

# CONNECTIONS

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## ***Managing Problem Behaviors in Long-Term Care Facilities***

### ***Alzheimer's Disease Caregiver Training is Critical for Reducing Vocal Outbursts and Wandering***

Disruptive vocal outbursts and wandering are two of the most common forms of behavioral disturbances symptomatic of Alzheimer's disease (AD). To manage these problem behaviors effectively, special intervention training and AD education are essential for staff in long-term care (LTC) facilities. Insufficient training can have serious consequences for both patient and caregiver. Over-medication, inappropriate use of restraints, physical attack, retaliation, or resident isolation can result when staff are ill prepared to apply behavior management techniques. Poor training also contributes to staff stress, a leading cause of high turn-over (see second article). Successful behavioral interventions preserve the resident's dignity and help staff gain confidence, improve morale, and increase job satisfaction.

**Successful behavioral interventions preserve the AD patient's dignity and help staff gain confidence, improve morale, and increase job satisfaction.**

LTC staff benefit from comprehensive training and education about AD to understand that the resident is not purposefully misbehaving. Staff can learn not to take attacks or accusations personally, nor

should they try to reason with, or expect a rational explanation from, a resident with AD. A thorough background on the effects of memory loss and dementia helps staff remain calm during disruptions, seek innovative, non-medication intervention, and shift emphasis away from the "problem patient" to the problems caused by the dementia.

Patterns of problem behaviors often are well established before a resident is admitted to the LTC facility. These behaviors and increasing care needs frequently are the main reasons why exhausted family caregivers turn to an LTC facility for relief.

*(Continued on page 2)*



*Mary G. Austrom, PhD.*

## ***Training, Respect, and Participation Essential for Job Satisfaction Preventing Staff Burnout in Long-Term Care Facilities***

Editor's Note: Mary Guerriero Austrom, Ph.D., an Associate Professor in the Department of Psychiatry and the Educational Core Leader for the Indiana Alzheimer's Disease Center at Indiana University, has written several articles about the importance of staff training and ways to prevent or minimize staff stress in dementia care units. Dr. Austrom is a highly respected trainer and is an expert on staffing issues in long-term care (LTC) facilities. She has conducted NIA-funded studies of LTC staffing issues, with an emphasis on dementia care units.

*Q. Why should LTC facility managers and administrators be concerned about high staff turnover?*

*(Continued on page 4)*



**News From the ADEAR Center  
Alzheimer's Disease Education & Referral Center  
A Service of the National Institute on Aging**

## Managing Problem Behaviors (Continued from page 1)

LTC staff should rely on the family caregiver to provide a behavioral history and use it for intervention planning. Along with this baseline information, psychological and medical evaluations can help alert staff to problem behavior triggers. To develop effective interventions, staff should observe and document the type of behavior:



- What happens?
- Where?
- When?
- What is the resident doing at the time?
- Who is present and how does the person with AD respond?
- What recent changes have there been in medication, personal history, health, or routine?

## Vocal Outbursts

Disruptive vocal outbursts are among the most persistent behaviors found in nursing homes. These outbursts include screaming, swearing, crying, shouting, loud requests for attention, negative remarks to other residents, and self-talk. As AD progresses, such outbursts tend to increase, except during the late stages of AD. Men tend to exhibit more aggressive vocalizations, such as cursing, while women tend to have more agitated vocalizations, such as complaining.

The emotions that can lead to disruptive outbursts include anger, fear, depression, grief, confusion, helplessness, loneliness, sadness, impatience, and frustration. Other physical and environmental triggers of vocal outbursts may include: pain, hunger, thirst, incontinence, constipation, urinary tract infection, respiratory infection, sleep disorders and circadian rhythm disruption, poor lighting, seasonal changes,

over-stimulation, under-stimulation, sharp noises, and excessive heat. Environmental and physical stimuli can be managed by identifying sources of pain and treating physical problems, alleviating hunger, guiding the resident to the bathroom, adjusting diet, changing lighting, exercising the resident, or reducing noise.

Disruptive vocal outbursts due to emotional or psychological stimuli are not as easily managed, but with proper training, staff can better identify the underlying causes of outbursts and apply effective interventions. Interventions involve distracting and diverting the resident. While no one tactic is completely reliable, and each AD patient is unique and requires thoughtful management, LTC staff can reduce vocal outbursts through creative use of such tactics as:

- distracting the resident by talking or prompting him or her to reminisce
- engaging the resident in cooking, arts and crafts, games, makeup and manicure sessions, singing, or listening to music
- touching the resident—hugging, holding hands
- handing the resident something to hold, such as a stuffed animal
- showing movies or interactive videos that feature sing-alongs or question/response activities
- using “white noise” such as from a hair dryer, or gentle sounds of mountain streams or the ocean via headphones
- playing audio tapes of spouse or family members recalling cherished memories

These distracting techniques work best as prevention management. Once agitated behaviors occur, more direct distracting techniques

to disconnect the resident from the perceived or existing problem will be more successful. The caregiver should avoid reinforcing “inappropriate” behaviors, because these strategies may result in increasing the frequency of emotional outbursts. Staff training should emphasize that dismissing outbursts as temper tantrums is inappropriate. The wrong response can further agitate the resident and increase vocal outbursts, causing even more disruption.

## Wandering

Wandering, another persistent problem behavior of great concern to LTC staff, generally falls into two categories: goal-directed, in which the resident attempts to reach an unobtainable goal such as going home or to the store, and non-goal-directed, in which the resident wanders aimlessly. Residents with AD are more likely to wander than those diagnosed with vascular dementia or other dementias. This produces increased restlessness and unintentional movement. Wandering patterns include:

- moving to a specific location
- lapping or circling along a path or track
- pacing back and forth
- wandering at random

Memory loss may contribute to wandering because the resident may be unable to keep a clear destination in mind. Sleep disturbance is a significant predictor of wandering.





Erosion of language skills also may contribute to wandering because the resident is looking for social interaction, and wandering fills that void. The resident may simply be attempting to keep busy through walking or repeating actions. Wandering also may result when an AD resident is seeking a childhood home or a loved one, or, in late afternoon, because that is the time he or she left work to go home.

Delusions, hallucinations, and severe depression tend to be more frequent in wanderers. Long-term use of neuroleptics, such as haloperidol (Haldol), chlorpromazine (Thorazine), or thioridazine (Mellaril) can induce aimless wandering. Men tend to wander more than women, and wandering often becomes more pronounced as AD progresses.

The family can provide information to help staff identify and anticipate wandering in the newly admitted resident. Staff will find it useful to know as much as possible about the resident's prior lifestyle, type of work, previous patterns of exercise, stress, and response to touch. Once a wanderer is identified, the LTC facility can have photographs made and distributed to other units in the facility, and use special clothing or identification bands.

**Treating the resident with respect sets the tone for appropriate diversionary tactics.**

Wandering may be prompted by a physical need, such as toileting. Staff can use large print signs to mark destinations, with a drawing of the activity. A photo of the resident as a young adult placed on his or her room door also may help guide a wanderer "home."

Wanderers often seek an exit from the LTC facility, thus staff may want to conceal or camouflage doors by:

- placing a Velcro cloth strip or panel across doors
- painting doorknobs the same color as doors
- installing grid patterns on floors in front of doors

Locks, alarm systems, and wandering monitoring devices also can be effective in managing persistent wanderers.

LTC staff should focus interventions to reduce, redirect, or prevent wandering on using the least restrictive methods possible. Interventions for goal-directed wandering, such as exit-seeking, involve distracting the resident. Staff are advised to remain calm, establish trust with the resident, and slowly approach the wanderer from the front. Treating every resident with respect sets the tone for appropriate diversionary tactics. Staff can learn to interpret nonverbal cues and facial expressions.

Using simple commands, gentle touch, and clear direction, staff can validate the wandering behavior, change direction (if necessary for safety reasons), and guide the wanderer. Once the resident is distracted, activities such as listening to music, looking at photos, and exercising may help. Staff should avoid negative commands such as "Don't go out there!" and refrain from arguing with the resident.

Giving the resident a safe place to wander is particularly useful for managing non-goal-directed wandering. Facilities designed with sheltered courts, gardens, lounges,

nooks, or circular pathways, safely guide wandering residents.

With appropriate training, staff can learn how to identify problem behaviors, use innovative diversion techniques, reduce their feelings of helplessness, and sustain quality of life for residents with AD. Knowledgeable staff gain confidence as they gain competence, positively impacting the LTC facility's image and reputation.

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## Preventing Staff Turnover

(Continued from page 1)

A. The turnover rate of nursing assistants in LTCs can range from 40 to 75 percent, with costs of recruiting, hiring, and training as high as \$5,000 per individual employee. Beyond financial considerations, high turnover contributes to stress through constant understaffing, creating a "crisis mode" operating style with few opportunities for planning.

*Q. What is the root cause of staff stress in LTC facilities?*

A. LTC staff are at particular risk for stress due to the demanding nature of the job, coupled with low morale and often, low self-esteem. Many of the direct-care staff work for low wages, have a high school education or less, and see limited opportunity for career advancement. Where there is high staff turnover, there is often a disconnect between the facility's mission, as stated in its literature, and the actual culture of the facility. Results of employee surveys I have conducted indicated several negatives about management that contribute to stress and turnover, including:

- lack of trust and genuine respect
- undervalued talents, especially prior experience
- lack of recognition for a job well done
- little or no teamwork
- poor compensation
- few development opportunities
- overuse of negative reinforcement
- lack of control or involvement in decisions



- reprimands for failure to follow procedures for which there had been little or no guidance
- poorly defined roles and responsibilities, and failure to provide up-to-date job descriptions or policy manuals
- lack of timely feedback or performance appraisals

*Q. Is compensation the number one concern?*

A. Surprisingly, no. Of course, successful LTCs must have adequate compensation and promotion packages in place. But perhaps more important is that staff members need to feel they are being treated with dignity and respect at all times. Staff say that to work effectively, they need to feel trusted and to be valued for their skills and prior experi-

ence. Staff members also report the need to work together as a team; to develop stable interpersonal relationships with patients, coworkers, and supervisors; and to feel that they can participate in decision-making, especially if the decisions concern their jobs. In addition, staff appreciate it when they are recognized for a job well done.

**Thorough training will teach staff how to remain calm, supportive, and comforting.**

*Q. How should management identify issues of concern?*

A. Staff surveys can help management identify issues and document what staff know, what they don't know, and what they want to know. The survey or needs assessment

tool should be administered by someone the staff respects or by an outside consultant, and all answers should be anonymous. If there is a culture of mistrust in the facility or fear of retribution, the staff will not necessarily complete the tool honestly.

*Q. Once surveys have identified areas of concern, what is the next step?*

A. Training and development of employees is probably the single most important step to reducing turnover. Training programs should:

- involve staff in developing the program
- set clear goals and objectives to define length of training, frequency of meetings, measurement of success
- use existing training packages and handouts
- be conducted by an experienced educator
- offer staff an outlet to unwind from the stress of dementia care
- acknowledge and reward efforts and accomplishments

*Q. What specialized training is needed for staff in facilities that admit AD residents?*

A. Learning about the effects of AD on the personality and understanding the psychological responses of the AD patient are essential for staff to provide better quality care. Good training will encourage experimentation for successful behavior management. Training sessions for professional AD caregivers should be short and include:

- an overview of AD
- information on the common problems associated with memory loss
- effective communication skills with patients, staff, and family members

- coping skills and effective interventions for challenging behaviors
- an understanding of the family as an important part of the treatment team

Simultaneously, administrators and managers should continuously develop their leadership skills. I have found that while many managers are excellent clinicians, they are not necessarily excellent leaders. Many department heads, unit directors, or shift supervisors lack the communication and leadership skills necessary to make them effective as managers and leaders. Managers should be given opportunities to meet together and plan ahead. They need to attend leadership training, and they need to know how to provide effective feedback.

Lack of AD training increases the risk of dehumanizing the AD resident. Eventually, the resident may become institutionally 'invisible.' Thorough training will teach staff how to remain calm, supportive, and comforting. They will learn how to deal with many common problem behaviors, such as denial of memory loss, vocal outbursts, wandering, lowered inhibitions, accusations of theft, repetitive questions, and combative or aggressive physical reactions. Staff will understand that the AD resident is not being lazy or misbehaving. They will learn that AD residents have good days and bad days and will be alert to nonverbal cues. Through education, training, and ongoing support, staff members can become a cohesive team and partners with family members in helping to care for and preserve the dignity of the person with Alzheimer's disease.



*Q. What would you recommend as good resources for training packages and handouts?*

A. The literature in this area has grown in the past few years. A couple of excellent sources include the

ADEAR Center (1-800-438-4380) and Health Professions Press (1-888-337-8808), which have several training manuals available. If the facility is fortunate enough to be near an NIA-funded ADC or ADRC, contact the director of the Education Core, and of course, local chapters of the Alzheimer's Association also have excellent resource materials for LTCs.


*Q. How can management sustain the beneficial aspects of a training program?*

A. Managers should learn that staff development and training are hard work. A serious commitment of time, energy, and resources is required throughout the organization. That includes everyone from the corporate office, to the administrator, department heads, and shift supervisors.

By holding regular meetings to encourage feedback, in-service training at periodic intervals (in which the managers also participate), and routine and extensive orientation of new staff, managers will find that turnover decreases over time. The importance of training and orientation programs cannot be overestimated. It takes

people time to learn systems, procedures, and especially to get to know the residents. Rewards and recognition of employee performance are very helpful, along with celebrations of success and social gatherings. If you tell prospective employees that you have a specific incentive program, review process, or recognition ceremony in place, be sure to follow through. If an employee's trust is broken, it may never be regained. Hiring the right staff is essential. When interviewing a candidate, managers should discuss the position at length and evaluate the candidate's skills, interests, and experience. Your best staff can help with the interview process since they know what the job really entails and they are the ones who will work with the candidate. With the right staff, proper training, and orientation, managers can align the mission and culture of the facility. Remember, it is hard work and takes time, but is worth the effort.

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## Journal Briefs

# Assessing Competency in AD Patients

A major issue for physicians and other clinicians in evaluating and treating patients with Alzheimer's disease is judging an individual patient's decision-making capacity to handle a number of tasks, including competence to consent to medical treatment or to manage finances. Family and other caregivers depend on clinicians making sound decisions related to competency, and there are legal considerations as well. A new focus in clinical research involves assessing the competency of patients with AD, and one group of scientists, Daniel C. Marson, J.D., Ph.D., and colleagues at the University of Alabama at Birmingham (UAB), is at the forefront of such research. Dr. Marson, who is both a lawyer and a neuropsychologist, is Associate Director of the NIA-supported Alzheimer's Disease Research Center at UAB.

In two publications, Dr. Marson, Kelly S. Earnst, Ph.D., Lindy E. Harrell, M.D., Ph.D., and colleagues, describe measures that can help physicians making competency judgments, and they examine the consistency with which physicians approach legal standards and personal judgments of competency. In the studies, five experienced physicians were asked to judge the capacity to consent to treatment of 31 participants (10 controls, 10 with mild AD, and 11 with moderate AD). The participants were videotaped responding to two clinical vignettes under the CCTI, or Capacity to Consent to Treatment Instrument, a measure in which participants are asked about a hypothetical medical problem and its symptoms and about treatment alternatives. Participants were asked questions

designed to examine competency under a series of well-established legal standards (LS): (LS1) the ability to evidence a treatment choice, (LS2) the capacity to make the reasonable treatment choice, (LS3) the capacity to appreciate the consequences of a treatment choice, (LS4) the capacity to provide rational reasons for a treatment choice, and (LS5) the capacity to understand the treatment situation and choices.

Marson and colleagues found in one analysis that overall competency judgments of the five physicians centered, appropriately, on the legal standards most difficult for the AD participants to meet (LS5, LS4, and LS3, as listed above). The researchers found that incompetence in these areas was associated with specific cognitive functions related to semantic knowledge, verbal recall, and simple reasoning abilities. Clinical assessment of competency, the investigators suggest, might need to focus in part on measurement of these particular cognitive skills.

The researchers also examined how consistent the physicians were in their evaluation of competency among the participants. There was a high level of agreement among the physician group, from 84% to 67%, depending on the legal standard analyzed. This agreement was substantially higher, the researchers said, than personal competency judgments of physicians in a previous study, where the specific legal standards benchmarks were not used. This finding supported the potential value of competency assessment training for physicians and other clinicians.

Marson and his colleagues have also turned their attention to developing new instruments for assessing financial capacity among people with AD. The Financial Capacity Instrument (FCI) measures performance on 14 tasks, in the areas of basic monetary skills, financial conceptual knowledge, cash transactions, checkbook management, bank statement management, and financial judgment. Initial testing of the instrument, reported in the *Archives of Neurology* (cited below), is promising, the researchers say. In these tests, patients with mild AD showed problems in the more complex financial abilities and impairment in most financial activities, while those with moderate AD demonstrated severe impairment of all financial abilities and activities.

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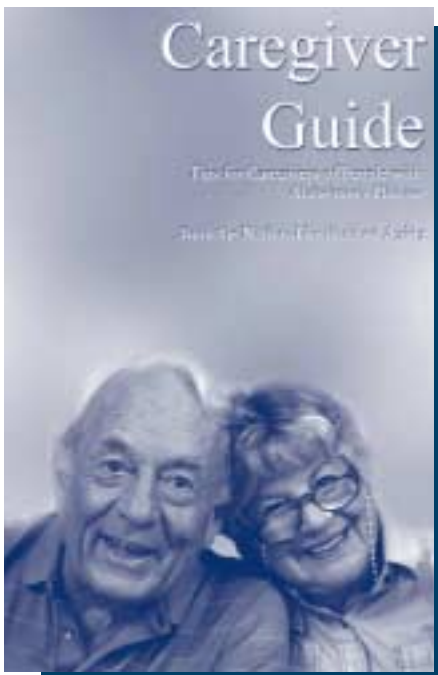
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## New Guide Offers Tips for Caregivers

How do I communicate with my family member who has Alzheimer's disease? What are some tried and true strategies for helping someone with AD bathe and dress? How can I make our home safe? When and how do I choose a nursing home? Where can I get help?

Caregivers of people with AD face these and many more challenges every day, and they can become overwhelming. But, resources are available to help.

The National Institute on Aging and the ADEAR Center are pleased to present a new, free publication offering tips and support for family caregivers of people with AD: the *Caregiver Guide*.



The *Caregiver Guide* is a handy, concise booklet with specific tips for day-to-day caregiving for people with AD. The information is drawn from up-to-date AD caregiving research at NIA-funded Alzheimer's Disease Centers.

The Guide addresses the following common issues for caregivers and their family members with AD:

- Dealing with the diagnosis
- Communication
- Bathing, dressing and eating
- Activities and exercise
- Incontinence
- Sleep problems
- Hallucinations and delusions
- Wandering and home safety
- Driving
- Visiting the doctor
- Coping with the holidays
- Visiting a person with AD
- Choosing a nursing home

In addition, the Guide lists organizations and resources for the family caregiver.

To order: Single copies of the *Caregiver Guide* are available free of charge from the ADEAR Center. Call toll-free, 1-800-438-4380, or complete the form at the back of this newsletter to fax or mail your order.

## Forgetfulness: It's Not Always What You Think

Spanish Version Available

The NIA's popular Age Page, *Forgetfulness: It's Not What You Think*, is now available in Spanish. This Age Page discusses memory loss, dementia, Alzheimer's disease, treatment, and advice. To order a copy, please call the NIA Information Center at 1-800-222-2225 or 1-800-222-4225 (TTY), or fax or mail the order form on the back page.

## La Mala Memoria No es Siempre lo que Usted Piensa

Versión en Español está Disponible

La popular, Información de Salud para las Personas de la Tercera Edad, *La Mala Memoria No es Siempre lo que Usted Piensa*, de el Instituto Nacional sobre el Envejecimiento (NIA), ahora está disponible en español. Este boletín comenta

sobre el consejo y tratamiento de la falta de memoria, la demencia y la enfermedad de Alzheimer. Para solicitar una copia por favor llame el Centro de Información al 1-800-222-2225 o 1-800-222-4225 (TTY), o envíe por fax o correo la hoja de pedido que está detrás de este boletín.



## Caregiver Resources Abound on the Internet

Alzheimer's disease caregiver resources continue to expand on the Internet. Whether you are a professional or family caregiver, you can find information on basic caregiving, support groups, environmental design, respite care, and stress relief, as well as advice, publications, chat rooms, and reading/resource lists. The following select list of web sites is not intended to be comprehensive, nor does its inclusion represent an endorsement of content or philosophy by the National Institute on Aging. Remember: most of the Alzheimer's Disease Research Centers maintain web sites with excellent information on local support groups, caregiver advice, and current research. The ADEAR Center web site is a good starting point to locate the ADCs/ADRCs at <http://www.alzheimers.org/pubs/adcdir.html>.



### Administration on Aging

➤ <http://www.aoa.gov/caregivers/default.htm>

The U.S. Administration on Aging, part of the Department of Health and Human Services, features an online guide for caregivers and the Eldercare Locator – (1-800-677-1116) with information about services in specific communities. AoA provides a caregiver resource called Because We Care - A Guide for People Who Care. This guide offers suggestions to make caregiving easier and more successful. The AoA Alzheimer's Disease Resource Room contains information for families, caregivers, and professionals about AD, caregiving, working with and providing services to persons with AD, and where you can turn for support and assistance. In addition, AoA offers the 2001 *Fact Sheet on Family Caregiving; Elderpage: Information for Older Persons and Their Families*; and a listing for State and Area Agencies on Aging.



### Ageless Design

➤ <http://www.agelessdesign.com>

Ageless Design, Inc., a consulting, education, and information company, helps in home design issues for someone with an age-related condition such as AD or Parkinson's disease. Ageless Design studies age-related conditions, then examines the problems the home environment presents, and recommends creative, cost-effective solutions. Services include consultation and architectural plan reviews for homes and institutional projects; specialized design for facilities; and professional training programs for visiting nurses, social workers, home health care workers, discharge planners, occupational and physical therapists, and architects and interior designers. Books, articles, brochures, pamphlets, and audio tapes are provided, as well as speakers for national and local conferences, support groups, and special events. The web site also provides a news update e-mail headline service, the newsletter *Advice & Advances*, and an online chat service.



### Alzheimer's Association

➤ <http://www.alz.org>

The Alzheimer's Association has long been a national resource for family and professional caregivers. This site provides family caregivers and friends with valuable information on providing quality care for and maintaining a meaningful relationship with the person who has AD. In addition to providing links to all the local chapters and their web sites, the Association offers a caregiver's guide with tips on how to handle various caregiving responsibilities while maintaining mental and physical health. Links to legal

and financial planning, day-to-day care, hygiene and personal care, choosing health care providers and facilities, and coping are provided. A professional caregiving section includes links for an overview of AD, diagnosing AD, treatment options, counseling caregivers and families, providing quality care, insurance coverage and reimbursement, expert opinion, programs and resources, and message boards.



### Benefits Checkup

➤ <http://www.benefitscheckup.org>

The National Council on the Aging, with funding assistance from the NIA, has built a free, easy-to-use, confidential service that identifies Federal and State assistance programs for older Americans. BenefitsCheckUp helps older adults and their children quickly identify programs for which they may be eligible. It takes about 10 or 15 minutes to enter information, such as your age, income, and ZIP code into an online questionnaire. Benefits CheckUp does not require your name, address, phone number, or Social Security number. Food stamps, the Supplemental Security Income program, pharmacy assistance programs, and Medicaid are often underutilized. Many middle- and upper-income seniors are also missing out on Veteran's programs, property tax relief, nutrition programs, and educational benefits.







### Caregiver's Handbook

- <http://www.biostat.wustl.edu/ALZHEIMER/care.html>

The *Caregiver's Handbook* is available at the Washington University at St. Louis Alzheimer's Disease Center web site. The handbook contains chapters on many topics of interest to caregivers, including common problems in caregiving, when community agency help is needed, services available to impaired elderly, caring for the caregiver, joining a caregiver support group, communications skills, personal care, nutrition, medical aspects of caregiving, emotional and intellectual well-being, legal/financial affairs, when it is time to stop caregiving, and choosing a residential care facility.



### Caregiver Media Group

- <http://www.caregiver.com>

Caregiver Media Group provides information, support, and guidance for family and professional caregivers. Caregiver Media Group produces *Today's Caregiver Magazine*, a national magazine dedicated to caregivers, and the "Sharing Wisdom" caregivers conferences. The web site includes topic-specific newsletters, online discussion lists, back

issues of *Today's Caregiver Magazine*, and chat rooms. Caregiving advice and tips for AD care on such topics as traveling with an AD patient, safety tips, and dealing with difficult behaviors are offered.



### Children of Aging Parents

- <http://www.Caps4caregivers.org>

Children of Aging Parents is a non-profit organization providing information and referrals for nursing homes, retirement communities, elderlaw attorneys, day-care centers, medical insurance providers, respite care, assisted living centers, and State and county agencies. Links will take browsers to educational outreach through fact sheets on various topics, a bimonthly newsletter with news and advice for caregivers, conferences and workshops, support group referrals, and a speaker's bureau.



### Elder Care Online

- <http://www.ec-online.net>
- <http://www.alzwell.com>

Prism Innovations, Inc. maintains two companion caregiver-focused web sites: ElderCare Online and Alzwell Caregiver Support. Each provides information, education, and support to families caring for aging loved ones, especially those coping with AD and related dementias. The Prism Caregiver Education Series distributes print and electronic booklets and workbooks and offers specialized editorial consultations. Prism also provides knowledge management services for eldercare professionals and companies. Alzwell Caregiver Support has numerous caregiver support and AD information links, including the *Beacon Newsletter*, news and research, question and answer section, caregiver stories, resource lists, and chat rooms. ElderCare Online offers information, education and support for people caring for aging loved ones, with links to Alzheimer's and dementia care, home care, insurance coverage, legal and financial matters, longevity and wellness, residential options, and spirituality.



### Family Caregiving Alliance

- <http://www.caregiver.org>

Family Caregiver Alliance (FCA) is a community-based nonprofit organization in San Francisco offering support services for those caring for adults with AD, stroke, traumatic brain injuries, and other cognitive disorders. Caregiver Alliance programs and services include an Information Clearinghouse for FCA's publications. Online Services, including a problem-solving consultation program (designed primarily for California residents), an online support group feature, and Link2Care, a pilot program in California linking families with a more intensive level of online services. FCA conducts research and assists organizations to establish new programs for caregivers and offers caregiver workshops, research presentations, professional training, and public policy conferences. FCA also works with human resource departments and employee assistance programs to establish programs that support employees who are juggling the dual demands of work and eldercare.



### Florida Caregiver Learning

- <http://www.floridatelecare.com>

The State of Florida Department of Elder Affairs, the University of Florida (UF), and the UF Center for Research on Telehealth and Healthcare Communications have teamed up to provide caregivers a place where they can participate in caregiver educational support classes and find the latest information on caregiving. Services are available either through the web site or by calling toll-free, 1-866-260-2466. Florida residents can participate in interactive caregiver education classes to learn practical behavioral and educational techniques. A trained professional can assist in practicing positive caregiving and coping skills.

*(Continued on next page)*



### National Family Caregivers Association

➤ <http://www.nfcacares.org>

NFCA is a grass roots organization created to educate, support, empower, and act as an advocate for the millions of Americans who care for chronically ill, aged, or disabled loved ones. NFCA addresses the common needs and concerns of all family caregivers. The NFCA provides a newsletter, *Take Care! Self Care for the Family Caregiver*, and an 800 number, or Internet access, to professional caregiver advisory services. Web browsers can order the *Caregiver Survival Kit*, which includes:

- Linda Dano's *Caregiving: What Everyone Should Know*
- "Alzheimer's Disease: What Everyone Should Know" educational video
- Alzheimer's Disease Question and Answer brochure



### Well Spouse Foundation

➤ <http://www.wellspouse.org>

Well Spouse is a national, nonprofit membership organization which gives support to wives, husbands, and partners of the chronically ill and/or disabled. Spouses in caregiving situations face similar problems of anger, guilt, fear, isolation, grief, and financial threat. Web browsers can visit a link to determine if a Well Spouse support group exists in their area. Well Spouse publishes a bimonthly newsletter, *Mainstay*, and also helps set up letter writing "round robins" to help members break the bonds of isolation.



### Pharmaceutical Company Web Sites

Several pharmaceutical companies that make the drugs approved for treatment of mild to moderate Alzheimer's disease maintain Web

sites providing information that may be useful to caregivers:

➤ <http://www.alzheimersdisease.com>

This web site is sponsored by Novartis, the manufacturer of Exelon® (rivastigmine tartrate).

➤ <http://www.aricept.com>

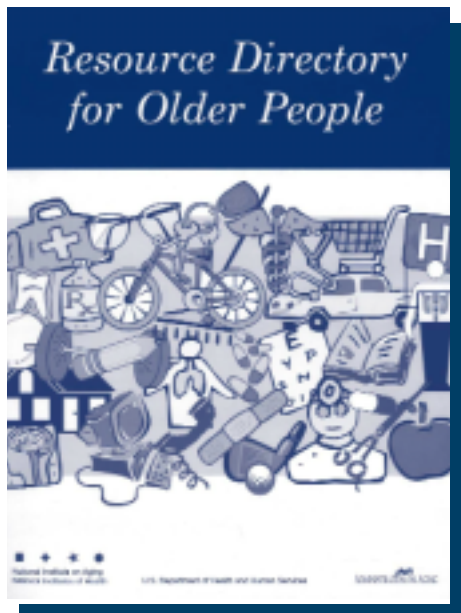
Sponsored by Eisai Inc., this Web site provides information on Aricept® (donepezil).

➤ <http://reminyl.com>

Janssen Pharmaceuticals, the makers of Reminyl® (galantamine), maintains this Web site.

Note: Parke-Davis, the manufacturer of Cognex® (tacrine) is no longer actively marketing this drug and does not provide information about this medication on a Web site.

## ***New Resource Directory for Older People Offered by NIA & AoA***



The new *Resource Directory for Older People* is a comprehensive listing of services and organizations compiled by the National Institute on Aging (NIA) and the Administration on Aging (AoA). The directory contains listings for almost 300 public and private organizations.

Each organization is briefly described, with mailing addresses, phone numbers, and Internet and e-mail addresses listed. State agencies on aging and ombudsman programs are listed in the appendices.

The directory is particularly useful to health and legal professionals, social service providers, librarians,

researchers, and others with an interest in aging. It is also available online at the NIA and AoA web sites at [www.nih.gov/nia](http://www.nih.gov/nia) and [www.aoa.gov/directory](http://www.aoa.gov/directory).

A single copy is available free of charge by calling the NIA Information Center at 1-800-222-2225 or 1-800-222-4225 (TTY), or by faxing or mailing the order form on the back of this newsletter. A nominal fee to cover shipping and handling will be charged for multiple copies as follows:

2 - 50 copies: \$5 per copy

51+ copies: \$3 per copy

## Alzheimer's Disease Clinical Trials Expanded, Expedited

As part of intensifying efforts to expand and expedite the search for Alzheimer's disease treatments, the National Institute on Aging has awarded \$54 million to support the Alzheimer's Disease Cooperative Study (ADCS), a national consortium of medical research centers and clinics. The network of 83 sites in the U.S. and Canada, coordinated by the University of California, San Diego (UCSD), will develop improved diagnostic tools and test a variety of drugs to slow down the progression of AD or prevent the disease altogether.

The consortium was first organized in 1991 under a cooperative agreement between NIA, part of the National Institutes of Health, and UCSD. During its first decade, the ADCS put in place an infrastructure of leading researchers to carry out clinical trials for promising new therapies for AD, developed new and more reliable ways to evaluate patients enrolled in these and other studies, and initiated a number of clinical trials. This next 5-year award will allow that work to continue and will move AD treatment research in new directions, including the study of a cholesterol-lowering statin drug, an antioxidant, and a high-dose vitamin regimen. The ADCS will also develop evaluation tools for AD prevention research.

It is estimated that as many as 4 million Americans suffer from AD. Some 2,500 people have participated in 13 ADCS research studies over the past decade. Their contribution has greatly informed medical practice, as ADCS findings over the past few years have suggested what may—and what may not—work against the disease. Previous ADCS studies have looked at the use of vitamin E, the anti Parkinson's dis-

ease drug selegiline, and estrogen, among other drugs. Several studies are continuing or are being initiated in the 5-year effort. These include:

- ◆ Vitamin E and donepezil—This ongoing prevention trial, begun in 1999, examines whether vitamin E, an antioxidant, or donepezil, an agent that slows the breakdown of the neurotransmitter acetylcholine, may keep patients with mild cognitive impairment from “converting” to AD. Some 700 patients are participating.
- ◆ Statins—This new study will test evidence from population and animal research that cholesterol might play a role in AD development. Patients with mild or moderate AD taking a cholesterol-lowering statin drug will be compared with AD patients of similar age and stage after one year to see if the use of the drug slowed down the progression of clinical signs of AD.
- ◆ High-dose folate/B6/B12 supplements—Research has shown that blood levels of homocysteine may be elevated in AD patients. This study is an 18-month clinical trial designed to test whether reducing homocysteine levels with the high-dose vitamin supplements can slow the rate of cognitive decline in people with AD.
- ◆ Valproate—Psychiatric symptoms associated with AD include agitation and psychosis, especially in later stages of the disease. In this 2-year trial, scientists will study whether low-dose valproate, an anticonvulsant drug, can help delay the emergence of agitation and psychosis. They will also look at whether the drug may also delay clinical progression of AD as well, since new studies suggest that the drug may also be neuroprotective.
- ◆ Indole-3-Propionic Acid (IPA)—IPA, a highly potent, naturally occurring antioxidant, has been shown

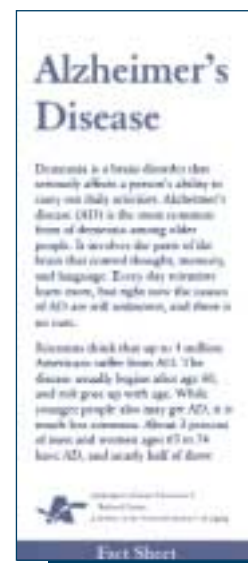
to interfere with the action of enzymes contributing to amyloid plaque formation, a hallmark of AD. This preliminary study will look at the safety and tolerability of IPA in patients with AD.

- ◆ Improved Assessment Measures—ADCS researchers will continue their work developing new or improved measures for evaluating the clinical effectiveness of drugs being tested for prevention or treatment of AD.

Find out more about clinical trials through the ADEAR web site at <http://www.alzheimers.org>.

## AD Fact Sheet Revised

A new version of one of the Alzheimer's Disease Education and Referral (ADEAR) Center's most popular publications, the *Alzheimer's Disease Fact Sheet* is now available. Updated with the latest developments in AD research, the Fact Sheet is an essential, easy-to-use, educational tool for the public and health care professionals. The *AD Fact Sheet* lists currently approved medications, discusses possible causes of AD, describes symptoms and diagnostic advances, and provides resources for additional assistance. Copies may be ordered by calling ADEAR at 1-800-438-4380 or by mailing or faxing the order form on the back page.



# CHID Highlights CHID Highlights

*CHID Highlights* describes materials recently added to the Alzheimer's disease file of the Combined Health Information Database (CHID). The items selected represent topics and formats of general interest to readers of *Connections* and ADEAR Center users or their clients. Please order directly from the source listed for each item. Journal articles are available in many university and medical school libraries. CHID is accessible on the Internet at <http://www.chid.nih.gov> or by following the link at <http://www.alzheimers.org>, or by following the National Library of Medicine's link to CHID at <http://www.nlm.nih.gov/medlineplus/databases.html>.

## Behavioral Interventions

Interventions in Dementia Care: Toward Improving Quality of Life

*Lawton, M.P.; Rubinstein, R.L., eds. Springer Publishing Company, Inc. 2000. 188 p.*

*Available from Springer Publishing Company, Inc., 536 Broadway, New York, NY 10012-3955. 212-431-4370; FAX: 212-941-7842. Internet: <http://www.springerpub.com>. PRICE: \$38.95 plus \$4.75 shipping.*

Interventions in dementia care designed to improve the quality of life of patients and reduce the burden of caregiving are explored in this book. Chapters address the following topics:

- development of treatment guidelines for AD
- maximizing the functional abilities of people with AD and related dementias
- approaches to the management of disruptive behaviors
- psychotherapy with cognitively impaired individuals
- emotion in people with dementia
- enhanced interdisciplinary care planning for nursing home residents with dementia
- family caregiving, research activities, and caregiving themes

Handbook on Dementia Caregiving: Evidence-Based Interventions for Family Caregivers

*Schulz, R., ed. Springer Publishing Company. 2000. 330 p.*

*Available from Springer Publishing Company, 536 Broadway, New York, NY 10012-3955. 212-431-4370; FAX: 212-941-7842.*

*Internet: <http://www.springerpub.com>. PRICE: \$49.95 plus \$4.75 shipping.*

An overview of evidence-based intervention approaches to dementia caregiving is provided in this book. Chapters include:

- unique challenges experienced by family caregivers of dementia patients
- a theoretical and conceptual framework for intervention approaches to caregiving
- a review of the research on interventions for in-home caregivers
- the pragmatics of implementing intervention studies in the community
- development and implementation of intervention strategies for culturally diverse caregiving populations
- measurement issues in intervention research
- assessing mechanisms of action in intervention studies
- translating intervention research into practice
- future directions in caregiver intervention research

He's Doing This to Spite Me: Emotional Conflicts in Dementia Care

*Hartman, S.; Kleber, D. Terra Nova Films. 2000. 22 mins.*

*Available from Terra Nova Films, 9848 South Winchester Avenue, Chicago, IL 60643. 1-800-779-8491, 773-881-8491; FAX: 773-881-3368. Internet: <http://www.terranoval.org>. PRICE: \$179.00 plus \$9.00 shipping.*

How to cope when the caregiver is upset with the behavior of a family member with AD is discussed in this video and accompanying workbook. Primary caregivers discuss their experiences in the video. Scenes include caregivers arguing or trying to reason with their family member. Caregivers discuss their feelings of anger, sadness, guilt, frustration, and resentment. Daniel Kuhn, educational director at the Maher Institute on Aging, is also interviewed. He explains that patients are not responsible for the disease or resulting behaviors. He recommends that caregivers identify their feelings, talk with others about those feelings, accept the disease and the patient's disabilities, and encourage the patient to use remaining abilities. The workbook defines dementia, its stages, and warning signs, and offers practical suggestions for coping with problem behaviors.

# CHID Highlights CHID Highlights

## Environmental Design

Healing Gardens: Therapeutic Benefits and Design Recommendations

*Marcus, C.C.; Barnes, M., eds. John Wiley and Sons, Inc. 1999. 610 p.*

*Available from John Wiley and Sons, Inc., Distribution Center, 1 Wiley Drive, Somerset, NJ 08875-1272. 1-800-225-5945, 732-469-4400; FAX: 732-302-2300. Internet: <http://www.wiley.com>. PRICE: \$79.95 plus \$2.50 shipping.*

This book describes the therapeutic effects and design recommendations of gardens in health care facilities. It includes research findings, site plans, photographs, design guidelines, and case studies in a range of health care settings including nursing homes and facilities for people with AD. The chapter on AD treatment gardens discusses the importance of the outdoor environment for people with AD, the need to provide safe walking paths, the therapeutic value of gardening and other outdoor activities, and design recommendations. Design guidelines for paths, places, landmarks, nodes, edges, views, furnishings, plantings, and symbolic cues are provided.

## Caregiving

Male Caregivers' Guidebook: Caring for Your Loved One With Alzheimer's at Home

*Alzheimer's Association Mid-Iowa Chapter. 1999. 69 p.*

*Available from the Alzheimer's Association Mid-Iowa Chapter, 700 East University Avenue, Des Moines, IA 50316-2392. 1-800-738-8071, 515-263-2464; FAX: 515-263-2466. PRICE: \$15.00.*

Support for male caregivers in their new role, and solutions to common problems of caring for a loved one with AD are available in this manual. The first section explains how to assess the situation to make informed decisions about a loved one's care. The second section offers practical advice about daily care at home. It includes strategies for maintaining independence, communicating, coping with behavior and personality changes, and assisting with personal care such as bathing, food, and activities. The third section discusses ways the caregiver can help take care of himself. It also discusses issues related to changes in sexuality and intimacy, and the benefits of attending a men's discussion group. The last section lists resources that are available to caregivers.

## Overview of AD

Guide to Alzheimer's Disease

*Harvard Health Publications. 2000. 45 p.*

*Available from Harvard Health Publications, PO Box 421073, Palm Coast, FL 32142-1073. Internet: <http://www.health.harvard.edu>. PRICE: \$16.00.*

This guide provides an overview of AD. It includes basic information about AD, differentiating between normal forgetfulness and dementia, and describes symptoms, brain structure, causes of AD, diagnosis, different types of dementias, therapies, behavior management, caregiving issues, stages of AD, wandering, long-term residential care, and drugs used to treat AD.

## Memory Activities

Series: Eldergames: The 30s

Eldergames: The 40s

Eldergames: The 50s

*Rothschild, M., Eldergames, United Seniors Health Cooperative. 2000.*

*Available from Eldergames, United Seniors Health Cooperative, 409 Third Street, SW, Suite 200, Washington, DC 20024. 202-479-6615; FAX: 202-479-6660. Internet: [http://www.unitedseniorshealth.org/html/pubs\\_eldergames.html](http://www.unitedseniorshealth.org/html/pubs_eldergames.html). PRICE of each book: \$10.50, plus \$3.00 shipping and handling.*

These three separate books are part of a series of memory stimulation activities for older adults, including those with memory disorders. Themes celebrate the people, events, and lifestyles of the 1930's, 1940's, and 1950's. Entries are designed to stimulate memories and conversation in categories such as headlines, popular reading, defining features of the decade, music, fads and fashions, community and daily life, sports, musicals, movies, television shows, innovations in science and technology, celebrities, and famous quotes. At least one clue is given for each entry, and additional clues can be used as prompts or separate topics of conversation. The entries were selected for participants from diverse backgrounds and of varying levels of cognitive ability. The format is intentionally flexible so the activity leader can determine an appropriate level of simplicity or complexity for presenting the materials. Each book includes general instructions and suggestions for using the entries in different games.




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### **November 4-7, 2001**

AAHSA's 40th Annual Meeting and Exposition: Advancing the Vision of Healthy, Affordable, Ethical Long-Term Care for America  
San Diego, CA

**Contact:**

American Association of Homes and Services for the Aging  
2519 Connecticut Avenue, NW  
Washington, DC 20008-1520  
1-888-508-9441

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### **November 7, 2001**

Emerging Alzheimer's Disease Therapies: Focusing on the Future  
Philadelphia, PA

**Contact:**

Center for Neurodegenerative Disease Research  
University of Pennsylvania  
Hospital of University of Pennsylvania  
3rd Floor, Maloney Building  
3600 Spruce Street  
Philadelphia, PA 19104  
215-662-4708

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### **November 8-9, 2001**

Brain Aging — Identifying Accelerators and Breaks  
San Diego, CA

**Contact:**

Brain Aging Conference Secretariat  
10b Littlegate Street  
Oxford  
OX1 1QT, UK  
011-44-1865-794-727  
011-44-1865-794-695 (Fax)  
enquiries.oxconf@pop3.hiway.co.uk

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### **November 10-15, 2001**

Society for Neuroscience Annual Meeting  
San Diego, CA

**Contact:**

Society for Neuroscience  
11 Dupont Circle, NW, Suite 500  
Washington, DC 20036  
202-462-6688

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### **November 14-18, 2001**

Gerontological Society of America Annual Meeting: A Gerontological Odyssey — Exploring Science, Society, and Spirituality  
Chicago, IL

**Contact:**

Gerontological Society of America  
1030 15th Street, NW, Suite 250  
Washington, DC 20005  
202-842-1275

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### **February 7-8, 2002**

Sixteenth Annual Joseph and Kathleen Bryan Alzheimer's Disease Research Center Conference  
Durham, NC

**Contact:**

Joseph and Kathleen Bryan Alzheimer's Disease Research Center  
2200 W. Main Street, Suite A230  
Box 3503  
Duke University Medical Center  
Durham, NC 27705  
919-660-7510 or  
1-800-672-4213 (in NC)  
jardi001@mc.duke.edu

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### **February 15-16, 2002**

(Rescheduled from September, 2001)  
3rd Leonard Berg Symposium - Neurobiology of the Aging Nervous System: Models, Manipulations, and Alzheimer's Disease  
St. Louis, MO

**Contact:**

Alzheimer's Disease Research Center  
Washington University School of Medicine  
4488 Forest Park Avenue, Suite 130  
St. Louis, MO 63108  
314-362-6891 or  
1-800-325-9862

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### **February 24-27, 2002**

AAGP 15th Annual Meeting: Scientific Discovery in Geriatric Psychiatry  
Orlando, FL

**Contact:**

American Association for Geriatric Psychiatry  
7910 Woodmont Avenue  
Bethesda, MD 20814  
301-654-7850  
<http://www.aagponline.org>

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### **April 3-6, 2002**

7th International Geneva/Springfield Symposium on Advances in Alzheimer's Disease Therapy  
Geneva, Switzerland

**Contact:**

South Illinois University School of Medicine  
Office of CME  
P.O. Box 19602  
Springfield, IL 62794-9602  
217-545-7342  
<http://www.siumed.edu/cme/geneva.pdf>

### **April 4-7, 2002**

Second Joint Conference of the National Council on the Aging and the American Society on Aging: Crossing the Great Divide - A Call for Compassion and Creativity  
Denver, CO

**Contact:**

American Society on Aging  
833 Market Street, Suite 511  
San Francisco, CA 94103-1824  
1-800-537-9728 or  
415-974-9600  
415-495-6509 (Fax)  
info@asaging.org

### **April 13-20, 2002**

2002 Annual Meeting of the American Academy of Neurology  
Denver, CO

**Contact:**

American Academy of Neurology  
1080 Montreal Avenue  
St. Paul, MN 55116  
651-695-1940  
<http://www.aan.com>

### **April 19-20, 2002**

ASPET - Ray Fuller Symposium:  
Alzheimer's Disease  
New Orleans, LA

**Contact:**

American Society for  
Pharmacology and Experimental  
Therapeutics  
9650 Rockville Pike  
Bethesda, MD 20814-3995  
301-530-7060  
markin@aspet.org  
<http://www.aspet.org>

### **April 21-27, 2002**

7th Neurodegenerative Disorders:  
Common Molecular Mechanisms  
Conference  
Montego Bay, Jamaica

**Contact:**

World Events Forum, Inc.  
5030 N. Marine Drive, Suite 2608  
Chicago, IL 60640  
773-784-8134  
208-575-5453 (Fax)  
jamaica@worldeventsforum.com

### **May 2-3, 2002**

Alzheimer's Disease: Update on  
Research, Treatment, and Care:  
UCSD Alzheimer's Disease Research  
Center's Annual Conference  
San Diego, CA

**Contact:**

Alzheimer's Disease Research  
Center  
UCSD  
8950 Villa La Jolla Drive, Suite 1200  
La Jolla, CA 92037  
858-622-5800  
858-622-1017 fax  
adrc@ucsd.edu

### **May 8-12, 2002**

2002 Annual Scientific Meeting:  
Shaping the Future for Older Adults  
Washington, DC

**Contact:**

American Geriatrics Society  
The Empire State Building  
350 Fifth Avenue, Suite 801  
New York, NY 10118  
212-308-1414

### **May 10-12, 2002**

Statistical Methodology in  
Alzheimer's Disease Research II  
Lexington, KY

**Contact:**

Alzheimer's Disease Research  
Center  
Sanders-Brown Center on Aging  
101 Sanders-Brown Building  
University of Kentucky  
Lexington, KY 40536-0230  
859-257-1412  
859-323-2866 (Fax)

### **June 20-23, 2002**

Annual Meeting of the American  
Association of Neuropathologists  
(AANP)  
Denver, CO

**Contact:**

American Association of  
Neuropathologists  
Office of the Secretary-Treasurer  
Department of Laboratory Medicine  
and Pathology  
Mayo Clinic, 200 First St SW  
Rochester, MN 55905  
507-284-3394  
507-284-1599 (Fax)  
aanp@mayo.edu

### **July 20-25, 2002**

8th International Conference on  
Alzheimer's Disease and Related  
Disorders  
Stockholm, Sweden

**Contact:**

Alzheimer's Association International  
Research Conference  
P.O. Box A3498  
Chicago, IL 60690-9564  
312-335-5813  
312-335-5781 (Fax)  
[www.alz.org/internationalconference](http://www.alz.org/internationalconference)



## *Order Form*

### *Alzheimer's Disease Education and Referral Center*

- AD Fact Sheet (No. Z12)*  
 *Caregiver Guide. (No. Z169)*  
 *Forgetfulness: It's Not Always What You Think Spanish Age Page (No. Z46A)*

### *National Institute on Aging Information Center*

- Resource Directory for Older People (No. HP14)*

You may ask the ADEAR Center for a topical search (a list of materials) on another subject related to Alzheimer's disease. Outline the subject for your search in the space below.

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To ensure that we can contact you with any questions regarding the search, please provide a daytime telephone number: ( \_\_\_\_ ) \_\_\_\_\_.

Name: \_\_\_\_\_

Title: \_\_\_\_\_

Organization: \_\_\_\_\_

Address: \_\_\_\_\_

- Check here if you are a health professional or a professional caregiver and would like your name added to the ADEAR Center mailing list to receive future issues of *Connections*.

To order any of the above materials, send this page to:

**ADEAR Center, PO Box 8250, Silver Spring, MD 20907-8250**

You also may call our toll-free telephone number: 800-438-4380; reach us by fax: 301-495-3334; or contact us on the Internet: e-mail = [adear@alzheimers.org](mailto:adear@alzheimers.org) and Web site = <http://www.alzheimers.org>



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