.

### **Reassure**

“We love you and we’ll always be here for you.”

“We’ll do everything we can to help make it easier.”

Reassurance is what the person with memory loss seems to need most.

### **Redirect**

The shock and intensity of feelings are great. Both your family member and you need time and space. Distract the person with food, a change of room, activity.

## **MAKING A SMOOTH TRANSITION**

Moving a person with Alzheimer’s to a long term-care facility can be a traumatic experience for both the individual and the caregiver. There are several things that can be done to make this transition go more smoothly. In approaching ways to make the transition a more positive experience, look for signs from him to determine how much information is helpful. Generally, telling a person several days or weeks ahead of time results in increased trauma and anxiety. Consider sharing information on the person’s upcoming move based on the person’s ability to understand what is happening to handle stress.

Generally, the transition is easier if a family member or another familiar person spends time with the person at the time of admission. Many care facilities will make arrangements for you to have the first meal together, which can make him more comfortable.

There are other steps you can take before and during the transition to help the person adjust more easily. To smooth the transition for your loved one:

- **Personalize the room before admission.** Decorate your loved one’s room with personal items such as pictures, a favorite chair, end tables or a bedspread. Familiar items provide reassurance.
- **Choose the right time for the move.** Try to arrange the admission time during the individual’s “best” time of day. Avoid staff shift changes or mealtimes when facilities tend to be loud and hectic. Mid-morning hours are usually best because generally more staff are present and there is an activity he can attend right away.
- **Try not to show fear or sadness.** Do your best not to appear upset. A person with Alzheimer’s can be very perceptive of the emotions of others around him.

To prepare yourself for the transition:

- **Plan ahead.** Research the care that is available in your community soon after you receive a diagnosis. Many long term care facilities have long waiting lists. It is important to get your name on the waiting list before a crisis occurs. Becoming familiar in advance with the staff will also help you to become more familiar with the facility.

- **Define your new caregiving role.** Your role changes (but doesn't end) when a loved one moves into a care facility. You may want to come in for meals or do an activity together. This change can be very difficult, so you will want to stay active and pursue some of your own interests, as well. Enjoying yourself in no way means that you are abandoning or forgetting your loved one.
- **Talk with others about your feelings and emotions.** Many people find it helpful to join a support group sponsored by the Alzheimer's Association. You may also want to spend time getting to know other family members who visit loved ones at the care facility. Talking to others who are experiencing similar situations can be very helpful.
- **Maintain good communication with staff.** Share your concerns and suggestions with staff so they can provide a safe and comfortable environment for your loved one. Your information can not only help the staff to better understand your loved one as an individual, but improve his quality of life in his new home.
- **Develop a visitation schedule that is comfortable for you.** At first you may need some time away to define your new role and to accept the changes. When you visit, you may want to take along a friend or a family member if it is too difficult to visit alone at first. Encourage other family members to visit with you or at times when you are not able to visit. This is a good way to involve the family in the person's care.

## **EMOTIONAL FACTORS IN LONG TERM CARE PLACEMENT**

Love is ordinarily associated with acts of nurturance, generosity, attentiveness, steadfast devotion, and active, heartfelt support. Placing a loved one in an assisted living facility or a nursing home requires some degree of separation and estrangement, while the nurturing care is provided by professional staff at your loved one's new home. Even though you know intellectually that is your best remaining choice, the emotions of guilt a caregiver often feels can create painful emotions during this time of transition.

The high costs of out-of-home placement can also produce turmoil and guilt when balancing how to help to cover these expenses while safeguarding your own life savings and financial future. It is a good idea to discuss and evaluate this decision with those who are knowledgeable and supportive (other family members, an Elder Law attorney, members of your support group, the family doctor or social worker).

Caregivers can assuage their feelings of guilt and better cope with their feelings by understanding that the eventual placement of a loved one when the care needs can no longer be met at home is an act of love and genuine caring. Sometimes feelings of envy and competition with professional caregivers can emerge when one has been the primary caregiver for a long time.

Another factor that often makes the adjustment process for the family caregiver difficult, is the common confusion and fear their loved one feels, and the initial resistance to his new environment. However, many of these initial fears and the accompanying resistance are overcome relatively soon simply through his familiarity with his new home, the caregiving staff and other residents.

Placing a loved one can be a cause for relief for an exhausted caregiver. Feelings of relief can also bring feelings of grief and guilt when the family caregiver confuses these natural feelings with a lack of love or caring. Social pressures can increase the stress when others, due to ignorance, a

lack of empathy or just plain cruelty, harshly judge the caregiver who places a loved one in a long-term care home. Support groups can be enormously helpful in counteracting the negative effects of these kinds of pressure.

In general, spouses have the most difficult and complicated feelings about placing a wife or husband in a new home. This is related to the interdependency of spouses, as well as the deeper level and longer time of the commitment that exists in the spousal relationship than generally exists in the parent/child relationship.

Garner all of the support that you can at this critical time. *When you find yourself listening to that nagging internal voice that is making you feel guilty, recognize it as a negative feeling that is interfering with your well-being and causing you additional pain.* Refuse to listen to that negative refrain, and when you catch yourself listening, and feeling guilty, tell yourself “Stop!” and remind yourself that this difficult period of adjustment will be over soon, and it is *keeping you from a healthy adjustment* that will come given time. Reach out to friends and family who are supportive of you, and who have empathy. Push yourself a bit to begin to resume some of the activities you once enjoyed, and explore new activities.

Adapted from “Emotional Factors In Nursing Home Placement”, Gerald Amanda, PhD, Lincoln/Greater Nebraska Chapter Newsletter, October, 1999, Alzheimer’s Association



### **Help Care Providers Get To Know Your Loved One Better By:**

- **Providing photographs**
- **Sharing stories or memories**
- **Preparing a written personal history**
- **Explaining favorite hobbies, activities & interests**