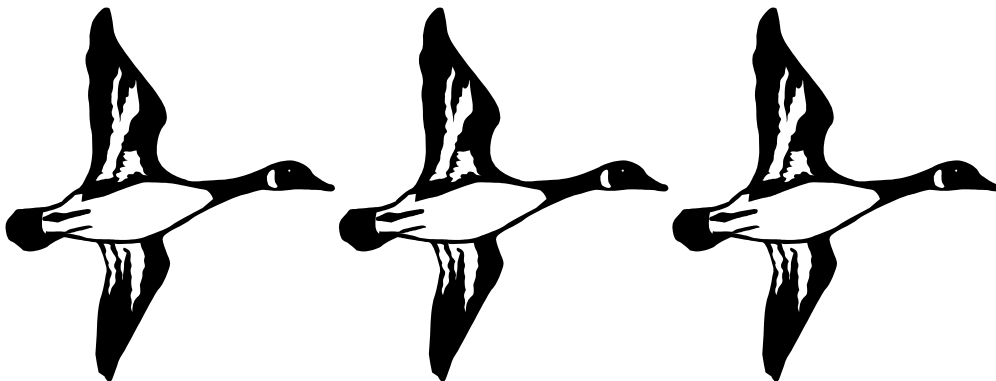


Increasing Your Support

What could you do with this extra time?

- Companion Care
- Day Centers
- Common feelings



Every time I close the door on reality
it comes in through the windows.

Jennifer Unlimited, Workman Publishing

Care Options

One of the most difficult decisions a loving spouse or adult child must make is the decision to accept outside help. On "good days," you may think that you can continue to be the primary person providing services to your loved one. But after a particularly trying period of time, you may be ready to accept the help of an outside agency in order to provide the relief that you need. The journey can be a long one, and in order to ensure a good quality of life for both you and your loved one, you will need to consider getting outside support.

When Should You Enlist the Help of Agencies?

The time comes when the realization dawns that the relationship has evolved primarily into roles of caregiver and care recipient. The intimate bond of husband/ wife has changed and no longer looks like a marriage of equality and partnership. The relationship that once was characterized as parent/ adult child has now shifted and the adult child is making the decisions.

Do not dwell on the past, do not dream of the future; concentrate on the present moment. Buddha

The old family roles and patterns of interaction no longer exist. This is the time for outside support. Your loved one can learn to accept help from others. However, your attitude is critical in helping the person with memory loss accept other care providers.

Determining the level of help you need

Consider the type of assistance that you need. Keep in mind that your needs will continually change as the disease progresses, so proactively prepare for other levels of care as well as selecting care options for the present level of need. Considerations for help involve two categories: help for the caregiver and help for the person with dementia.

Help for the caregiver can take the following forms:

- Shopping
- Bill paying, *e.g.* health insurance
- House cleaning, maintenance
- Meals
- Laundry
- Transportation
- Errands

Help for the person with memory loss includes:

- Social interaction, companionship
- Mental stimulation
- Physical exercise
- Support with activities, *e.g.* golf, cooking, hobbies
- Personal care

Beginning the Search for Help

Family and Friends

Family and friends are a valuable free or low cost resource, and often they have already offered assistance in the past. If you initially said, "I'm managing, but thanks anyway", now is the time to say, "You know, when you offered to help me last month, I wasn't ready, but now things are a little more difficult and I'd like to accept the offer." Some families choose to pay the person who is helping. This can make it easier for you and your person to accept this help. There are willing hands and hearts out there.

The following tips may ensure success:

Ask the right task of the right person

When people ask how they can help, what they are really saying is, how can I help within my comfort zone and my strengths? For example, if the person offers help, and he isn't a pet owner, he probably will not want to walk the dog or take the family pet to be groomed! Giving someone a task

that is outside the person's interest or experience may curtail any future offers.

Don't expect a friend or neighbor to supervise personal care. Those tasks are best performed by immediate family members or hired health aides. However, neighbors are often willing to run a few errands while they are out, or to pick up some groceries when they are doing their own grocery shopping. Longtime friends are often comfortable spending a few hours with the person with memory loss, providing a break for you to enjoy a hobby or a luncheon with a friend.

Be Specific with A Date and Time

Tell anyone who offers exactly how help could be given. Keep a list of ways to help by the phone so that if someone calls with an offer, you can respond with a request. Say "I would really like to go to a Bible study on Wednesday evenings. It starts at 7 pm and I would be home by 9. Would you be able to help me this Wednesday?"

THIS Wednesday is better than SOME Wednesday. If someone says that the date or time isn't good, ask what specific day or time would be convenient.

Overcome Your Reluctance to Ask

It may feel awkward at first, but as you get positive responses from others and a few hours of well-deserved free time, it will get easier. You will also give these family members and friends the opportunity to feel that they have truly been able to help without feeling burdened.

Selecting an Appropriate Activity to Pass the Time

Provide a familiar activity to keep the person with memory loss occupied, so that the time with the family member or friend passes quickly, *e.g.* looking at photo albums, going out to lunch, visiting a museum, taking a walk. Reading aloud is another good activity. Select articles from an inspirational book or community newspaper, *e.g.* movie reviews.

Make sure that the person doesn't feel pushed to make conversation or entertain the person. Just watching a favorite T.V. show or movie, baking,

or listening to music is fine. Assure the person that his presence alone will be all that is needed to provide an enjoyable experience.

Yesterday is experience

Tomorrow is hope,

Today is getting from one to the other

As best we can.

Tapping into Community Care Providers

Not all the needs of care giving can be met through your existing relationships. That is why there are so many agencies and services out there to assist individuals today. Because of the variety of services, you must determine what services are appropriate for your budget and your loved one's needs before getting on the phone.

Preparing for Agency Contact

Once you have made the decision to get supplemental help, pick a time when you will not be interrupted. Have a concise statement of your loved ones needs in front of you and be ready to answer questions concerning his level of functioning. For help with this, you could use our checklist on daily functioning in the back of this module.

1. Be ready with a pad of paper. Write only one agency and its phone number at the top of each page so that all the information doesn't run together in your head when you get off the phone. When you rule an agency out, don't throw away the page; just draw a line through the page and write WHY you think they are not appropriate. You may be coming back to this list again as your needs change down the road.
2. Decide what you need to ask of the agency and write it down so that nothing important is forgotten.

3. Have information like social security numbers, health insurance, and medications on hand so that you are ready to share this if asked.
4. Know that you will be put on hold, transferred, and compelled to repeat your situation several times. You may want to consider completing the checklist of daily functioning, making photocopies, and mailing these to a provider under consideration so that you do not have to keep giving the same information out repeatedly over the phone. The investment in copies and stamps will save you valuable time and will put the ball in the court of the agency after your information has been received.
5. NOTE: Omit health care and social security numbers until you are sure you will need to release this information and have settled on a provider.

We must be willing to let go of the life we have planned, so as to have the life that is waiting for us. E.M. Forster

What is Available?

Senior Centers

Perhaps you are seeking an occasional outing or some activities to keep your loved one busy. Consider paying a companion or asking a friend to attend some activities at a local Senior Center with your loved one. Senior centers are designed to enhance the quality of life for mature adults. They provide activities and events that might be of interest to your loved one. The Centers provide opportunities for socialization with older adults in the area and the chance to participate in scheduled, ongoing activities designed especially for the senior population. Contact your local Office for Older Adults to get more information about these programs.

Home Delivered Meals

Meals are available for those who are housebound, unable to cook, and have no one else at the home to prepare nutritious meals. Many people begin receiving meal delivery after they have been hospitalized or when a caregiver is recuperating from a hospital stay. The meals are also helpful

when the person with memory loss is on a special diet that would make it difficult for him or others to prepare meals around those restrictions.

A needs assessment is completed by a staff member to determine the type of meal that accommodates the client's needs. This may be a regular meal, a meal modified to address a special diet with caloric restrictions, or a therapeutic meal, which accommodates texture modifications and food allergy issues. The cost is about \$5.50 a meal but subsidy funding is available for those who qualify.

The meals are generally delivered between 11:00 a.m. and 1:00 p.m. Frozen meals are also available. Meal delivery has the added benefit of providing a friendly face and a safety check on the recipient.

Transportation

The local Office on Aging provides information on transportation for Senior Citizens who cannot access regular public transportation.

Companion Care

If you have concerns about leaving your loved one alone, consider employing a companion. This person may simply visit with your loved one while you are out. Companions also perform routine household tasks and provide reminders or cueing. Knowing that someone is at home with your loved one and that he or she is safe, will allow you to enjoy the time you have set aside for yourself.

Companion Care includes such things as:

- Assisting with entertainment
- Providing transportation; accompanying to sporting events or religious services
- Meal planning, simple food preparation and clean-up
- Playing simple games such as *Uno* or *Bingo*
- Providing cueing for hygiene and grooming
- Scheduling and escorting to appointments

- Light housekeeping and straightening
- Laundry, ironing and changing bed linens.
- Pet care
- Medication reminders and prescription pick-up
- Exercising and walks

Home Health Services

Home care workers offer a variety of services and may be called home health aides, certified nursing assistants (STNAs), or nurse's aides. They are state tested and certified to provide assistance with bathing, dressing, and eating. They also manage incontinence, wandering, behavior and communication issues.

Other In-home Health Care Professionals

Skilled professionals such as registered nurses, therapists, or licensed practical nurses (LPN) can administer medication, monitor blood pressure or blood sugar, supervise nutrition, provide acute care and oversee occupational, speech or therapy regimens.

Companion services are not covered by Medicare. However, Medicare may cover skilled services for rehabilitation for a short period of time after a hospital stay. The Area Agency on Aging screens for Medicaid eligibility, and will fund home care for Medicaid eligible individuals through a program called PASSPORT. PASSPORT clients require a doctor's orders for medical necessity.

There are many companion / home care agencies in your area. The Alzheimer's Association can provide you with a list of these agencies by county.

When calling agencies for information on home care, here are some questions you may want to ask:

- ✓ Is the agency a certified Medicare or Medicaid agency? If it is, it will automatically be bonded. If not, is it bonded?

- ✓ How long has the agency been in business?
- ✓ What services does the agency offer?
- ✓ What is the hourly rate?
- ✓ Is there a minimum time and charge?
- ✓ Are there different rates for different services?
- ✓ Are there different rates for holidays, nights, weekends, or vernights?
- ✓ What hours are aides available for work?
- ✓ How far in advance do arrangements have to be made?
- ✓ What type of training or experience do the aides have?
- ✓ Does the company do background checks, including fingerprinting, on employees?
- ✓ Are TB tests and physicals required of all aides as a pre-requisite of caregiving?
- ✓ Will the same caregiver be available for all care?
- ✓ How often does a supervisor make home visits?
- ✓ How are complaints and emergencies handled?
- ✓ What options are available to help pay for services, *e.g.* Veteran's benefits, PASSPORT?
- ✓ Does the agency have a large number of Alzheimer's patients?
- ✓ How much Alzheimer's training does each aide receive?
- ✓ Is a care plan made? When?
- ✓ What if an aide calls off? Is there back up?
- ✓ Can you change aides if dissatisfied?
- ✓ Can the agency provide references for the agency? For the aide?

Adult Day Services

These community-based centers offer care and activities for disabled adults in a safe setting. They provide social interaction and stimulation that keep the mind functioning at an optimal level. Most programs operate on weekdays. However, some programs also have evening and weekend hours. The fees range from \$40 to \$85 a day. Forms of payment include Medicaid, Veteran's benefits, PASSPORT, and private pay. Ask the day center for guidance in this.

Not only do the day programs provide caregiver relief and the opportunity for the caregiver to continue to hold a job, but the mental and social stimulation that it provides to the person with memory loss is invaluable. See the reference page at the end of this module on Adult Day Care. There is also a section on how to encourage your loved one to take this step.

Board and Care

A residential care facility commonly known as a group home is often utilized for persons with memory loss. These group homes normally house 4 individuals of the same sex who need supervision and help with personal care. The homes are staffed by state tested nursing assistants and supervised by group home managers. A nurse visits regularly to monitor medical conditions. Supplemental Security Income (SSI) and veteran's benefits or private pay are the primary sources of payment. Call the Alzheimer's Association for guidance on how to go about this and also information on your local Long-Term Care Ombudsman Service.

Respite Care

Many nursing homes offer short-term respite care, ranging from overnight to a few weeks' stay. Short term care can be utilized when a caregiver is recovering from injury, surgery or illness and plans to return home and resume care for the person with memory loss. It can be a good way to temporarily try out a nursing facility to see if it is appropriate for your loved one's needs. During this trial period, the caregiver can observe how the facility accommodates the person with memory loss. It is also a useful way to determine the level of care that might be needed if the person with

memory loss becomes a permanent resident there. See the guide to respite care at the end of the module.

Nursing Home Care

Long-term care is a viable option when the person with dementia has physical and emotional needs that outweigh the benefits of home care. Perhaps the stress of having many caregivers in different capacities coming to the home on an ongoing basis is taking its toll emotionally. Or perhaps the care is no longer financially feasible. Often, difficult behaviors, the amount of care needed, or changes in the caregiver's health necessitate this service. Call the Alzheimer's Association for guidance on how to go about this and also information on your local Long-Term Care Ombudsman Service.

The Realities of Caring for a Person with Memory Loss

Physical Effort and Time Commitment

Help with bathing, eating, dressing and other activities of daily living takes a lot of time. As the disease progresses, the need for this kind of help increases. Behavior problems and safety concerns mean that the family member is always "on duty", even when not actively helping the person.

Financial costs

The costs of care vary, but can be high depending on whether the person is cared for at home or in a residential care setting and how much help the caregiver has. Many caregivers give up their jobs or cut back on their work hours and this also has financial implications.

Redefining relationships

Family members often experience a profound sense of loss as the disease causes shifts in their person's ability to converse and to enjoy previous activities. Decisions that you always made together now have to be made alone. Emotional needs may go unmet and a feeling of isolation may occur.

...BUT research has shown that caregiving also has important positive effects:

- A new sense of purpose or meaning in life
- Fulfillment of a lifelong commitment to a spouse
- An opportunity to give back to a parent some of what the parent has given to them
- Renewal of religious faith
- Closer ties with people through new relationships or stronger existing relationships.

Taken from *Alzheimer's Disease: Unraveling the Mystery*
National Institute on Aging, U.S Department of Health and Human Services
National Institutes of Health, NIH Publication Number 02-3782, 12/03, p. 51

Life becomes harder for us when we live for others, but it also becomes richer and happier.
Albert Schweitzer

Accepting Imperfect Help

When resentment and martyrdom begins to take hold, you have waited too long to seek help. Sometimes, refusing help is a sign that the caregiver cannot let go of control. You may be stuck in the bind of the overachieving caregiver*.

1. Do you feel that no one else can look after your relative as well as you can?
2. Do you go for weeks without taking even an hour off?
3. Would you feel you had abandoned your relative if you took him or her to a day respite program?
4. Do you feel that only you can understand him or her and that letting others provide care would hurt, frighten, or otherwise damage your relative?

5. Do you feel anxious, exhausted or irritable most of the time?
6. Do you secretly feel angry with your relative, and then feel deeply ashamed of your feelings and become obsessed by guilt?
7. Have you dropped most of your previous hobbies, friends and interests?
8. Do you avoid going to support groups because you could never share your feelings with strangers, and/or you are sure such groups are full of people who just make each other miserable?
9. Do you keep all your fears, needs, and feelings to yourself because you aren't the kind of person who shares such things with others?
10. Are you sure that no good caregivers can be found (paid or otherwise)?

If you answered yes to three or more items, you are a member of the Overachieving Caregiver's Club. Don't feel bad; here is how to let your membership expire!

DO accept imperfect help. Admit that you are not a perfect caregiver during those moments when impatience, anger, and resentment well up inside of you. Admitting your lack of perfection gives you permission to let someone else help out "imperfectly" on occasion, as well.

DO let go of being indispensable. It is very possible that trained caregivers who specialize in providing services to persons with memory loss may actually do certain facets of the job better than you! So give them a chance to prove it, and let go of the need to control how the care is given. A different approach than the one you use doesn't mean that it's the "wrong" approach or that your way is necessarily the "right" one.

DO join a support group. The tips and knowledge of individuals who have this common bond with you are invaluable. Those who have been caregivers for a longer period of time have had experiences with the agencies and the health care systems that can help you narrow down your possibilities. They will also support your decision to get outside help. Many caregivers will tell you that their support group has been a life line

for them and that they formed friendships there that lasted long after their caregiving experience had ended.

DO use some of the care options discussed in this module. You deserve it!

Adapted from, *The Overachieving Caregiver*, The Alzheimer's Sourcebook for Caregivers: A Practical Guide for Getting Through the Day, by Frena Gray Davidson, Contemporary books, Chicago. 1993, pages 187-188.

What We Have In Common With Geese

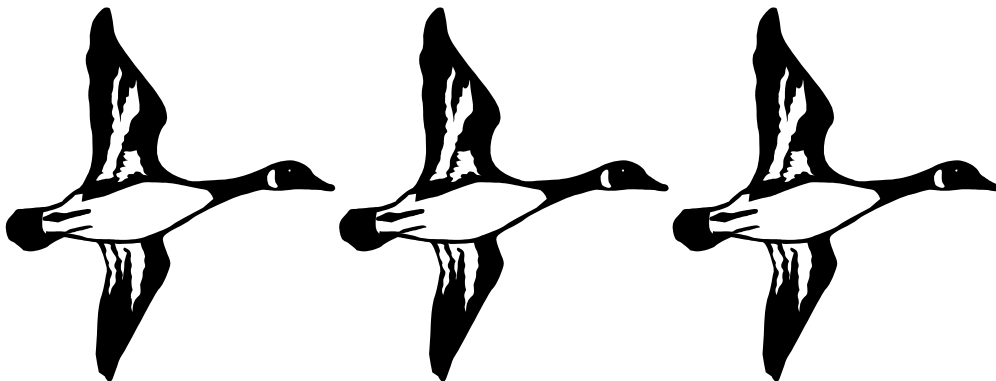
When you see geese flying in a "V" formation, you might be interested in knowing what facts scientists have discovered about why they fly that way.

1. **FACT:** As each bird flaps its wings, it creates an uplift for the bird immediately following. By flying in a "V" formation, the whole flock adds at least 71% greater flying range than if each bird flew on its own.

TRUTH: People who share a common direction and sense of community can get where they are going quicker and easier because they are traveling on the trust of one another.

2. **FACT:** Whenever a goose falls out of formation, it suddenly feels the drag and resistance of trying to go it alone and quickly gets back into formation to take advantage of the lifting power of the bird immediately in front.

TRUTH: There is strength and power and safety in numbers when traveling in the same direction with those with whom we share a common goal.



3. **FACT:** When the lead goose gets tired, it rotates back in the wing and another goose flies point.

TRUTH: Each of us needs to take our turn in giving direction for the good of the whole.

4. **FACT:** The geese honk from behind to encourage those up front to keep up their speed.

TRUTH: We all need to be remembered with active support and praise.

5. **FACT:** When a goose gets sick, or is wounded and falls out, two geese fall out of formation and follow it down to help and protect it. They stay with it until the crisis resolves, and then they launch out on their own or with another formation to catch up with their group.

TRUTH: We must stand by each other in times of need. We are fortunate that there are more geese in life than turkeys. Let's remember to uphold each other in friendship and to give each other a big "honk" more often. Makes you think doesn't it?

Taken from the Newsletter Archives, Alzheimer's Association



Brilliant Insights From Persons Living with Memory Loss

1. My husband is good about things. He does the grocery shopping. I used to love to do it, but now I just give him the list.
2. My girls always asked for help when they needed it. They now realize the tables are turned.
3. I need help with my checks now. I just can't do it all anymore.
4. I don't cook much anymore, but I do the dishes and my husband and I shop together.
5. What bothers me most is that I've always been fiercely in control. I don't want to lose my independence!
6. I'm ok unless I spend too much time alone.
7. Wanting to help while I'm being helped – a double whammy.
8. Many days I really get down on myself. I think that I should be working.
9. Once I ask for help, I'm afraid he (my husband) will try to take that job away.
10. I don't want someone making all the decisions. I want to have a choice.
11. The mailman gives the mail to my husband instead of me. Hello, I'm here. I live here, too!
12. My dog saves me from boredom.
13. I'm at the point now where I don't want to go out socially – I get too upset inside.

14. My daughter calls me all the time to see if I'm okay. I would like the message on my answering machine to say, "I am not home right now, but I'm okay. I have not fallen and I can get up!"
15. I feel like I'm the same person, a husband, a father, grandfather.
16. My husband keeps following me around. He wants to know if I'm okay. I say, "I'm right here!"
17. I get tired of my wife asking if I took my pills. She listens for the pill container to open. "I didn't hear the clicking; did you take your pills?"
18. When there is friction between us and our families over issues like driving, it takes the pleasure out of the whole day.
19. Without love and sensitivity, there is nothing.

I Think There Are Two Worlds

There's my world, and this can be upsetting
if I focus too much on things I can't do anymore.

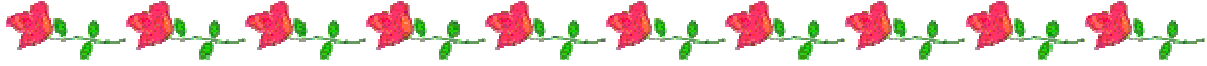
But then there's my wife's world, which is much harder.
She has to do so many things that I used to do or used to help her with.

Our world will get easier as we go into a kind of blissful unawareness;
but their world will get harder and harder. That's why I try to do
everything I can now to show her that I love her, and to help her in as
many ways as I can.

By Reverend Bill Hull

20. The change has to take place within us and this kind of session helps us to do that.
21. You have to look for what's left, even if it's not what you wanted to be there.

The Serenity Prayer



God, grant me the

SERENITY

to accept the things I cannot change ~

the COURAGE

to change the things I can;

and the WISDOM

to know the difference.



By Reinhold Neibuhr

Making the Decision

When is the right time for facility care?

It is difficult to know when to begin looking for facility care for a loved one. However, if you are the primary care provider for someone with Alzheimer's disease, you may begin asking this question as the disease progresses. The most important thing to remember is that there is no "right" time for everyone. Each person and family is different, and there are several factors to consider. To discuss these factors, a family meeting is recommended, including family, close friends and neighbors, and, when possible, the person with Alzheimer's disease. Use the checklist below to assess your caregiving situation.

What Are the Important Issues?

Safety

Energy

Personal Hygiene

Financial Concerns

Behavioral Concerns

Caregiver Issues

Nutrition

In-home Options

Time

Safety

___ Does your loved one forget or refuse to use safety equipment such as wheelchairs, walkers or grab bars?

___ Is the home environment becoming more difficult for the person with AD, *e.g.*, stairs, accessible doors, dark hallways?

___ Has your loved one had accidents with the stove, appliances, or other household items?

___ Has the person with AD had trouble getting around the house without falls or extensive help walking?

___ If your loved one smokes, has he had smoking accidents, *i.e.*, forgetting to extinguish cigarettes, burning holes in clothing?

Personal Hygiene

___ Is it difficult for your loved one to get to the bathroom when needed?

___ Is the person with AD unwilling or unable to bathe?

___ Is the person with AD unwilling or unable to change clothing when needed?

___ Is your loved one unable or unwilling to help with personal care tasks?

___ Have care needs for your loved one become too difficult or too demanding for you?

Behavioral Concerns

___ Has your loved one ever wandered away from home or been lost?

___ Is your loved one combative, suspicious, angry or refusing care?

___ Has the person with AD physically harmed himself or you at any time in the past?

Nutrition

___ Does the person with AD have trouble preparing meals or eating independently?

___ Do you have difficulty encouraging your loved one to eat appropriate, nutritious foods?

___ Is your loved one having health problems associated with poor nutrition, *i.e.*, vitamin deficiency, dehydration, weight loss, illness?

___ Has eating and swallowing become difficult for the person with AD?

Time and Energy

___ Does your loved one need help with most ADLs, *i.e.*, eating, bathing, dressing, personal hygiene)?

___ Do housekeeping duties need to be done so frequently that care becomes an excessive demand?

___Have you frequently lost sleep at night due to caregiving?

Financial Concerns

___Would/Do you have difficulty affording in-home help 24 hours a day?

___Have the financial strains of caregiving been difficult on your personal budget, *i.e.*, medical equipment, incontinence, food).

___Do you miss work frequently due to caregiver responsibilities?

Caregiver Issues

___At the end of the day, have you felt like you couldn't make it through another day? Is this a recurrent thought?

___Is your health at risk or beginning to suffer because of your caregiving responsibilities?

___Have you lost privacy or the ability to organize and run your household?

___Is there frequent conflict between household members related to caregiving issues?

___When you get a break from caregiving, do you still feel overwhelmed and exhausted?

In-Home Care

___Have you tried and been unsuccessful with in-home services such as housekeeping, delivered meals, personal & companion care?

___Have you had difficulty getting your loved one to attend adult day programs?

___Has overnight respite care been used?

___Have you had difficulty enlisting the assistance of family and friends to give yourself a break?

If you answered **"yes"** to many of these questions, you may need to begin thinking about alternative care options. These are just some of the factors to consider when making this difficult decision. Individual personalities, family history and outside support should always be a part of your decision.

Remember.....

- **Plan ahead to prevent making decisions during a crisis.**
- **It is ok to ask for help – you need emotional and physical support.**
- **You are doing the best you can.**


By Amelia Schafer Grundy, Oregon Trail Chapter

NOTE: If you would like help with the nursing home placement decision, and you live in Portage or Summit counties, you can contact the Nursing Home Placement Assistance Program at (330) 896-9712 ext. 3203 or 1-800-421-7277 ext. 3203. In Medina County, contact the Long-Term Care Ombudsman Program at 1-800-365-3112.

Some helpful websites:

<http://content.gannettonline.com/gns/nursinghomes/index.html>

www.medicare.gov/NHCompare/Home.asp



Never let what
you can't do
Interfere with
what you can
do.

Why the Nursing Home May Be the Right Choice

By the time the person with dementia can no longer recognize members of the family, the kind of care he/she gets matters more than who is giving it. Our culture seems to disapprove of putting a family member in a nursing home, even when the care the impaired family member requires is destroying the family who are trying to provide appropriate home care. However, this is not realistic.

The decision is hard to make whether the person is mentally intact or not. Nursing home placement can be beneficial to the caregiver and the person with dementia. If you wonder about a nursing home for a person with dementia in your family who is no longer sure where "home" is, think about these points:

- The staff of a nursing home comes on fresh and alert three times a day. The caregiver is on duty around the clock and therefore can be less alert.
- The people who work in nursing homes have had some training on how to work with people with dementia. This can make care somewhat easier on both the staff and the person with dementia.
- The staff and other residents of the nursing home accept the person with dementia where he/she is at now, whereas almost every caregiver tries (although not meaning to) to force the mentally impaired person to be the person he/she can no longer be.
- The person with dementia can be more social when around others who have the same level of impairment he/she does.

Listen to the advice of experienced caregivers who have tried to continue home care long after it stopped helping the person and was actually providing poorer care with greater strain on everyone. The very fact that a person with dementia will ask to go "home" when in a house that has been a home for quite a period of time should be a clue as to how little one place or another means anymore.

How to Make the Move to Residential Care

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 and simple: When you tell your family member about the move, the simple facts work best, *i.e.*, "It is not safe for you to live alone anymore; we have found the best place we could for you." Long explanations or attempts at trying to convince the person will only increase his/her resistance. It is usually best to tell the person only a few days in advance.

Acknowledge Feelings: It is crucial to acknowledge whatever feelings the person expresses. Anger and/or sadness are normal reactions to the anticipation of a move and a loss of independence. If the person expresses sadness such as crying, join him/her in his/her 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, *i.e.*, "I do not want to move; I want to stay in my own home," acknowledge these feelings by saying, "I know you do not 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 do not have a choice."

It is difficult to listen to feelings of anger, especially if they seem directed at you. However, 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 will always be here for you” “We will do everything we can to help make it easier.” Reassurance is what the person 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 or an activity.

Team it: You can team with a sibling, spouse other relative, friend, or more than one person. It is too stressful to try to do yourself. During the critical days before the move and the week after, you or the other person may need a time out. Other times you will need the mutual support and presence of being together. Discuss your needs daily. Reinforce your successes. Give each other verbal “pats on the back.” Vent your feelings – sadness, frustration, and often exhaustion – emotional and physical.

Know and Support the Person’s Coping Skills: Some people adjust by retreating and by allowing themselves to become dependent. Others adjust by trying to regain control, making increased demands – typically on you!! Try not to take this personally. Reassure the person, “We’ll try to take care of it,” or “We’ll see that it’s taken care of” without making a specific commitment. It is important to be realistic and say “No” when appropriate. It is crucial to realize you cannot make another person happy; that is not within your power. What is important is that your family member is safe, taken care of, and that his/her quality of life is the best possible.

Seek Counseling if Needed: If you have unresolved issues from the past (anger or guilt toward the person with dementia), it is helpful to seek counseling, hopefully before you need to move your loved one. It can make all the difference!!

Explore Your Options: Gather information. Explore alternatives. Try what you need to try. Realize that at some point most persons with progressive dementia will need the equivalent of 24-hour nursing care and supervision. For some families, the best care can be given at home. For other families, the best decision is to use a residential care facility.

THERE IS NO RIGHT ANSWER AND NEITHER DEICISION IS A MEASURE OF YOUR LOVE!!!

*Courtesy of Joan Scharf, A.C.S.W., L.I.S.W.
Alzheimer's Association Cleveland Area Chapter January 2000*

When a Loved One Enters a Nursing Center

The decision of placing a loved one in a nursing home can stir up feelings of self-doubt, anxiety, grief, and guilt. People tend to think that no one will watch out for their family member the way they do. People also tend to think about what would happen if they have to enter a nursing home themselves. Guilt and sadness can drain your energy and self-esteem. The following are some tips to help you let go of these negative emotions:

Acknowledge your true feelings: Grief is a normal and healthy reaction to any loss, not just death. It is supposed to happen. Anyone who has a friend or relative with dementia will grieve over and over again during the course of the illness. Join a support group to share your experiences and feelings. Do not set a timetable for when you should expect to "get over" your loneliness or allow anyone else to set one for you. It is a lot to get over. However, realize that you will survive.

Put any "broken" promises into perspective: Did you already make a promise not to place your loved one in a nursing home? A lot of people make that promise. However, competing burdens may leave you with no alternative but nursing home placement. You must tell yourself that you have honored your promise to the best of your ability. According to Naomi Nelson, Ph.D., of the Alzheimer's disease Center at Baylor College of Medicine in Houston, TX, "*Placing a loved one in a nursing home is not a denial of duty. Regular visits, telephone calls, and participation in the nursing center's activities will show your loved one that you are still very much a part of his/her life.*"

Concentrate on the positive: Dr. Nelson says that many individuals who enter nursing homes find new lives for themselves and make new friends. The health of the very frail may markedly improve with regular

medical care and the attention of therapists and other health professionals. Look forward to the future and plan for your life without the full-time responsibility of caregiving. Comfort yourself with the memories of times shared with your loved one and realize that not everyone has those special moments. Give yourself credit for the sacrifices you made.

Do not forsake your own life and deeds: Remember that you have given for a very long time and have made a more comfortable life for your loved one. “Never forget that you have a life that is separate from that of your loved one. Individuals who are able to carry on with their lives are typically the ones best equipped to let go of negative feelings,” says Dr. Nelson. If one day you do not think of the person who is in the nursing home, do not feel guilty. It is not necessary to spend the rest of your days feeling guilty about your own good health just to prove your love.

Put together a support system of friends and relatives: Invite others into your life. Invite someone to share coffee or potluck with you. Give your friends and relatives the opportunity to help. Remember, helping you means helping them deal with the absence of this person.

Remember that you will not heal overnight: Letting go of negative feelings is a gradual process. You may never get rid of all these negative feelings completely. However, your negative feelings should never eat away at you either. You must make peace with yourself.

Know your rights: The adjustment can be made easier by knowing about your resident rights and some special protections under the law. If you want to know about nursing home resident rights, you can consult the following sources:

Long-Term Care Ombudsman:

(330) 896-9712 or 1-800-421-7277 (Portage and Summit counties)
1-800-365-3112 (Medina County)

Medicare: 1-800-MEDICARE

State Survey Agency: 1-614-466-5357

How Often Should I Visit?

Visiting a loved one with dementia in a facility can be a challenge. Guilt, dread, feelings of loss, and hopelessness are some of the emotions families describe as they work to retain a connection with their loved ones. Daily visits may be a difficult or unrealistic expectation. However, the frequency of visits is a very personal decision for each family. Here are some tips that may help take some of the stress out of visiting decisions:

- Focus on quality, not quantity. Learn how to make visits count by asking other families how they do it. Make friends with families in the facility and consider attending a support group.
- Define whether the focus of the visit will be social, problem-solving or both. Allot time and make appointments accordingly. If you have just attended a care plan meeting, you may peek in on your loved one and call it a day.
- Share the care. Ask other people to supplement your visits such as neighbors, church associates, etc.
- Start each visit with a ritual. This may include bringing a favorite food, going for a walk or humming a familiar tune.
- Value a quiet presence. If conversation is no longer possible, try sitting next to the bed sewing, reading, listening to soft music and holding your loved one's hand. We can often connect physically if language is no longer a realistic bond.
- Use props. Bring a cartoon to read, a photo album, videos. Participate in pleasurable activities offered at the facility during your visit.

- Give yourself permission **not** to go. Love is portable. Physical presence is not always a requirement. Remember, your loved one wants you to be as healthy, balanced and relaxed as possible even though he/she cannot express this wish for you.

Excerpts from "How Often Should I Visit?" by Janis McGillick, M.A., St. Louis Alzheimer's Association

One Dozen Ways of Adjusting to Nursing Home Placement

1. Accept the change and recognize that you will survive.
2. Allow yourself to feel the pain. It hurts and that is what is supposed to happen.
3. Remind yourself, if you are feeling guilt and punishing yourself with a thousand "if onlys," that you have given for a very long time and that you made a more comfortable life for your loved one.
4. Give yourself time to rest and take care of yourself during this vulnerable time. Do not try to fill the void right away. Do not make any major decisions that you do not have to make. Allow yourself time off from responsibility.
5. Maintain a routine and a schedule. Go to work, or, if you had been able to do so prior to nursing home placement, keep up with clubs and hobbies, etc.
6. Put together a support system of friends and relatives. Give them the opportunity to help. Remember, helping you means helping them deal with the absence of this person.
7. As you begin to feel better, look forward to the future and plan for your life without the full-time responsibility of caregiving.
8. If one day you do not think of the person who is now in a nursing home, do not feel guilty. It is not necessary to spend the rest of

your days feeling guilty about your own good health just to prove your love.

9. Use the skills and character traits you have built during the years of caregiving. You are an exceptional person— strong, creative, and capable of growth.
10. Invite others into your life. If you were unable to accept the help of friends and relatives immediately after the person went to live in the nursing home, seek those people out now. Stop by for coffee. Invite someone to share potluck with you. Giving, as you have already learned, is a great healer.
11. Comfort yourself with the memories of times shared with the person you cared for. Know that for many, those special moments never come. Give yourself credit for the sacrifices you made.
12. Finally, do not set a timetable for when you should expect to “get over” your loneliness or allow anyone else to set one for you. If you have been married to a person for over 50 years and given total care to that person for the last 10, that is a lot to get over.

And, join a support group to share your experiences and feelings. You need others and they need your input. Don't put it off.

Courtesy of the Eastern Tennessee Alzheimer's Association Chapter

When a 'No Nursing Home' Promise Must Be Broken

Lindsay R. Curtis, M.C.

"I'll never let them put you in a nursing home. I promise I'll always take care of you at home". Many couples exchange such tender and sincere declarations while both partners are still of sound mind and body. But when an aging spouse undergoes a personality change, commitments of this kind can exact an enormous price from the healthy spouse.

After Bill's retirement five years ago, for example, Edna noticed that her husband's personality had slowly changed. Always a forceful and well-organized man, Bill had retired as the head of a multimillion-dollar corporation.

But the sparkle had gone out of Bill's eyes, leaving a blank stare in its place. He had taken to calling their friends and annoying them with endless, rambling conversations that harped upon two or three disjointed topics. It was as if his cerebral function had, like his arteries, become narrowed and hardened. Bill's behavior put a strain on many of Edna's friendships, and she came to feel increasingly isolated.

When Edna came in for routine exam, she appeared frail and distraught. Once vigorous and hale, Edna had begun to show signs that her own health was breaking down. I asked how things were at home. Edna gave a long sigh and hung her head.

She told me she loved her husband and that she had promised him many times she would take care of him at home. She had been getting some help from a home-care aide, but that arrangement no longer seemed sufficient. When I pressed the point, she said – a little tearfully – that she didn't know if she could keep going the way things were. Then she looked up at me and asked, "Doctor, what happened to the man I married?"

It was clear to me that Edna had reached a time when it was no longer possible for her to care for her husband at home. But almost without exception, a decision to institutionalize the ailing spouse provokes devastating feelings of guilt in the healthy partner – even if such a decision is clearly the best for all concerned. Often the caring spouse is overwhelmed by a sense of failure, of disloyalty, even of betrayal.

In my 35 years of practice, I have found that many couples exchange promises like the one by which Edna had felt bound. But such contracts can imprison a healthy mate in an unhappy and one-sided relationship. Healthy partners may sacrifice their own well-being – and sometimes even their own health – for the care of loved ones who may no longer even recognize them.

While a dilemma such as Edna's is a matter of very personal judgment, I believe that promises exchanged by healthy spouses must be reevaluated when one partner undergoes a change in personality. And we can offer meaningful assistance to the mates of such "changed" elders. Such spouses may, like Edna, need the opportunity to discuss a very difficult decision. They may need reassurance that there is no dishonor in getting help – even institutional care. Or they might simply need help recognizing that a changed personality may require a change in care giving arrangements.

A personality change can be associated with psychosis, dementia, arteriosclerosis, or some other illness or injury. Often the change in personality is accompanied by physical problems that make home care even more difficult for the unaffected spouse.

The husband of one of my patients, for example, was having a hard time taking care of his wife after her stroke. Once a loving wife, Melba had become demanding, obstinate, and abusive – all of which was a trial in itself for Jim. But Melba also became incontinent, and Jim found it nearly impossible to deal with the constant soiling of her clothes, their furniture, and their floors. But like Edna and Bill, Jim and Melba had exchanged promises that they would care for each other at home, whatever happened. Now Jim felt locked into a contract with a woman who bore little resemblance to the wife he had known and loved.

Perhaps if Melba's personality had not changed, Jim would not have found it so difficult to deal with her incontinence, but the combination was defeating him. He needed to be reassured that placing his wife in a nursing home did not amount to abandonment or betrayal.

In some cases a change in personality can wreak havoc with a spouse's well-being. Another of my patients found that dealing with her husband's Alzheimer's disease required a thicker skin than she possessed. Lillian stopped feeling comfortable in public with Carl after he made a scene at a church social – accosting everyone he met to “play some blackjack” and making suggestive comments to many of the women in the congregation.

In addition to acute embarrassment, Lillian felt an acute sense of loss. Not so many months before, Carl had been an attentive husband and a highly respected member of the community. But because of his dramatic change in personality, Lillian was having a hard time caring for Carl at home. Yet she had promised Carl long ago that she would never put him in an institution. Could she, in good conscience, place him in the full-time care of a nursing facility? Until we began to discuss the matter, Lillian had been unwilling even to entertain the possibility.

Although I certainly don't consider it my province to tell patients how to handle important personal questions such as these, I do try to offer them the opportunity to discuss these matters in an open and non-judgmental manner. And I often ask patients like Edna and Jim and Lillian to think about what they would consider appropriate care if the situation were reversed. Would they really want to put their own loved ones through the hardship of caring for them at home? Would they want others to feel guilty about placing them in a nursing home if they were to undergo radical changes in personality or level of functioning?

The spouse of an afflicted partner may welcome the chance to discuss his or her situation with you. And healthy partners may be greatly relieved to have you point out that – at least in some sense – they are now dealing with a different person than the beloved partner they had promised to look after at home.

Certainly it isn't our role to tell people how to live out their commitments to others. But in dealing with the companions of older patients whose personalities have changed, we can raise the possibility that some kinds of promises may become untenable. When older couples have exchanged promises to care for each other at home, we can help them see the limitations of such agreements. And we can reassure the healthy partner that there is nothing shameful in admitting the need for help. In doing so, we may be lifting an unbearable burden.

Many Hands Make Light Work

Home care is care that is delivered in a person's home. Home care agencies can provide a multitude of services. Services range from skilled nursing care to help with bathing and dressing to just visiting with your loved one while you are out. Knowing that someone is at home with your loved one and that he or she is safe, will allow you to enjoy the time you have set aside for yourself.

There are many home care agencies in your area that you can choose from. The Alzheimer's Association can provide you with referrals to these agencies.

When calling agencies for information on home care here are some questions you may want to ask:

- ✓ Is the agency a certified Medicare or Medicaid agency? If it is, it will automatically be bonded. If not, it is bonded?
- ✓ How long has the agency been in business?
- ✓ What services does the agency offer?
- ✓ What is the hourly rate?
- ✓ Is there a minimum time and charge?
- ✓ Are there different rates for different services?

- ✓ Are there different rates for holidays, nights, weekends, or overnights?
- ✓ What hours are aides available for work?
- ✓ How far in advance do arrangements have to be made?
- ✓ What type of training or experience do the aides have?
- ✓ Does the company do background checks on employees?
- ✓ Will the same caregiver be available for all care?
- ✓ How often does a supervisor make home visits?
- ✓ How are complaints and emergencies handled?
- ✓ What options are available to help pay for services?
- ✓ Does the agency have a large number of Alzheimer's patients?
- ✓ How much Alzheimer's training does each aide receive?
- ✓ Is a care plan made? When?
- ✓ What if an aide calls off? Is there back up?
- ✓ Can you change aides if dissatisfied?
- ✓ Can the agency provide references for the agency? For the aide?

Learning Together II Leaders Manual: Family Members

Focus: Increasing Your Support

Supplies:

Handouts for workbooks (3-hole-punched, paper clipped to take home)

Discussion handouts (copies at end):

1. *Never Let, p. 24*
2. *What We Have In Common with Geese, pp. 12-13*
3. *Serenity Prayer, p. 19*

1. Welcome individuals. If there are new people, ask each person to introduce themselves (without giving a snapshot view) and mention confidentiality.
2. Note the focus for this session is Increasing Your Support.
3. Begin by setting the tone:

The reality is that, sooner or later, you will need to ask for support from others. It may be from other family members, friends or an agency.

In your handouts, there is extensive information on the “nuts and bolts” of arranging for help. These can be saved for your study as a resource down the road.

The decision regarding asking for help and the tips for doing it are what I would like to discuss now. May read quote:

Every time I close the door on reality it comes in through the windows.

4. There is a section in your manual entitled *Accepting Imperfect Help*. This is really what it boils down to: the common feeling that no one could care for your husband, your mother, your wife as well as you.

Let's look at how to accept the help that is offered. Read/discuss each of the following:

DO accept imperfect help. Admit that you are not a perfect caregiver during those moments when impatience, anger, and resentment well up inside of you. Admitting your lack of perfection gives you permission to let someone else help out "imperfectly" on occasion, as well.

DO let go of being indispensable. It is very possible that trained caregivers who specialize in providing services to persons with memory loss may actually do certain facets of the job better than you! So give them a chance to prove it, and let go of the need to control how the care is given. A different approach than the one you use doesn't mean that it's the "wrong" approach or that your way is necessarily the "right" one.

DO join a support group. The tips and knowledge of individuals who have this common bond with you are invaluable. Those who have been caregivers for a longer period of time have had experiences with the agencies and the health care systems that can help you narrow down your possibilities. They will also support your decision to get outside help. Many caregivers will tell you that their support group has been a life line for them and that they formed friendships there that lasted long after their caregiving experience had ended.

DO use some of the care options discussed in this module. You deserve it!

5. (Optional) Discuss the quotes:

Things won't be the same, but they can still be acceptable.

Accept that the decision for help may be a compromise.

Accept help on a trial basis.

Leader may note that "Once is not a fair trial" opening discussion to the group on how to proceed if the first try wasn't successful. What do you say/do if your person refuses to go?

Handout/read, *Never Let*, p. 24

6. In the other group your loved ones are discussing the need to be open to accepting help. They have the quote:

Peace of Mind is an Important Need for the Person Who Loves You.

They are being asked to consider the benefits of trying a companion or day center – now or in the future. These are things you can talk about long before they are needed. Have any of you talked about these things with your person? How did it go?

There are also handouts on nursing home placement for you to consult in the future. Everybody's experience is different, but knowing what is available if needed is an important step.

7. Read and discuss the handout: *What We Have In Common with Geese, pp 15-16.*
8. End with *Serenity Prayer, p. 19.*

What We Have In Common With Geese

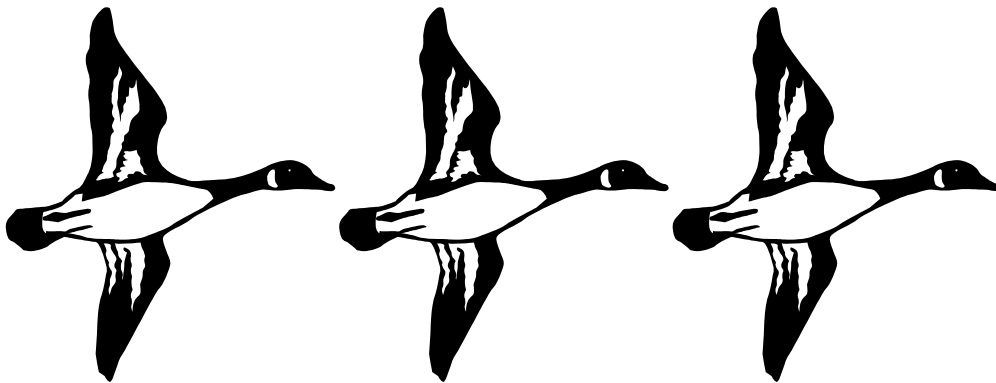
When you see geese flying in a "V" formation, you might be interested in knowing what facts scientists have discovered about why they fly that way.

1. **FACT:** As each bird flaps its wings, it creates an uplift for the bird immediately following. By flying in a "V" formation, the whole flock adds at least 71% greater flying range than if each bird flew on its own.

TRUTH: People who share a common direction and sense of community can get where they are going quicker and easier because they are traveling on the trust of one another.

2. **FACT:** Whenever a goose falls out of formation, it suddenly feels the drag and resistance of trying to go it alone and quickly gets back into formation to take advantage of the lifting power of the bird immediately in front.

TRUTH: There is strength and power and safety in numbers when traveling in the same direction with those with whom we share a common goal.



3. **FACT:** When the lead goose gets tired, it rotates back in the wing and another goose flies point.

TRUTH: Each of us needs to take our turn in giving direction for the good of the whole.

4. **FACT:** The geese honk from behind to encourage those up front to keep up their speed.

TRUTH: We all need to be remembered with active support and praise.

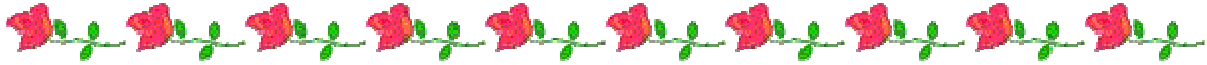
5. **FACT:** When a goose gets sick, or is wounded and falls out, two geese fall out of formation and follow it down to help and protect it. They stay with it until the crisis resolves, and then they launch out on their own or with another formation to catch up with their group.

TRUTH: We must stand by each other in times of need. We are fortunate that there are more geese in life than turkeys. Let's remember to uphold each other in friendship and to give each other a big "honk" more often. Makes you think doesn't it?

Taken from the Newsletter Archives, Alzheimer's Association



The Serenity Prayer



God, grant me the

SERENITY

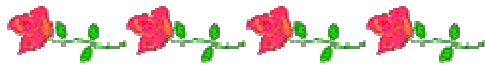
to accept the things I cannot change ~

the COURAGE

to change the things I can;

and the WISDOM

to know the difference.



By Reinhold Neibuhr