TargetTopic™: Alzheimer's

A PUBLICATION SERIES DEDICATED TO SUPPORTING PHYSICIAN AWARENESS ISSUE 4

"It's time to discuss managing treatment at home..."

LIVING WITH ALZHEIMER'S DISEASE

During the screening and testing phase of diagnosis, it is necessary (and practical) to distinguish between patients with AD and caregivers. That distinction, however, blurs as medical treatment begins. Alzheimer's disease affects not only the patient, but also family and friends as they all begin the real work of living with AD. Equipping everyone involved to deal with this new reality takes time, effort, and expertise.

Primary care physicians who treat AD will need to frankly discuss how to manage a slowly progressive disease that may last from two to 20 years. What is the family already doing to face the challenges of patient care? What is the family willing to do so that the patient may remain in familiar surroundings as long as possible? What resources are available if the patient doesn't have family support? Patients and their families need to know, in very practical terms, what will most likely happen after they head for home. "It's critically important to set expectations, not only about medication and treatment, but about what's going to happen behaviorally and emotionally," says Dr. Gus Alva.

While these conversations rarely fit neatly into the time generally allotted for patient examinations, our experts agree that making the time is a wise investment in patient care. "If you start having conversations early on about the right level of care, it's more likely that appropriate caregiving will be on board already once the patient enters an advanced stage," counsels Dr. Rachelle S. Doody. Setting up a series of brief patient and caregiver visits on a bi-weekly basis might be a more effective way to convey information that would be difficult to deliver — or receive — in one extended meeting.

Dr. Pierre Tariot considers having such conversations an essential form of intervention. "The interventions we advocate involve educating everyone about the nature of illness; validating the experience of living with Alzheimer's disease as either a patient or caregiver; explaining how to simplify communications at various stages of the illness; making environmental adaptations; ensuring that medications are taken properly; enhancing nutrition; reducing the risk of financial exploitation; minimizing social isolation and maximizing social stimulation; and optimizing exercise and intellectual stimulation."

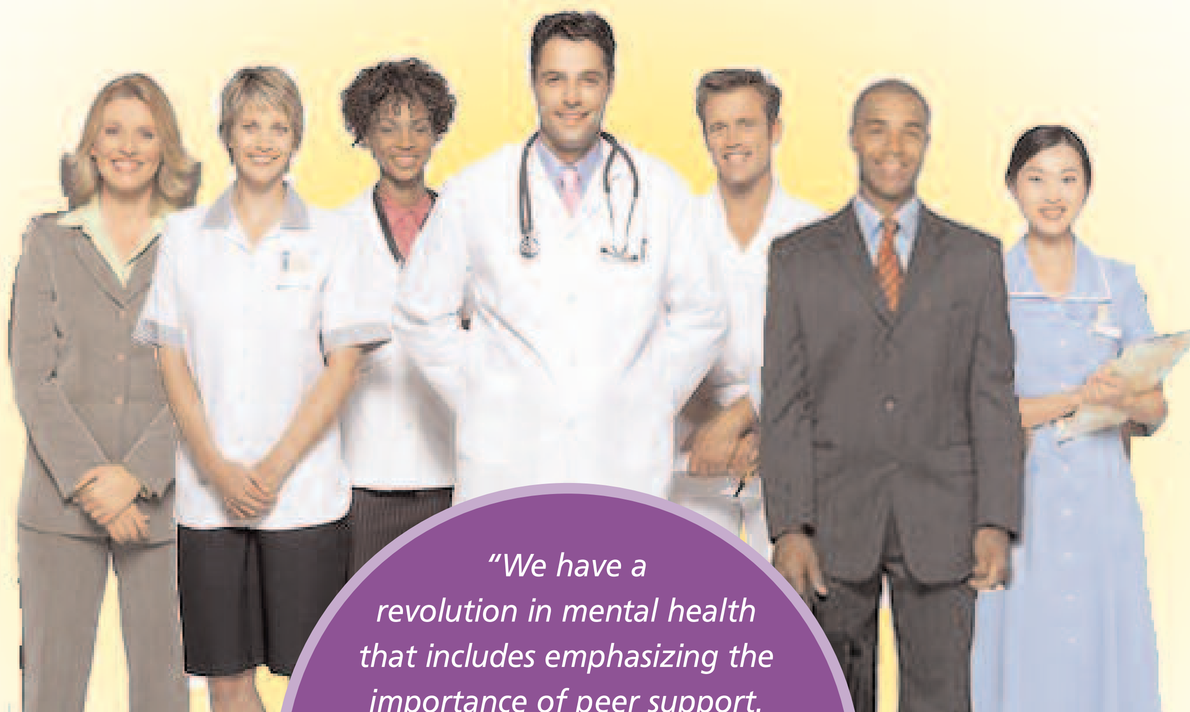
Because treating the patient with AD also means helping the family, primary care physicians often find themselves juggling multiple roles. Concerns about significant changes in behavior may require moderating a family meeting. Worries about functional decline may necessitate delivering a short course in home healthcare and nutrition. Should the primary care physician be providing this level of detail and support? When does it make sense to bring in other healthcare professionals? (See next page.) This much is certain: once they leave their doctor's office, the burden and responsibility for daily patient care rests on caregivers. The responsibility is huge and the burden is often heavy. How will treatment be managed at home?

At the same time, you cannot assume that this is every family's goal. "I've seen amazingly different ways of approaching this," says Dr. Gus Alva. "Some people want to do as much as they possibly can. Others want to know how soon they can put someone in a nursing home. It seems to have to do with the constitution of caregiver."

Primary care physicians face the challenge of bringing competence and compassion to every variation of caregiver involvement. This, too, is a huge responsibility, which is why doctors who treat AD must take measures to deal with their own compassion fatigue.

Courtesy of Forest Pharmaceuticals, the maker of Namenda®

It takes a team



"We have a revolution in mental health that includes emphasizing the importance of peer support. There's something about talking with someone in the same situation that's a powerful human experience, but half of our patients think it's valuable; half do not."

Dr. Pierre N. Tariot

Primary care physicians, especially those who do not have a long-term relationship with patients with AD and their families, may feel uncomfortable assuming the roles of counselor, confidante, and expert. Fortunately, it has become easier to locate and set up sources of support. Our experts recommend setting up mini-networks, consisting of expert providers, to deliver information, guidance, and support — for everyone involved. "Refer to learn" says Dr. Pierre N. Tariot. "Refer for a road map, not for ongoing care by the specialist, except in extreme or atypical cases."

"In a lot of communities, there are public or private sector organizations that provide case management by a team that offers both social work and nursing assistance," Tariot explains. "They'll have someone show up and do an assessment, and then come up with a treatment plan that includes emergency procedures." Our experts agree that an increase in ancillary support for the patient and family will yield a corresponding decrease in phone calls to the primary care physician's office.

But referral also involves a philosophical choice on the part of primary care physicians. Dr. Rachelle S. Doody recommends that doctors make some time to ask themselves: How do I view aging? How do I view the aging process? "Personal beliefs will frame how dementia is treated and prompt the choice of referrals," she observes.

As a practical matter, it will be important to clarify at the outset who is going to treat which aspect of the dementia and who will take responsibility for patient follow up. Additional recommendations include:

- Create an information sheet about the value of creating a care team, the types of practitioners that might be required and guidelines about when to seek a referral.
- Ask patients and their caregivers to create a list of family and non-family members who can and should be given information about patient care.
- Create a consent form that will give you and your office personnel permission to contact a predetermined list of family and non-family members about patient care. (This would be in addition to whatever HIPAA forms are being signed.)

It also may make sense to establish a system of regular teleconferences with other practitioners on the patient's care team as the disease progresses. Dr. Lori A. Daiello, who makes house calls, notes that "when you sit with people and develop a rapport with them, they will tell you what's going on" but that this is near impossible within the limits of a seven-minute consultation. "Many doctors I work with are eager and ready to help, but just don't know what's going on in the home and family," she says, which is yet another good reason to put a care team in place.

Living with AD: Players for the Home Team*

Elder Law Attorney
Will be able to explain issues in connection with creating a durable power of attorney for healthcare and finances; living wills; planning for future medical care, housing, and financial management; and estate planning. Services may be supplemented by those of an accountant or financial advisor.

Home Healthcare Aide
Will be able to help with bathing, dressing, feeding, light housekeeping assistance, and companionship. May be provided by public or private agencies; may be covered by public or private insurance.

Visiting Nurse
Will be able to provide skilled nursing care in the home setting. May be provided by public or private agencies; may be covered by public or private insurance.

Nutritionist
Will be able to review food and feeding options; develop a food plan to optimize nutrition and account for feeding issues (eg, swallowing, digestion, elimination); and provide menu suggestions.

Pharmacist
Will be able to review medications prescribed by all practitioners on the case; flag possible drug interactions; and provide information about side effects.

Social Worker
Will be able to provide counsel and guidance to support the family and their network of friends; tips and techniques for communications and environmental management, (reconfiguring the living space to minimize confusion); and information about community-based peer support groups.

Psychiatrist
Will be able to evaluate behavioral and emotional changes; prescribe medications specific to behavioral and emotional changes; monitor treatment; and depending on training and specialty, may provide psychotherapy.

Neurologist
Will be able to test and evaluate brain and nervous system functioning; prescribe medications specific to neurological functioning; and monitor improvement/ deterioration.

* Remind caregivers that they may find free/low-cost help for transportation, shopping, and respite care services through their church or synagogue, neighborhood association, or community volunteer organizations. It's also worth contacting local colleges and universities that have healthcare and social work programs; students may need to fulfill work-study requirements.

Treating Behavior

Early treatment for AD may slow the onset of behavioral problems, but these seem to be an inevitable outcome of this devastating disease.

Of all the challenges faced by caregivers of patients with AD, dealing with changes in personality and behavior are among the most difficult to handle emotionally as well as practically. Treating these disturbances also presents a challenge for primary care physicians. "Behavioral problems make care of an Alzheimer's patient much more difficult, so you want to do everything to minimize these problems," advises Dr. Eric Pfeiffer. At first, "doing everything" involves behavioral and environmental strategies.

Dr. Pierre N. Tariot advocates making every effort to understand factors that might be either triggering or making behavioral problems worse. Are caregivers' anxiety or depression being transmitted to the patient? Does the caregiver need to modify ways of communicating in order to reduce patient resistance or combativeness? Are environmental factors such as noise, harsh lighting, or clutter in the home contributing to the patient's agitation? "As a general rule, I try to encourage caregivers to explore interpersonal and social interventions, such as softening voice tone, using simple language, and making the living space an easier place to manage," Tariot explains. Managing behavioral problems will make it easier to treat other aspects of AD.

Practical Solutions for Caregivers

By encouraging the use of respite care, giving caregivers short periods of time off, primary care physicians can play a significant role in reducing caregiver stress. More often than not, the caregiver will welcome professional permission to take a much-needed break from attending to the patient with AD. Options to suggest include:

Adult Day Care
Adult Day Care programs provide supervision, activities, and personal care for patients with AD in early and moderate stages. Attendance can range from two to seven days a week; three to twelve hours a day. Adult Day Care may or may not be associated with a nursing home.

Residential Respite
Longer periods of overnight care may be available through respite centers, skilled nursing facilities, or hospitals. Short-term stays can range from a few days to a few weeks.

Senior Companions
The Senior Companion program, a service of Senior Corps, matches age-60+ volunteers with other adults who need help to remain independent and living at home, or with caregivers who need respite care. Local AARP and Alzheimer's Association chapters can provide referrals to this program.

Presenting…special challenges of patient caregiving

Practical Advice for Caregivers about FUNCTIONAL CHALLENGES

As Alzheimer's disease progresses, caregivers will notice a decline in the patient's ability to handle activities of daily living. Behavioral changes will also emerge to present special challenges, especially ones that tug at the heart. In addition to fielding inquiries about medication and other forms of treatment, expect to be asked about how to manage these functional and behavioral changes. At some point, caregivers will probably express some or all of the following concerns and fears. Our experts provide suggestions for how to respond to the top issues.

BATHING

"He refuses to bathe and won't let me help."

When caregivers have to help with personal hygiene, much of the patient with AD's resistance is due to resentment about losing independence and embarrassment about nudity. Bathrooms, which tend to have hard, cold surfaces and fixtures, can also be frightening places for someone who is confused. Reassure caregivers that a daily bath probably isn't absolutely necessary if the patient is still continent; a sponge bath, which allows the patient with AD to remain partially clothed, is an excellent option.

DRIVING

"I worry about her ability to drive a car."

If diagnosis and treatment for AD begins at an early stage, encourage caregivers and patients to discuss when and under what conditions it makes sense to stop driving. If reasoned conversation is no longer possible, suggest that the caregiver:

- Offer to do the driving or sign on with a "dial-a-ride" program.
- Distract the patient with another activity.
- Take the car keys.
- Disconnect the car's battery so it doesn't start.
- Remove the car altogether.

At some point, it may make sense to step in and advise the patient against driving or taking the more drastic measure of notifying the Department of Motor Vehicles and requesting a new road test for the patient with AD.

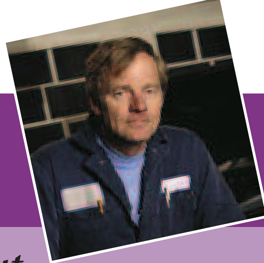
FEEDING

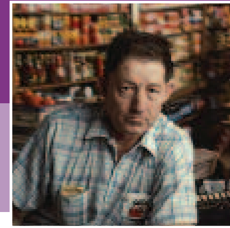
"Meal times have become a nightmare. Nothing I prepare seems appealing."

Feeding and eating problems often have more to do with the environmental conditions than the food itself. Counsel caregivers to create a calmer environment with fewer distractions: swap calming music for the blare of television or radio; use plain plates, placemats, and tablecloths instead of ones with patterns; minimize the number of utensils; serve one type of food at a time instead of filling the plate; and stick to "finger foods" when utensils become unmanageable.

Choking problems can be avoided by cutting food into small pieces and then making sure the patient chews and swallows. Increasing liquid intake will help digestion, reduce constipation, and keep the patient with AD hydrated. Sipping cups with lids will make drinking easier; bendable straws will, too.

Courtesy of Forest Pharmaceuticals, the maker of Namenda®





Practical Advice for Caregivers about *BEHAVIORAL CHALLENGES*

INSOMNIA

"She seems to wander around at night and sleep away the day."

According to Dr. Lori A. Daiello, caregiver education about the nature of sleep disorders among dementia patients should be a key part of any treatment plan. Except in the case of severe and ongoing dementia-related sleep disorders, these non-pharmacological strategies can be used with great effectiveness:

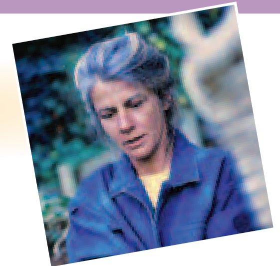
- Increase daytime exercise and limit daytime naps.
- Limit or remove caffeinated beverages from the patient's diet.
- Schedule a bathroom visit right before bedtime.
- Make the sleeping environment inviting with soothing music, soft lighting, and comfortable bedding.
- Invest in a reclining chair; some patients with AD find them more comfortable and secure than a bed.

INTIMACY

"Sometimes he's very clingy and other times he flips out if I go near him. Conversation is becoming more difficult by the day."

Although negative behaviors may get in the way, patients with AD and their caregivers will still have the very human desire for intimacy. In fact, "touch hunger" and the inability to communicate may exacerbate frustration and irritability for everyone. Help caregivers understand that patients with AD are extremely sensitive and reactive to loud and excessive noise; activity and sudden movement; clutter; and voice tone. Caregivers need to make every effort to remain calm, make eye contact, speak softly, touch gently, and sustain fonder memories of the patients with AD.

OVERREACTING



"I don't understand and am having trouble coping with sudden bursts of anger."

Outbursts of anger, excessive arguing, and other forms of overreacting by patients with AD can generally be traced to people, places, or situations that are causing stress and fear. Creating structure as well as calm will help, as will simplifying choices. Counsel caregivers to notice if extreme reactivity occurs during any special type of activity, at particular times of the day, or when certain people are around and to make adjustments accordingly.

ACTING OUT

"She's starting to undress at the strangest times and places."

Changes in energy are very common and usually in the form of an increase. Extreme forms of social disinhibition (eg, embarassing or unusual public behaviors, disrobing, etc.) are rare but significant signs of dementia that needs to be treated. "Sometimes it comes up as a legal problem before people realize it's a medical issue," says Dr. Pierre N. Tariot. Experts suggest that caregivers can reduce their own stress by deciding in advance how to react if inappropriate behavior should occur. Caregivers need to know that if this happens, it's because the patient with AD simply does not remember what is socially acceptable. The goal is to remain calm and not add to stress and confusion.

Compassion Fatigue

Caregiving is so exhausting that mental health professionals have coined the term "compassion fatigue" to capture the experience of burnout among professional caregivers (eg, first responders, nurses, doctors, victim advocates). The early behavioral signs of compassion fatigue among family and friends who provide care include:

Anger	Depression	Irritability
Anxiety	Exhaustion	Insomnia

Take the Compassion Fatigue Self-Test developed by Florida State University's Psychosocial Stress Research Program: www.ace-network.com/cftest.html

Emotions & Behaviors Translated

"Getting and giving information about psychological issues is probably trickiest for folks in primary care," says psychiatrist Dr. Pierre N. Tariot. That's why he advises talking about the "changes in emotions or temperament" that go along with memory loss rather than the precise clinical terms.

Clinical term	*Translation*
agitation	upset, angry, irritable, grouchy, grumpy
anxiety	frightened, nervous, worried, apprehensive
apathy	disinterested, indifferent, listless, sluggish

FOR MORE INFORMATION

It doesn't seem to matter whether a patient still lives in familiar surroundings or has moved into a nursing home, the challenges of caring for someone with Alzheimer's disease can still seem overwhelming. Caregivers for your patients with AD may find help and comfort in some of these selected resources. This list is for information only and does not constitute an endorsement of the resources included.

www.aarp.org/caregiving

AARP devotes a section of its website to issues affecting caregivers, including ways to find help at the local level. Content includes tips, links to other websites, and more lengthy articles that can be forwarded via email: 1-888-687-2277.

www.caps4caregivers.org

"Children of Aging Parents" is a nonprofit, charitable organization providing information, support, and referrals to caregivers of the elderly or chronically ill. Members receive a quarterly newsletter. The website includes a Caregiver Guide and links to state-based support groups: 1-800-227-7294.

www.ec-online.net

"ElderCare Online" provides an online community of peer support and professional counsel to help improve the quality of life for the caregiver aging spouse, parent, relative, or neighbor. Bi-monthly newsletters include tips and chat schedules. The site also hosts "The ElderCare Forum" and links to other online resources.

www.ethnicelderscare.net

"Ethnic Elders Care Network" provides information, education, and support for ethnic minority elders and their caregivers. This site includes special sections about dementia among African Americans, Chinese Americans, Hispanic Americans, and Japanese Americans, as well as a resource section that includes information about home care, adult day care, and nursing home/respite care.

www.n4a.org/locator/

"The Eldercare Locator" is a free service of the Administration on Aging, U.S. Department of Health and Human Services. The "Locator" connects users to resources that help the elderly live independently in their communities and provides information about support services for caregivers. The National Association of Area Agencies on Aging (n4a) administers "The Eldercare Locator" in partnership with the National Association of State Units on Aging (NASUA): 1-800-677-1116 weekdays, 9 am to 8 pm EST.

www.elderweb.com

"ElderWeb" includes thousands of reviewed links to long-term care information, a searchable database of organizations, and a library of articles and reports, news, and events. "These links allow users to search for services by state, county, and zip code and include information about applying for Medicaid in various states. Site founder's goal: "…to include as much direct online information as possible, so someone like a worried adult caregiver browsing at 3 am is not forced to wait until normal business hours to get help."

www.nfcacares.org

"The National Family Caregivers Association" (NFCA) is an educational and activist organization that serves as an advocate for those providing care for the chronically ill, elderly, or disabled. They are committed to improving the overall quality of life for caregivers: 1-800-896-3650.

Courtesy of Forest Pharmaceuticals, the maker of Namenda®

Our Editorial Consultants

Gustavo Alva, MD

Gus Alva, MD, the Medical Director of ATP Clinical Research, Inc., is a diplomate of the American Board of Psychiatry and Neurology. He has a special interest in psychiatric research and education pertaining to Alzheimer's and related dementias, schizophrenia, bipolar disorder, major depressive disorder, and anxiety disorders. Dr. Alva's work focuses on genetics, neuroimaging, and the latest treatments available for each condition, as well as the way ethnicity correlates with these clinical conditions. He is an Associate Clinical Professor of Psychiatry at the University of California, Irvine Medical Center, and is a Forensic Psychiatric Consultant for the Orange County Superior Court.

Rachelle S. Doody, MD, PhD

Rachelle S. Doody, MD, PhD, is Board Certified in Neurology and is the Effie Marie Cain Chair in Alzheimer's Disease Research at Baylor College of Medicine. Her medical training and a Ph.D. in Cognitive Anthropology inform her current research, which includes studies to understand and model the progression of Alzheimer's disease, studies of clinical heterogeneity, and developing new medications to treat Alzheimer's disease. Dr. Doody is a member of the Active Staff of the Methodist Hospital, sees patients in the Department of Neurology, and teaches medical students, residents, and fellows at Baylor, where she also directs the Alzheimer's Disease and Memory Disorders Center. She is listed in *The Best Doctors in America.*

These women and men are experts whose extensive knowledge of Alzheimer's disease is based on a dynamic combination of medical research, teaching, and hands-on clinical practice. They are internationally known and respected, and all regularly share their expertise with both professional and lay audiences. We're honored to bring their insights about diagnosing and treating Alzheimer's disease to you.

Lori A. Daiello, PharmD, BCPP, FASCP

Lori A. Daiello, PharmD, BCPP, FASCP, is president of Pharmacotherapy Solutions, an independent consulting firm offering individualized psycho-pharmacology consultations to the elderly and educational programming to professional and lay audiences. Dr. Daiello's research interests include Alzheimer's disease with related behavioral symptoms, drug-induced cognitive impairment, and geriatric mood disorders. She is known for developing one of the first pharmacist-led pharmacology consultation services for nursing homes in Columbus, Ohio, during the early 1990s.

Eric Pfeiffer, MD

Eric Pfeiffer, MD, is Professor of Psychiatry and Founding Director of the Suncoast Gerontology Center at the University of South Florida Medical Center in Tampa, Florida. A diplomate of the American Board of Psychiatry and Neurology, with additional qualifications in geriatric psychiatry, he is author of several major books on the psychiatry of old age and long-term care. The two best known, *Behavior and Adaptation in Late Life* and *Mental Illness in Late Life*, were co-authored with Dr. Ewald W. Busse. Throughout his career, Dr. Pfeiffer has received awards and honors for his distinguished work in the field of geriatric psychiatry. He is listed in *Who's Who in America* and in *The Best Doctors in America.*

Pierre N. Tariot, MD

Pierre Tariot, M.D., is the Associate Director of the Banner Alzheimer's Institute (BAI) in Phoenix, Arizona. He's a geriatric psychiatrist and internist known internationally for his research into drug therapies for Alzheimer's disease and other forms of dementia. Before joining BAI, Dr. Tariot was a professor of Psychiatry, Medicine, Neurology, and Aging and Developmental Biology at the University of Rochester Medical Center. Dr. Tariot recently received the Turken Award, presented each year by the Alzheimer's Disease Center at the University of California at Los Angeles to a leading researcher . His research has also won recognition from the American Geriatrics Society, the NIMH and the Gerontological Society of America.

When patients ask about clinical trials...

With so much information about AD treatment currently available in the popular press, it's quite likely that some patients might want information about how to participate in clinical research studies.

Patients motivated by a desire to enhance the greater good or curious about new treatments may be good candidates for this endeavor. Your patients with AD and their caregivers will need to know that clinical trial participants are expected to make a commitment of time and energy. You'll need to underscore the point that participating in a clinical trial will not necessarily lead to an immediate cure. They'll also need to know that for most clinical trials, participants are:

- expected to pass a screening process that will include a full physical exam, a range of tests to assess memory, cognitive, functional, and physical impairment, and meetings with study staff;
- randomly assigned to either the test group that will receive the experimental drug or one that receives another drug or placebo;
- scheduled to visit the study site more often than regular doctor visits and perhaps be hospitalized for observation; and
- required to follow precise medication or treatment protocols, and patients or caregivers may be asked to keep accurate records of symptoms and responses.

"I think I feel more optimism than the average clinician because I know about the many things coming down the pipeline..."

Dr. Gus Alva

The most significant consideration for those who participate in trials for AD has to do with consent. Because AD involves cognitive impairment, many studies require the full participation of an "advocate" who knows and has complete access to the patient. Identifying an individual who is willing and able to serve in this role should be given serious consideration.

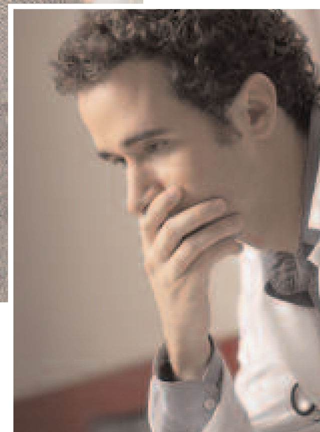
For many, the valuable benefits of participating in clinical research studies outweigh whatever challenges might be involved. Most significant of these is receiving state-of-the-art care and regular contact with healthcare professionals who are on the front line of combating this devastating disease.

For information about clinical trials that are currently open and offering free access to therapies that may not yet be on the market:
www.alzheimers.org/trials/index.html

Telling Others

Increased public awareness about AD does not necessarily mean that patients and family members will feel competent to explain what the diagnosis means to others in their social network. Doctors can help them by providing talking points about what AD is and is not:

- AD is a disease of the brain and not a normal part of aging.
- AD is a medical condition and not a psychological disorder.
- AD is progressive and decline does not happen all at once.
- AD is not contagious and social contact is beneficial during early and moderate stages.



TargetTopic™ Knipper Healthcare Marketing Support

TargetTopic™ is a publication of J. Knipper and Company, Inc.

All rights reserved. No reproduction of any portion without the written permission of J. Knipper and Company, Inc.

One Healthcare Way, Lakewood, New Jersey 08701

Project Director: J. Douglas Reiff Editor: MeredithGould.com Design: ThreeBears.com

The viewpoints expressed herein are those of our editorial consultants and do not necessarily reflect those of Forest Laboratories, J. Knipper, or others involved in the development of TargetTopic™: Alzheimer's.

Courtesy of Forest Pharmaceuticals, the maker of Namenda®

TargetTopic™: Alzheimer's

For Healthcare Professionals

Issue № 4:

Living with Alzheimer's Disease

- It's Time to Discuss Managing Treatment at Home
- Living with AD: Players for the Home Team
- Treating Behavioral Disturbances
- Practical Advice for Caregivers

… and more