

## 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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This newsletter is published four  
times per year by the Alzheimer's  
Association, a non-profit,  
tax-exempt charitable organization.

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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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