

Earlier AD diagnosis creating demand for early-stage support groups

Many people are being diagnosed earlier in the course of Alzheimer's disease (AD) because of improving sensitivity and specificity of diagnostic techniques and increased awareness of the disease. Health care professionals, the Alzheimer's Association, and other organizations are responding by offering a broader range of support services to ease the emotional and social strains of people with early-stage AD and their families. As these support programs expand, new research is finding that people with early-stage AD retain more cognitive capacity than previously thought.

People with early-stage AD often have preserved personality and coping skills and remarkable awareness of themselves and their symptoms. However, they may experience considerable distress, embarrassment, and isolation because of perceived stigma of the disease. Thus, they are seeking, along with their family members, new coping strategies, meaningful activity, and mental stimulation. They are eager to educate themselves, to share common experiences, and to break potential barriers and isolation imposed by the early diagnosis and symptoms of AD.

What exactly is a support group?

The Alzheimer's Disease Education and Referral (ADEAR) Center receives thousands of calls and e-mails a year from families, professionals, and people living with AD who need help in addition to medical care. They may be seeking respite, a safe place to express concerns, tips for care, resources, or just reassurance that they are not alone. ADEAR information specialists often refer the caller to a local office of the Alzheimer's Association, whose services include a variety of support groups led by a caring, compassionate group of health care professionals and/or trained volunteers.

Although support groups vary in structure, format, membership, and leadership, all offer a forum for education and learning as well as a positive, safe, and nonjudgmental place to discuss concerns for people with AD and their family members, together or separately. Many diagnosed people and their family members acknowledge the need to connect with others who are facing similar challenges, loss, anxiety, confusion, depression, isolation, and grief, and specialized support groups may offer the right help at the right time.

Early-stage support groups

Within the last decade, a number of support groups specific to the unique needs of people with early-stage AD and their families have been established. With greater public awareness, earlier diagnosis, and advocacy to reduce the social stigma of AD, there is greater demand for this early-stage support.

Generally, most support groups offer participants an opportunity to share common personal experiences with others in similar situations. Early-stage support groups are usually facilitated or led by a professional and/or a trained volunteer and commonly meet once a week for 6, 8, or 10 weeks. Participants can expect to share common experiences, and learn tips from the insights and materials prepared by the professional or trained facilitators. Some sessions are for both care partners, and others are mainly for people living with the diagnosis of AD. When people with AD talk with each other, common themes come up, such as dealing with loss of independence and driving, money management, self-esteem, how to tell others about the diagnosis, and how to reduce embarrassment or fear of making mistakes in social situations.

Detecting AD early

Researchers and experienced clinicians agree that diagnosing AD in its earliest stages can be highly beneficial: the patient can seek optimal early treatment, participate in clinical trials, deal with emotional and practical issues, and make decisions with his/her family that reflect long-held values and beliefs. However, knowing the diagnosis earlier can take a significant emotional and psychological toll on the person with AD. Lisa Gwyther, MSW, CCSW, Associate Clinical Professor, Department of Psychiatry and Behavioral Sciences at the Duke University Alzheimer's Disease Center in North Carolina, says that "people with early-stage AD must address questions of how much to tell, to whom, and when, long before their disability may be recognized by others. It is extremely important that people with early-stage AD and their families get timely, consistent, open-ended support in learning to cope effectively and even thrive over time. People with AD retain a capacity for pleasure and take joy in nourishing and sustaining relationships."

Several types of support groups meet at Duke University Medical Center. Gwyther believes that people with AD need to find a comfortable level of familiar routines and social opportunities in their daily lives. Sometimes, because of geographic isolation or

other constraints, this can best be achieved in a dependable weekly or monthly support group. She finds that people with early-stage AD are willing and quite open, in most cases, to discuss their concerns with other support group members who become friends over time.

A recent NIA-supported study conducted by the Rush University Medical Center in Chicago found that while people with early-stage AD had identifiable characteristics and memory problems, they did not have the more serious cognitive problems found in mid-stage AD. These problems include confusion and disorientation, performance issues in social or work settings, or inability to plan ahead. This research suggests that, although hampered by memory deficits, people with early-stage AD can participate in many daily activities, including active involvement in a support group.

Support group structure

Generally, there are two major types of early-stage AD support groups. One model is the structured, time-limited, 6- to 10-week group of about 20 to 30 people (including both caregivers and the person with AD) attending for one to two hours at a time. The participants are provided with a list of topics to be discussed, by whom, and in which session(s). Guest speakers share expertise in particular subjects, such as the legal or financial burdens facing a family caring for a person with AD. In some programs, caregivers and care partners meet in separate but concurrent groups. In other programs, the person with AD and his or her caregivers are usually together for half of each session and then separated for the second half. Experts say this can encourage freedom to discuss issues or express concerns without the presence of the respective caregiver or diagnosed person.

At the end of the time-limited early-stage AD support group model, participants are encouraged to take advantage of existing community resources for more help, or to attend, if available, support groups that cater to the needs of mild-to-moderate AD. Some time-limited groups offer monthly “graduate groups” that afford participants the opportunity to continue meeting or to develop social networks. Sometimes these graduate groups focus on providing social activities and the social framework for leading a normal and healthy life (within the context of the limitations of early AD).

Researchers have found that, in many cases, AD families may withdraw or be gradually excluded from their usual social groups, friendship circles, or network of former work

colleagues. An Alzheimer's Association chapter may sponsor multigenerational pot luck dinners or trips to an outdoor concert or a bowling alley. Because of their non-demanding social nature, these activities would be appropriate for people in the moderate stages of AD. Sue Stone, of the Family Day Center in Fairfax, Virginia, says, "Alzheimer's patients need companionship and laughter through social situations almost as much as they need to learn what they should expect in the upcoming months and years ahead. We are focused on getting through today rather than what's going to happen tomorrow."

The second main type of early-stage support group is the "ongoing" model. It is less structured and gives participants the opportunity to initiate topic discussion and process complex issues over an extended period of time. Participants with AD may be in the group anywhere from many months to a number of years, depending on the rate of decline and their continued ability to participate meaningfully in group discussion. These weekly ongoing groups can also give families the opportunity to build long-term relationships.

There are many other types of support groups that are organized to help meet some of the needs of people with early-stage AD. They feature programs offering participants volunteer work, art, writing, and vocational pursuits.

Where are groups emerging?

In many areas of the country, the Alzheimer's Association, NIA-funded Alzheimer's Disease Centers (ADCs), and other organizations have created early-stage support groups. As health professionals gain experience and fine tune their approaches, they are also now offering more specialized, culturally diverse programs. But there are still

many places where lack of resources and skilled medical services results in fewer early-stage diagnoses. That means less awareness, less demand for local services, less education, and more potential social stigma of AD.

Who can participate?

To participate in an early-stage support group, people with AD and their care partners are usually screened by a clinical professional or a social worker. A comprehensive assessment or an interview will establish if the person with AD has the emotional, cognitive, and behavioral skills to function successfully in a group. Participation also may be based on whether the person with AD has a willing and able partner to escort to and, in most cases, participate in the sessions.

Robyn Yale, a social worker in San Francisco who pioneered the first early-stage support group in 1986 and consults for the Alzheimer's Association and other organizations, says, "It's important to screen people to select those who will be comfortable and do well in the group. We seek people with AD who have insight into their condition, the ability to articulate their feelings and concerns, and the desire to have the support group experience." Yale notes that while having a care partner to escort the person with AD and attend a concurrent support group is ideal, it is not a mandatory prerequisite.

Yale's book, *Developing Support Groups for Individuals with Early-Stage Alzheimer's Disease*, has been used as a guide for creating groups nationally and internationally. In it, she discusses planning, implementing, and evaluating group sessions. She identifies topics that are likely to arise and encourages group members to raise issues that are important to them. Suggested topics include questions and concerns about memory loss, relationships with family and friends, adjusting to new situations, and wellness and optimism. Yale's model has evolved from time-limited to ongoing groups, with individuals transitioning out of a group when they can no longer participate.

Group leaders vary in how long they permit participants to

remain in the group as their cognitive abilities decline. Clear guidelines and ongoing communication are essential so that group facilitators and people with AD and their families have a sense of how and when transitioning out may happen. While challenging, this is a necessary part of the process for individuals and the group as a whole, and, according to Yale, it can be managed successfully. Yale raises another concern: "The fact that there are few regions of the country with an appropriate program as a 'next step' for this population is also difficult, as they may not yet be ready for day care," she says. At the very least, group leaders hope they have instilled a spirit of

camaraderie, coping skills, and emotional support that will continue to help people with AD and caregivers when the sessions end.

An important point, many group leaders say, is that early-stage support groups are not for all people with early-stage AD and their family members. While most participants report positive outcomes, such as a greater sense of control over their lives and feeling that they are not alone, others may not participate due to family conflict, denial, significant cognitive impairment, or discomfort with the intimacy of a group experience.

How does the early-stage support group impact quality of life?

Rebecca Logsdon, a Research Associate Professor of Psychosocial and Community Health at the University of Washington Alzheimer's Disease Research Center, is collaborating with the Western and Central Washington State Alzheimer's Association Chapter to evaluate early-stage groups conducted by the chapter. "Early-stage groups are becoming more and more popular, but there is a wide range of practices among Alzheimer's Association chapters regarding who may participate and what type of group is offered," says Logsdon.

"The goal of our 3-year study, funded by the Alzheimer's Association, is to evaluate quality of life outcomes of early-stage group participants compared to a control group. We are evaluating specific benefits that were identified in discussions with early-stage participants and facilitators, including overall quality of life, depression, perceived stress, sense of control, communication between participants and caregivers, and decision making regarding legal, financial, and medical planning, says Logsdon. She believes her research ultimately "will allow us to provide the most appropriate and effective interventions and resources for individuals and families dealing with early-stage Alzheimer's disease."

Veteran social worker Lisa Snyder, of the University of California, San Diego, firmly believes that the criteria for participating in an early-stage support group should be strict. She believes that participants must be high functioning within the group and dedicated to participating in order to maximize the experience for everyone. Snyder has adopted an ongoing group model to keep the patient-caregiver pair as long as they are able. In *Coping with Alzheimer's Disease and Related Disorders: An Educational Support Group for Early-Stage Individuals and Their Families*, a manual created by Snyder for conducting an early-stage AD support group, an 8-week structured course highlights issues such as self-esteem, legal and financial concerns, health maintenance, and daily

living.

Kathleen O'Brien, Senior Vice President of Program & Community Services for the Alzheimer's Association, notes that the Association has more than 91 early-stage support programs offered across the country. Most adopt the time-limited model. O'Brien notes also that the Association is working hard to create more specialized AD caregiver support groups, particularly those serving

minority and bilingual populations such as African-American, Hispanics, and Chinese-Americans, as well as groups designed specifically for male caregivers.

While the level of resources for support group options may be uneven throughout the country, O'Brien encourages people to consider their options. "Practical and emerging alternatives to classroom-based support groups can be found in some locations via telephone or e-mail," she says. More and more people with AD and their families are finding that the Internet and telephone "help lines" are proving viable alternatives to classroom-based support groups. "These choices are especially helpful for those who cannot travel to a nearby support group or who do not have the resources in their area. The most important thing is to get help if they need it and to do that by any means possible, whether that's on the phone, on the Web, or in class," she emphasized.

Health professionals can help

Some AD caregiver advocates believe that health professionals are slowly becoming aware that support groups are positive options for families who are initially frightened and depressed by the Alzheimer's diagnosis. But more work is needed to inform health care professionals about the benefits of support groups for their early-stage AD patients. UCSD's Snyder says, "If health care professionals campaign for early-diagnosis for dementia patients, then they should also advocate for support groups and other services to help families in the early stages of the disease."

While support group models differ from one another significantly, each is intended to help people living with AD and ease the family's burden. Although formal studies of their effectiveness are ongoing, experience so far suggests that early-stage support groups allow those with AD and their caregivers to build the emotional structure they need to cope with the significant demands of the disease.

For more information

To find out if an early-stage AD support group is operating in your area, contact the Alzheimer's Association at 1-800-272-3900 or visit www.alz.org. Some ADCs also organize support groups. Call the ADEAR Center at 1-800- 438- 4380 to receive a print directory of the ADCs or visit www.alzheimers.org/adcdire.htm. Other resources include:

- Family Caregiver Alliance (FCA) at 1-800-445-8106 or www.caregiver.org
- Children of Aging Parents (CAPS) at 1-800-227-7294 or www.caps4caregivers.org

Suggested reading:

Yale, R. (1995). *Developing Support Groups for Individuals With Early-Stage Alzheimer's Disease: Planning, Implementation, and Evaluation*. Available from Health Professions Press, Inc. P.O. Box 10624, Baltimore, MD 21285-0624. 1-888-337-8808; 410-337-9585; FAX: 410-337-8539. PRICE: \$32.50.

Copies of Lisa Snyder's manual, *Coping with Alzheimer's Disease and Related Disorders: An Educational Support Group for Early-Stage Individuals and Their Families*, and a manual by Lisa Gwyther designed to help families in North Carolina, *Working with Family Caregivers of People with Memory Disorders*, can be requested from ADEAR at 1-800-438-4380.