

Brookdale Respite Reporter

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Early Stage Alzheimer's – A Positive Side

by Kristin Einberger, Program Manager at Adult Day Services of Napa Valley, in Napa, CA

This article is a service provider's perspective on supportive attitudes and effective approaches for working with elders in the early stages of Alzheimer's Disease (AD).

Much has been written regarding the devastating effects of Alzheimer's Disease and related dementias and the multitude of losses associated with the diagnosis. It's certainly true that people in the early stages have problems with recent memory, misplacing things, poor judgment, loss of initiative, occasional significant changes in mood and ability to perform routine tasks. However, it is also very true that people in the early stages can and indeed do lead active, full lives. They still have the ability to express feelings and fears. They have the capacity to be proactive in dealing with their diagnosis, to be social and to take care of themselves.

It is important that we refrain from classifying people with early stage memory loss as early stage patients but as people in the early stages of

memory loss, as they are not the disease. A useful tool when working with families of people in the early stages of AD is to key in on strengths (as well as the later stages) and less on incapacity. As service providers, it is helpful to focus on what *can* be done, not only with medications, but also in non-pharmacological ways. This is where we, in the professional caregiving field, can make a difference.

Focusing on what can be done is the primary goal of social day programs designed specifically for people in the early stages of memory loss. Participants in these programs are there because they *want* to be there. They are well aware of their memory loss, accept it and wish to take an active role in their future. Adult Day Services of Napa Valley offers one such program called Mind Boosters. Members who regularly attend this uplifting program believe that it is beneficial for following reasons:

- It's mental therapy that keeps you from getting depressed.

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Recent Developments

Specialized respite programs for Asian elders are teaching us the best practices for conducting outreach, building trust with family caregivers and meeting the needs of elders living with dementia in these communities. One lesson is that the skillful use of tradition, cultural values and sense of family are important factors in a successful day program. Read more inside.

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- I just like the people; it's a good group. It's great to be together.
- People have the same problems I do; it's just a good thing.
- I appreciate that there is something positive that I can come to – I often feel frustrated that I can't remember things. The most wonderful thing about this is the fact that we are in the same boat.
- We are gregarious in the way we can touch each other through eyes, hearing and touch. That is really helpful to me.
- This is a good course. The mental exercises help me think better.
- The variety of activities is very helpful and so are the people.

Care partners of those attending the group also report many benefits for both their loved ones and themselves. Betty G., wife of one of the men in the group, reports the following, "Not only does Mind Boosters give me a much needed break during the week, enabling me to feel renewed and energized when Ed returns, it also provides Ed with a positive, supportive, on-going social interaction which, I believe, gives him greater confidence

and a wider perspective on his 'new life'."

Members of Mind Boosters, along with members of other groups focusing on the early stages of memory loss, cite the following memory 'tips' which are helpful to them in the group and in their everyday lives:

- Make lists of everything you need to remember. Carry this with you at all times.
- Do something as soon as you think of it; don't wait until later.
- Keep a 'Memory Container' by the front door. Put everything in this basket that you need to take with you when you leave, like an umbrella, a map, your notes, your purse, and your grocery list.
- Use association, a clue to help you remember. Repeat things – the more you say something, the more likely you'll remember it.
- Try to avoid distractions such as excess noise and movement. These make comprehending and remembering difficult.
- If someone interrupts you, ask them to please wait until you have finished your thought.

It's difficult to 'put off a thought'.

Visualize what it is that you need to remember.

- Take your time with things. Don't rush yourself and don't let others rush you either.
- Keep involved. Participate actively.
- Use humor. It can be one of the most helpful of all tools. Laughter opens our minds and relaxes us, making both learning and remembering easier. It also reduces depression, a common problem for people with memory loss.
- Be sure to keep socializing to decrease the isolation that is so common.
- Keep on exercising in a variety of ways from walking around the block to taking an exercise class. This is a good thing to do with your care partner.
- Celebrate your strengths. They are plentiful.

These 'tips' are used continually in the weekly Mind Boosters group. Each meeting provides a multitude of activities both mental and physical



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stimulation, as well as time to socialize with others dealing with similar issues. The group learns new compensatory strategies for improving or maintaining cognitive skills and then takes the time to practice them. Weekly lunch outings and monthly field trips help to create a sense of community and a sense of belonging, of keeping people involved and constantly focusing on remaining strengths and promoting quality of life. Perhaps the most important thing gained by each participant is the realization that they are no longer alone, that they are a vital part of an active, positive group.

In addition to social day programs such as Mind Boosters, there are many other options that look at the positive side of early stage memory loss. Among these are concurrent support groups, developed by Robyn Yale in 1986. These innovative groups are for individuals in the early stages of Alzheimer's disease, related dementias and their families. Each group has the opportunity to share with others experiencing common issues, also encourages people with early memory loss to continue living full and meaningful lives for as long as possible. Barbara H., a caregiver involved in one such group feels very strongly about the impact the group has had on her life. She explains that "Thursday is the most important day of the week for me now—because that's when 'Care Partners' therapy & support group meets while my husband meets with "C'est la Vie" therapy & support group. 'Care Partners' plays a critical role in my mental and emotional health—and thus, my physical health. The opportunity to share experiences, feelings, problems, solutions, grief, humor, and moments of joy with a supportive group of women who are going through the same process of dealing with our husbands' mild cognitive impairment or early stage dementia—this group is a highlight of my week. This is a safe place to experience the grieving process for the changes in our hopes and dreams, and a supportive place to reinforce our new ways of feeling and behaving, as we learn so much from each other—different strategies and techniques for helping make life with a spouse with memory loss more comfortable for both parties. Some weeks, I leave emotionally drained and at peace, other weeks I leave energized and charged with new ideas. Always, I leave with a great sense of gratitude for this experience."

Other groups, in various locations throughout the nation are 'outings-based.' Capitalizing on the benefits of community involvement, these groups take participants out to restaurants, museums, theatres, special tours, etc., to help create a sense of normalcy and to stimulate socialization. These groups have had a very positive effect on the lives of its members who report benefits similar to those reported by members of Mind Boosters.

With all the possibilities for people in the early stages of memory loss, it is imperative that we do not focus on what's lost. A variety of programs around the country have shown that these services can make a difference in the person's quality of life. Howard H., a participant in the



Mind Booster's participant dancing with wife

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Mind Boosters group, sums up the feelings of participants and staff alike with this quote, "Let me say that since early diagnosis of MCI (Mild Cognitive Impairment) coupled with Mind Boosters early stage day program and the associated therapy/support group, my understanding and acceptance of my condition(s) have been accelerated. Due to twice weekly group meetings, my progress continues to be many times more rapid than without the safety, camaraderie, tips and useful information I glean from the groups. The bottom line: extremely helpful!"

A Community-Based Continuum of Care for Alzheimer's Families

An innovative approach to building formal and informal support networks for Alzheimer's families has been employed by a number of Brookdale programs around the country. To create a continuum of care, these organizations have paired the BNGRP grant, which funds social model group respite programs, with the Robert Wood Johnson Foundation's Faith in Action (FIA) grant initiative, that fosters in-home supportive services for special-needs populations.

Supportive services are provided to family caregivers and elders through a network of interfaith volunteer caregivers who are recruited, trained and coordinated by programs' staff. Services such as in-home respite, transportation, minor home repair, companionship, and telephone reassurance are often part of the menu of services offered in communities in which the FIA initiative has been implemented.

In rural Arizona, two Brookdale programs have successfully developed exten-

sive support systems for elders where none existed. Neighbor to Neighbor in Prescott Valley provides group respite in the town of Mayer, in Yavapai County. They coordinate transportation, provide in-home safety devices and other in-home support to the county's frail and isolated elders.

Catholic Community Services of Southern Arizona, Inc., has also implemented a broad based services system in multiple areas including Gila, and Navajo counties. This model of combining FIA and adult day services to provide choice and adequate respite for families is in place in five counties, with the newest program in Show Low. Strong collaborations are one of the main ingredients of this organization's success, with service partners that include town, community members, key leaders, businesses, faith congregations, non-profit service providers, and local, state and national funders.

In planning and implementing both the adult day programs and the FIA compo-

nent, tapping the strengths and assets of the rural areas chosen for the programs has been an effective means of enlisting the buy-in and ownership of communities.

In California, Catholic Charities of San Jose has developed two such service continuums within the city limits, with one designed specifically for Asian elders. Presbyterian Outreach, Inc., a Brookdale respite program in Omaha, Nebraska funded in 2003 is adding this adult day program to an existing FIA interfaith volunteer caregiver program. This agency, along with the other organizations discussed in this article, enjoys a corps of committed volunteers that serve the communities in which they are located. In fact, Neighbor to Neighbor has been designated a "Point of Light" agency, an honor bestowed for its successful network of volunteers. These programs are certainly all bright beacons for elders in need of support.



The Benefits of Caregiver Education

In a recent study conducted by researchers at Stanford University in California, the stress of caregiving can be eased by caregiver education and skill-building. According to the study leader, Dolores Gallagher-Thompson, Ph.D., Professor of Research in the Department of Psychiatry and Behavioral Sciences and Director of the Older Adult and Family Center at Stanford, "The women who participated in the skill-building program reported less depression, anxiety, stress and frustration. This type of program clearly helps family members manage the emotional and physical strain of caregiving."

The research was a part of the National Institute on Aging's multicenter study called "Resources for Enhancing Alzheimer's Caregiver Health (REACH)." The focus of REACH's caregiver education and skill-building interventions is explained by Gallagher-Thompson: We teach caregivers how to manage their time better, become more assertive in asking for help from others, channel their thoughts more positively and prepare for the future." Caregivers derived a greater benefit from this type of intervention than from traditional support groups, which focus on empathy and sharing feelings. Gallagher-Thompson noted, "There's no doubt that support groups are helpful but they're not for everyone."

Brookdale group respite programs around the country offer support groups and various types of caregiver education to ensure ongoing support for caregivers and is often part of a comprehensive approach to serving Alzheimer's families. For instance, "Our Time," the Merrill Senior Center's group respite program in rural Wisconsin, offers "Powerful Tools for Caregivers," a six-week course that is designed to educate families on the impact of caregiving and provide tools to improve their self-care. This educational program emphasizes building caregivers' capacity and confidence to cope with difficult situations, emotions and decisions. The course, "Taking Care of You: Powerful Tools for Caregivers" was developed as a three-year demonstration project by Legacy Health Systems in Portland, OR, and is now a nationally known model of caregiver education and empowerment. MatherLifeways, in Evanston, IL currently oversees the program and distributes the manuals *Class Leader's Guide* and *The Caregiver Helpbook* is provided to each course participant.

Jane Weddig, Director of "Our Time" and a Powerful Tools trainer, describes the course as "providing tools that we

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A Trainer's View of Caregiver Education

by Jane Weddig, Director of Our Time, a program of Merrill Senior Center in Merrill, WI

As an instructor of Powerful Tools for Caregivers, I have seen a wonderful response by those attending the program. The very first session was a learning experience for me as well as the 12 caregivers that attended the six week session. My mother (at the age of 67) suffered a severe stroke just months before I began teaching my first class. The role as a daughter and instructor for the class took on a whole new dimension. I now know firsthand about caregiving; even though I have provided care for loved ones my entire life, I never labeled myself a caregiver.

A number of the participants that attended the course were very emotional and quiet during the first session or two. It wasn't long before everyone opened up and shared stories with those around them that are dealing with the very same issues. Often, we caregivers feel that we are alone in all this, but we are not. The attending caregivers' confidence level grew and they were now sharing heartfelt stories and were looking at their lives in a little brighter fashion. One of the most difficult things for a caregiver is asking for help in order to take time for themselves.

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A Trainer's View

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A major part of this educational program is teaching each and every participant to take the necessary time out for their own needs. Every week our class took on an "Action Plan" for themselves. Within weeks, the caregivers' lives started to change. Before long, they were sharing their special "time outs" on a weekly basis. Whether it was taking a walk or reading a book, it was something that they did for themselves—a great breakthrough!

As caregivers, they shared a common goal. They wanted to provide quality care as well as the loving attention their loved one needed. The challenge of the class was to remind them to never forget that in order to provide quality care, they needed to "take good care of themselves" as well.

Both parties benefit from this program. A reunion picnic is scheduled for July for everyone to get together and spend some quality time. There is a bond, a true connection between the participants of Powerful Tools for Caregivers.

As a caregiver, I learned that at any moment your life can change. The role of a caregiver can also be a rewarding gift. With the proper tools, you can succeed in your caregiving venture and walk away knowing that you have a special gift... it is the gift of caring.

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take with us on a daily basis. Tools such as identifying and reducing personal stress, learning from our emotions, mastering caregiving decisions, enhancing our confidence and so much more." The Merrill Senior Center offers this popular course twice a year, free-of-charge.

The House of Welcome (HOW) Adult Day Services in Northfield, IL also offers "Powerful Tools for Caregivers" in addition to an array of services to support families in caring for a loved one with Alzheimer's. HOW approaches caregiver education by featuring speakers that present topics of interest at their regular caregiver support group. A manual developed by HOW on Alzheimer's care is also provided to each caregiver as a resource. Today, HOW employs a full-time staff person that supports and educates caregivers and coaches families individually on the challenges of dementia care. By offering this rich variety of support, caregivers have choices to better meet their needs, schedules and service preferences.

In Orlando, FL, Share the Care, Inc., sponsors an annual Caregivers' Forum, a three-day conference. Approximately 250 family caregivers attended the September event last year. Now in it's fifth year, this fun filled and relaxing Caregivers' Forum focuses on wellness, stress reduction techniques, good nutrition, self care and nurturing. Motivational speakers share insights, massage therapists ease tired muscles and caregivers enjoy each others' company in a memorable, supportive setting.



Participant and spouse/caregiver from the House of Welcome in Northfield, IL

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These are only a few examples of the creativity and resourcefulness demonstrated by organizations that serve and support Alzheimer's families in their quest to provide the best care possible for their loved ones. Caregiver education as a means of reducing the burden families experience, is clearly an effective, practical and complementary addition to adult day programming.

Reaching Out to Asian Elders: the Art of Serving Special Populations

by Tammie Nguyen, Program Manager for Day Break II Asian Respite & Caregiver Support Services, of Catholic Charities in San Jose, CA.

Day Break II Asian Respite & Caregiver Support Services provides a continuum of care to meet the needs of Chinese and Vietnamese dependent elders and their family caregivers. This continuum is accomplished through adult day programming, caregiver support and education, and a Faith in Action program for in-home support, including: in-home respite; and escorted transportation to medical appointments, the adult day program, and to grocery stores. The program's primary goal is to support and assist elders to build and maintain a more successful home care environment and help them "age in place," in the comfort of their homes and with their families.

Outreach activities and delivery of services to these ethnic communities are based on the principles of trust, cultural competency, linguistic needs, and ethnic values and

traditions. Culturally-appropriate practices include hiring staff who speak the clients' common languages, providing familiar ethnic foods, organizing recreational and spiritual programs to which the seniors can relate, and paying special attention to decor and cultural celebrations. This sensitivity and attention to culture and traditions is an essential element in reaching out to minority seniors who otherwise would not be able to access much-needed services.

The Adult Day Support Center opened in November 2002, provides linguistic and culturally specific services tailored for Chinese and Vietnamese seniors and family caregivers. Services include recreational activities (arts & crafts, calligraphy, reminiscence, games and puzzles, etc.) to stimulate cognitive functioning and improve or maintain social skills; physical activities (exercise and tai-chi) to maintain physical functioning; social interaction among peers to reduce loneliness and isolation; and hot meals and snacks to provide healthy nourishment. Additional services include caregiver support groups in



Participants enjoying themselves at Day Break II Asian Respite & Caregiver Support Services in San Jose, CA

Vietnamese and Chinese, case management, and information and referral.

The location of this program is also important. To be properly accessible to Asian elders, it is housed in downtown San Jose, in close proximity to the ethnic neighborhoods served by the program. The well-attended Adult Day Support Center is open four days a week. On Monday and Tuesday, we specialize in care for clients who have Alzheimer's and other related dementias. A sense of family is fostered among participants, volunteers and staff alike. Plenty of laughter, joking, festivities and camaraderie are the order for the day—everyday.





Participant and program staff working on a puzzle at Day Break II Asian Respite & Caregiver Support Services in San Jose, CA

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Group Respite Grant Initiative

Each year since 1989, BNGRP has announced a Request for Proposals (RFP) to develop new social model, dementia-specific group respite programs for Alzheimer's families. This year, grant applications were due on July 8, 2004. Non-profit organizations and public agencies are eligible to apply. Grantees are funded for up to two years (\$7,500 in the first year, renewable at \$3,000 in the second). Agencies must develop an adult day program that includes:

- Dementia-specific services serving two populations – the dementia participants and their family caregivers;
- Structured activities designed to provide socialization and cognitive stimulation, maximizing remaining functional and cognitive skills according to the needs of individual participants;
- Services provided in small groups (five to 15) outside of the home;
- Professional staff leadership supported by trained volunteers;
- Regular hours of operation, with availability of at least one day per week, four hours per session;
- Individual assessments, care plans, and defined admission and discharge criteria; and
- Access to supportive services for caregivers such as support groups, information and referral services, and education forums.

This service must be a new initiative. Expansion of existing dementia programs or the extension of days or hours is excluded. In addition to direct financial support, grantees receive ongoing technical assistance, and an orientation and training. This year's conference is scheduled for November, 2004 in Denver, CO.

To receive RFP guidelines and a grant application, or to request a free copy of the publication *How to Start and Manage a Group Activities and Respite Program for People with Alzheimer's Disease and Their Families*, please contact Evelyn Yuen, TA Resources Manager, Phone: (510) 540-6734, Fax: (510) 540-6771 or e-mail: bngrp@best.com. For more information, please visit our website at www.brookdalefoundation.org.

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Photo on the Cover: Participants doing calligraphy at Day Break II Asian Respite & Caregiver Support Services in San Jose, CA