

## Weighing Options for Respite Care

Deciding on care arrangements that are best for the person with Alzheimer's is one of the most difficult decisions families face. Often, families caring for a loved one with Alzheimer's are apprehensive about seeking outside care and accepting help from others. Yet, these willing caregivers can become exhausted and overwhelmed by trying to "do it all" on their own.

Respite care services can be of great help to families faced with such challenging circumstances. Respite care gives family caregivers a break from day-to-day duties while the person with dementia receives care from qualified individuals (*see related article on page 3*).

Respite care can be provided:

- in the home or outside the home at an adult day center or residential facility
- for part of the day, evening or overnight
- by paid staff, volunteers, family or friends
- occasionally or on a regular basis.

### Types of Care

There are many options for respite care; families can choose the setting and frequency that works best for their situation. Options include:

**In-home respite care** – Care is provided in the home by a professional



Mark Luinenburg/Alzheimer's Association

caregiver or trained volunteer who spends quality time with the person with Alzheimer's. Services may include companionship, personal care, homemaking, or skilled care.

**Adult day centers** – Adult day centers offer respite care in a group setting outside the home. Participants have the opportunity to interact with others and take part in activities that support their strengths and abilities.

**Residential/overnight respite care** – Many hospitals and nursing homes have specialized units that provide care for the person with dementia overnight or for a few days or weeks. In some areas, assisted living facilities and adult foster care homes provide this service.

**Informal respite care** – A family member, close friend, neighbor, or church volunteer can provide respite care. A trustworthy and caring person

can give caregivers time to run errands or just take a break.

Many families find that they need to combine several of these respite care options to adequately cover their needs. For example, a caregiver who works full-time might schedule the person with dementia to attend an adult day program twice a week and have an in-home provider come to her house the other three days. This same caregiver might also use residential respite care once a year to take a week-long vacation.

### Accessing Care

Consider using respite care services as early as possible. Seeking support early on may help lengthen the time a relative can be cared for at home before having to consider a move to a care facility.

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Cost is a concern for many families as respite care services are usually paid for privately by the person with dementia or family members. Medicare does not pay for this type of help. However, there may be sources of financial support available through community service agencies. There are many options to consider and the Alzheimer's Association can help. Contact the chapter office nearest you at 800.337.3827 to discuss respite care options in or near your community. •

**Recognizing the Benefits of Respite Care**

Respite care offers significant benefits for people with Alzheimer's and their caregivers. For those with Alzheimer's, respite care provides an opportunity to be around others who are experiencing similar challenges in living with dementia. It offers a chance to get out of the house, participate in enjoyable activities, and socialize with others. Caregivers, meanwhile, are reassured knowing their relatives are in a safe environment and are taking part in activities structured to meet their abilities and needs.

For caregivers, respite care offers time to take care of personal needs and other responsibilities. It also gives caregivers a chance to relax and spend time with family and friends.

Jan Fowler of Kalamazoo knows firsthand how much respite care can help. Jan enrolled her husband, Lloyd, in a day program in 2003. Lloyd attended Alliance Senior Day Services one day a week, gradually building to four days a week. After a period of adjustment, Jan saw a profound difference in her husband.

"Lloyd came to really enjoy it – I could tell he seemed more content," Jan explained. "He couldn't participate in a lot of activities but he observed. He just seemed happier – I think he was bored at home."

"It was just enough stimulation for him

that when he came home he seemed more satisfied and calm," she added.

As for the benefit to herself, Jan appreciated the few hours she had to herself each day. With no family members close by, Jan cared for her husband at home alone. Day care and visits from a home health aide two days a week helped her manage. "I'd head for my car (after dropping him off at day care in the morning) and I'd take a deep breath," Jan said. "It gave me a few hours to regroup myself."

Jan recently moved Lloyd to an assisted living facility near their home. Now, she can look back on how much respite care helped both of them.

"Because of day care, I was able to keep Lloyd at home for two more years," Jan said. "I worried about him going to long-term care but he's adjusted very well. Day care truly helped with the transition – I think it made it easier for him."

Jan's only regret about using day care services is that she didn't enroll Lloyd earlier when he could have participated more.

"You think of respite as helping you (as a caregiver) – I didn't realize how helpful it would be to Lloyd," Jan said. "I think it helped him as much as it helped me." •

## Important Questions to Ask When Selecting Respite Care Services

Once you've determined the type of respite care that will work best for your situation, you can focus on selecting a service that meets your needs.

If you decide to use in-home respite care, arrange an interview with the aide in your home. Ask questions that will help you gain a better understanding of his/her skills. You may want to ask:

- Why are you interested in this job?
- What is your training?
- What are your past/current home care experiences?
- Have you ever worked with someone with dementia?

- How would you handle...? (give examples of behaviors or challenges)
- When/how often are you available?
- Do you have back up if you are unable to come?

If you are considering using respite services at a local adult day center, arrange a meeting with the staff and look around the center. Ask lots of questions including:

- What are the hours? Fees? Services?
- Is transportation available?
- What types of activities are offered?
- Are people with dementia included in general activities?

- How many participants is each staff member responsible for?
- Do they assist with personal care?
- Are there individual plans of care? How are different functioning levels addressed?
- How do they handle .... (e.g., wandering)?

Most importantly, seek help from others when selecting a respite care service. Talk with your family members and friends and contact the Alzheimer's Association at 800.337.3827 for assistance. •

### How to Get Someone to Attend Day Care

Senior day centers offer activities and care to those with mild to moderate Alzheimer symptoms. But caregivers may find it hard to get their family members to attend. Here are some tips.

- **Convince yourself first.** Call for a tour, to see what might interest your family member and to discuss any obstacles you anticipate (e.g., There are too many "old" people).
- **Give a convincing reason.** Some people attend because they see the center as their "club" or "class." Some go for a particular activity, to be with a new friend, or to help others. Ask the doctor and others to back you up.
- **Look for a hook.** Schedule your family member's visit when there is an activity (e.g., music, crafts, exercise, or discussion) that they might enjoy.
- **Be firm.** Initially, the person may enjoy going, but complain to you of

being unhappy. Don't argue. Just assume that you will return the next day. Try saying, "They are expecting you today," or "I want you to go for a little while."

- **Get the right person to take him or her,** at least for the first few times. Choose someone who can usually get your family member to do things.
- **Start with a few, short days.** Two visits a week is a minimum for someone with memory loss. Short days are less taxing for newcomers. When the routine becomes comfortable, you can add days.
- **Try again later.** Sometimes a person frets so much that it becomes counterproductive. Some find that trying again after a few months' break is more successful. •

*Excerpted from Alzheimer's Association, Northern California-Northern Nevada newsletter, Winter 2005.*

### Resources

#### Brochures

***"Respite Care Guide: How to Find What's Right for You"***  
Alzheimer's Association  
Reprinted 2003

#### Fact Sheets

***"Respite Care: Consumer Fact Sheet"***

***Information and Referral Directory***  
(available for each county)

***"Signs That Your Relative May Not Be Safe Alone Anymore"***

***To obtain these and other resources, contact the chapter office nearest you at 800.337.3827***

## Chapter Offers Late Stage Program

Caregivers face many challenges during the late stage of Alzheimer's disease – connecting with family and friends is often more difficult, numerous decisions need to be made regarding care, and around-the-clock assistance is usually required.

The Alzheimer's Association offers information and support to families dealing with these difficult issues. The Association can provide information on a wide range of topics including personal care needs, feeding tubes and end-of-life decision making, hospice services, durable power of attorney, and coping with loss.

This spring, the Alzheimer's Association will host the education program **"Caring for a Person With Late Stage Alzheimer's"** in five area cities. The program will focus on what to expect as the disease progresses and will teach families how to make meaningful connections with their loved ones during this difficult time. Staff from area hospice organizations will also take part in the program.

**"Caring for a Person With Late Stage Alzheimer's"** is being offered in the following cities; for more information or to register, call the chapter office nearest you at 800.337.3827 or visit [www.alzmigreatlakes.org](http://www.alzmigreatlakes.org). •

### Ann Arbor

May 26, 2005  
12:00-2:00 p.m.

### Lansing

May 12, 2005  
6:00-8:00 p.m.

### Jackson

May 10, 2005  
6:00-8:00 p.m.

### Muskegon

May 3, 2005  
6:30-8:30 p.m.

### Kalamazoo

May 26, 2005  
1:00-3:00 p.m.

## For Caregivers: Get Into Action to Reduce Stress

Stress increases when you are the primary caregiver for a loved one with Alzheimer's. When you take control of stress by acknowledging it, you begin the process of healing and coping. These suggestions from the Alzheimer's Association can help you deal with stress:

- **Get a diagnosis as early as possible.** Early diagnosis helps you better manage the present and prepare for the future.
- **Know what resources are available.** Adult day care, in-home assistance, and visiting nurses are just some of the services that can help. Call the chapter office nearest you at 800.337.3827 for more information.
- **Become an educated caregiver.** Knowledge helps you cope with many of the behaviors and personality changes.
- **Get help.** The support of family, friends, and community resources can be an enormous help. Ask for help. If stress becomes overwhelming, seek professional advice.
- **Take care of yourself.** Watch diet and exercise and get plenty of rest. Use respite services to take time off

for shopping, a movie or an uninterrupted visit with a friend.

- **Manage your stress.** Stress can cause physical problems (blurred vision, stomach irritation, high blood pressure) and changes in behavior (irritability, lack of concentration, loss of appetite). Note symptoms and consult a physician.
- **Accept changes.** Acceptance can make transitions easier.
- **Do legal and financial planning.** Consult an attorney about durable powers of attorney, living wills and trusts, future medical care, housing and other key considerations. If appropriate, involve the person with Alzheimer's and other family members in planning and decisions.
- **Be realistic.** Neither you nor the person with Alzheimer's can control many of the behaviors that will occur. Grieve for the losses you experience, but also focus on memories and positive moments.
- **Give yourself credit, not guilt.** Remember, you're doing the best that you can. Your loved one needs you, and you are there. •

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- Register for programs
- Access Helpline online
- Register for Safe Return
- Donate
- Volunteer
- Locate a Lending Library
- Advocate

[www.alzmigreatlakes.org](http://www.alzmigreatlakes.org)

## Breakthroughs in Diagnosis, Treatment Possible

Unlocking the mystery of Alzheimer's may lie with the diagnosis and treatment of plaques and other abnormal protein aggregates called "tangles" in the brain, which many scientists think may be the traits of the disease, says Dr. Sam Gandy, vice chair of the Alzheimer's Association's National Medical and Scientific Advisory Council and director of the Farber Institute for Neurology at Thomas Jefferson University in Philadelphia.

The main component of plaques is a toxic protein fragment called beta-amyloid that forms clumps and sticks to brain cells. It's suspected to be the primary cause of brain cell death, which leads to the mental deterioration that marks Alzheimer's.

Gandy cites a breakthrough by Dr. William E. Klunk and his colleagues at the University of Pittsburgh. They recently developed a compound known as Pittsburgh Compound-B (PIB) that sticks to amyloid plaques, making them visible on positron emission tomography (PET) scans for the first time. "Amyloid imaging with PET may become useful for predicting which people with mild cognitive impairment will progress to Alzheimer's," says Klunk.



Mark Luinenburg/Alzheimer's Association

According to Gandy, the ability to finally view, monitor and measure amyloid may signal a new phase of Alzheimer research. "Combined with advances in medications to rid the brain of amyloid plaques, this could very well result in a major breakthrough in our understanding and successful treatment of Alzheimer's," Gandy says. "It not only will answer questions about how amyloid damages brain cells, but it will help us monitor whether and how well the new medications work."

As PET technology becomes more widespread, Gandy says, it will be easier to test the assumption that amyloid is the primary culprit in Alzheimer's. Within the next 10 years, we may see significant advances in diagnosis and treatment.

"Our inability to see or measure amyloid in the brain was a huge bottleneck for research," Gandy explains. "We should know very soon whether amyloid is the right target." •

### Mark Your Calendar for Legislative Day

*One Voice Can Make a Difference*

Alzheimer's Association volunteers from across Michigan will take part in the Association's third annual Legislative Day on Wednesday, **May 18, 2005** in Lansing. The event will begin at 10:00 a.m. in room 426 of the Capitol Building. Volunteers will have the opportunity to meet other advocates from across the state and educate state legislators about key public policy issues affecting people with Alzheimer's and their families.

Legislative Day will begin with a morning briefing where volunteers will receive an update on key issues as well as tips for meeting with their legislators. Following the briefing, volunteers will visit their lawmakers. Those interested in taking part in Legislative Day 2005 must register by contacting the Alzheimer's Association at 800.337.3827. •

### Chapter Participates in State Long-Range Planning Effort

Chapter staff and board members are serving on committees to develop Michigan's Long Range Strategic Plan. The committees developed recommendations that will be reviewed at community forums throughout the state and sent to the White House Conference on Aging. Participation in this planning process provided an opportunity to promote key issues of importance to the Michigan Council's legislative platform. •

## Make Plans Now to Take Part in Upcoming Special Events

Show your support for Alzheimer families by taking part in the Alzheimer's Association's Charity Golf Outing and Memory Walk fundraiser.

The Charity Golf Outing will be held July 18, 2005, at the University of Michigan golf course. Bo Schembechler and Red Berenson are honorary chairs for the event. Don't miss your chance to play this well-known course and, at the same time, help families coping with Alzheimer's. Call 734.677.3081 or visit [www.alzmigreatlakes.org](http://www.alzmigreatlakes.org) to find out how you can get involved as a sponsor, team or individual golfer.

In September and October, the chapter will host Memory Walks in 10 cities. Check the list below for the walk location nearest you and call 800.337.3827 or visit [www.alzmigreatlakes.org](http://www.alzmigreatlakes.org) to find out how you can get involved.

You can make a difference. Please join us! •



Ann Arbor October 2	Kalamazoo September 17
Battle Creek September 10	Lansing September 18
Coldwater September 24	Mason/Oceana September 24
Fremont September 10	Muskegon September 17
Jackson September 25	Three Rivers September 25

## Celebrate With Us: 25 Years of Leadership in Progress and Hope

The Alzheimer's Association, the first and largest Alzheimer voluntary health organization, is celebrating its 25<sup>th</sup> anniversary of incorporation by leading the fight against the disease and bringing hope to uncover its mysteries, prevent and treat its effects, and find better ways to support and care for those affected by it.



The coast-to-coast Alzheimer's Association network offers a broad range of services to people with dementia, caregivers, and health care professionals, including:

- More than 100,000 hours of education and support programs at 300 points of service
- Safe Return™, a national registry for those who wander
- 24/7 Contact Center Helpline for information, referral and care consultation in 140 languages
- Online communities of caregivers at [www.alz.org](http://www.alz.org) who share experiences and ask questions of our professional staff

The Michigan Great Lakes Chapter has been part of the Association's network since 1981. The chapter offers a wealth of community programs and services including education programs, support groups, care consultation services, and advocacy.

Every year our volunteers, like thousands of others in 600 communities across the country, participate in Memory Walk™ to raise funds to support services for those battling the disease. These events have raised more than \$175 million nationwide since 1989; local walkers and sponsors have raised more than \$2.5 million for Michigan Great Lakes Chapter services and programs.

Funding for critical research and improved care and diagnosis will help ensure that the rapid pace of scientific breakthroughs continues. In just the past 15 years, we have learned 95 percent of all we know about the disease. Federal funding for Alzheimer research will increase to \$700 million in 2005, and the Association continues to advocate for a yearly commitment of \$1 billion. Private donations have enabled us to award \$165 million to more than 1,300 important research projects worldwide.

Some of the most exciting recent science points to ways to reduce your risk of Alzheimer's. Our Maintain Your Brain™ public awareness campaign is educating people about a brain healthy lifestyle.

Last year's launch of the Coalition of Hope was a milestone in bringing together more than 65 million Americans from nearly 160 organizations to work toward increased awareness of Alzheimer's. We are thankful that so many people have joined our cause to create a world without Alzheimer's. •

## Chapter News

### Chapter Reaches Out to Meet Needs of Alzheimer Families in Outlying Areas

The chapter is conducting a community needs assessment in Lake County in collaboration with local agencies. A focus group will be held to determine what programs are available for those with dementia and their care partners, what are the needs, and what can be done to fill in the gaps. To gather information from Lake County caregivers, Sue Wilson, Program/Operations Manager for the West Shore region, will survey Baldwin support group members and other caregivers in Lake County. Shawn Washington, Program Coordinator at Family Health Care of Baldwin, will ask caregivers she interacts with to share their input as well. One community concern that will be addressed is the number of residents who have dementia and live alone.

A community needs assessment is also being conducted in Clinton County. The St. John's support group has been very active in raising awareness in the local community. Support group members are embarking on a promotional campaign to let local caregivers know that support is available. They are also assisting with the development of a caregiver survey that they will each complete. This survey will be mailed to other caregivers in Clinton County. Our goal is to determine if there are other ways caregivers prefer to receive support and education and if there are barriers to attending the support group that we may be able to address, e.g., transportation, need for respite care, time of day. Jennifer Burley, Lansing Area Program Coordinator, will conduct a focus group with providers in the Tri-County area who serve Clinton County to get their input on how to better meet the needs of local Alzheimer families.

Through community needs assessments we hope to increase our ability to meet the needs of people with dementia and their families residing in outlying areas. We also hope that the information gathered will be helpful for regional planning committees. By working together we will identify issues facing the aging population in these areas and develop solutions. •

### Chapter Updates Mailing List, Offers Newsletter by E-mail

We need to hear from you! It's time once again to let us know of your interest in receiving this newsletter. Each year, we ask you to resubscribe to our free newsletter and confirm that you wish to remain on our mailing list. Beginning this year, you have the option to receive your quarterly newsletter by e-mail. By choosing e-mail, you will help us increase our newsletter distribution while decreasing costs.

To continue receiving this newsletter, please complete the postcard inserted on page 4 of this newsletter and mail it to us by **May 31, 2005**. Or, if you prefer, call our office at 734.677.3081 or visit our Web site at [www.alznmigreatlakes.org](http://www.alznmigreatlakes.org) and complete an online subscription form. Please indicate on the postcard whether you wish to receive the newsletter by US Mail or by e-mail.

If you no longer need our newsletter, there's no need for you to respond. If we do not hear from you by the deadline, we will remove you from our mailing list. Thank you for your support. •

### Understanding Alzheimer's Program to be Presented in Spanish

For the first time, the chapter will offer the Understanding Alzheimer's education program in Spanish. This introductory program will be held at the Ypsilanti Family Practice Clinic on June 7, 2005, from 6:30 – 8:30 p.m. with registration and refreshments beginning at 6:00 p.m. The program is supported by a grant from the Rosebud Foundation and is offered in collaboration with the Michigan

Alzheimer's Disease Research Center. Dr. Lourdes Velez and Magali Velez-Nelson will present the program in Spanish and education materials will be distributed. This program will also be presented in Kalamazoo this summer. For more information or to register for one of these programs, please call 800.337.3827. •

### Law Enforcement Training Held in Kalamazoo

This spring, staff and volunteers from the Southwest Regional office trained more than 200 Kalamazoo County police officers on how to recognize and respond to people with dementia. They learned about Alzheimer's disease, the Safe Return program, and other programs and services provided by the Alzheimer's Association. •

## Together We Can Give Everyone a Reason to Hope

The record growth in the number of people we serve each year is made possible by the generous support of thousands of donors and volunteers. We could not offer our services and expert assistance without your support.

For people who live with Alzheimer's disease or dementia, we are a lifeline. As the number of people who live with Alzheimer's disease increases to epidemic proportions, we are challenged to ensure that our capacity grows as well so we can serve more of the people who need our help and hope right now.

With your support, we will meet the challenge. Please consider renewing and increasing your gifts to the Alzheimer's Association to help those fighting the battle against Alzheimer's disease. Your gifts of time and talent as a volunteer helping with chapter operations, Memory Walks, Helpline, or programs are invaluable. Your financial

support is also vital, and there are many ways to give.

**Gifts of cash** are quick and easy by check and credit card. **Long-term appreciated stocks** or **bonds** are a simple and frequently used alternative.

**Life insurance policies** with cash surrender value are another gift option. Donors who no longer need death benefits can discover hidden assets in paid-up life insurance policies. When you donate a life insurance policy, you receive an income tax deduction for the surrender value, avoid the need for any subsequent premium payments and remove death benefits from a possibly taxable estate.

Consider one of the simplest and most rewarding gifts you can make to the Alzheimer's Association: a **bequest** in your will or other estate plans. To make a bequest to the Michigan Great Lakes Chapter, consult a professional

– your attorney, accountant or trust officer – who will work with you to design a bequest that fits your situation and meets your goals. A professional will also make sure you receive the tax benefits allowed for your gift. If you already have a will, it may be amended by codicil to include the Alzheimer's Association.

Your attorney may have his or her own style for drafting a will, but the following statement contains the necessary elements for making a bequest to the Alzheimer's Association, Michigan Great Lakes Chapter: "I give and bequeath (describe dollar amount, property to be given, percentage or remainder) to the Alzheimer's Disease and Related Disorders Association, Michigan Great Lakes Chapter, 107 Aprill Drive, Suite 1, Ann Arbor, MI 48103." For information, contact Julie Seagraves, development director, at 734.677.3081 or [julie.seagraves@alz.org](mailto:julie.seagraves@alz.org). •