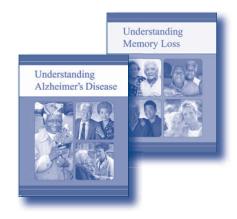
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Easy-to-Read Booklets on Alzheimer's Disease, Memory Loss Offered by NIA

The National Institute on Aging (NIA), a component of the National Institutes of Health (NIH), now offers two free booklets designed to help people with limited literacy skills learn about Alzheimer's disease (AD) and memory loss. In these easy-to-read booklets, the medical and technical language has been replaced by plain language, stories, photographs, and other features to help readers understand the content.

"Our goal was to produce strong, clear materials to make information about AD and memory loss accessible to everyone, including those with limited literacy skills," says

(see Easy-to-Read Publications, page 2)

Promoting Successful Eating in Long-Term Care: Relationships with Residents are Key

First of two parts

Anyone who has worked with mid- and late-stage dementia residents in long-term care can describe mealtime challenges they've encountered. Refusing to eat, rejecting food, becoming too distracted to eat, not being able to use utensils properly, not recognizing food, and difficulty chewing are among the dining difficulties commonly observed.

These challenges can be both perplexing and frustrating for frontline caregivers as they try to encourage residents to eat and drink. For the person with dementia, though, inadequate food and fluid intake can mean much more—malnourishment, dehydration, and unintended weight loss that can lead to a downward spiral in overall health and quality of life.

Malnourishment can increase the likelihood of infections, poor wound healing, pressure sores, immune deficiency, anemia, and abnormally low blood pressure (hypotension). Dehydration can also lead to problems such as constipation, urinary tract infections, renal

disease, pneumonia, hypotension, and delirium. In addition, lack of adequate nutrition and fluids can negatively impact the person's mood, behavior, and physical functioning as dementia progresses.

Research shows that as many as 85 percent of nursing home residents are undernourished, and as many as 60 percent of residents suffer from dehydration. According to



the American Dietetic Association (ADA), unintended weight loss also is common in long-term care (LTC), with 10 percent of residents losing 5 percent of their body weight within 30 days and 10 percent of residents

(see Tips for Successful Eating, page 2)





Easy-to-Read Publications

(from page 1)

Richard J. Hodes, M.D., director of the NIA. "These booklets also are excellent starting points for anyone who needs basic information about AD and memory problems, regardless of reading capability." They are valuable additions to the comprehensive collection of health education materials available from NIA's Alzheimer's Disease Education and Referral (ADEAR) Center, adds Dr. Hodes.

In addition to local field testing, education experts at NIA-funded Alzheimer's Disease Centers arranged a series of interviews with caregivers and people with AD to gather feedback about the booklets. "We carefully tested each booklet for overall appeal, format, graphic elements, comprehension, cultural appropriateness, and 'self-efficacy' (a measure of understanding the importance of taking action if signs of AD or serious memory loss are seen)," says Patricia D. Lynch, MS, project

officer of the ADEAR Center. "The testing yielded excellent feedback that we used to refine the booklets," explains Wendy Mettger, MA, the plain language expert who developed the booklets.

The ADEAR Center provides information to the public and health professionals about AD and age-related cognitive change and offers a variety of publications, as well as information about clinical trials. The NIA is the lead Federal agency conducting and supporting basic, biomedical, and behavioral and social research on aging and the special needs and problems of older people.

The National Institutes of Health includes 27 Institutes and Centers and is a component of the U.S. Department of Health and Human Services. It is the primary Federal agency for conducting and supporting basic, clinical and translational medical research, and it investigates the causes, treatments, and cures for both common and rare diseases.

Understanding Memory

Loss covers topics such as:

- differences between mild forgetfulness and serious memory problems
- causes of memory problems and how they can be treated
- what a person should do when worried about memory
- how family members can help

Understanding Alzheimer's Disease includes:

- signs of AD
- the importance of seeing a doctor early
- treatment for AD
- help for caregivers

To order copies or for more information about these booklets, visit the ADEAR Center website at www.alzheimers.nia.nih.gov, or call 1-800-438-4380

Bulk orders are welcome!

Tips for Successful Eating (from page 1)

losing 10 percent of their body weight within 180 days (ADA, 2005).

As with other LTC residents, people with Alzheimer's disease and other dementias are at risk for a variety of eating problems. Diminished

senses of taste and smell, difficulties chewing and digesting food, and other changes frequently seen in older adults may become more pronounced in people with dementia. Increased cognitive impairment, swallowing problems, and other difficulties in the later stages of dementia

also can affect a person's ability to consume adequate food and fluids, and to maintain a healthy weight (see box on page 5).

In an Alzheimer's Associationsponsored study of 407 people with dementia at 35 residential care/assisted living facilities and 10 nursing homes in four States,



Reed et al. (2005) observed low food intake (defined in the study as eating 75 percent or less of a meal) in 54 percent of residents and low fluid intake (defined as drinking 8 fluid ounces or less at a meal) in 51 percent of residents. The researchers also found that nursing home residents with

dementia were significantly more likely to have low food and fluid intake, compared with those living in residential care or assisted living facilities.

While they may acknowledge these problems, nursing home and assisted living facility administrators and frontline caregivers alike

often are stymied by the many obstacles to providing adequate nourishment and fluids to residents in the later stages of dementia. These challenges, they say, range from individual residents' refusal to eat to staffing issues to the need to comply with regulations.

Some dementia-care experts suggest that changing LTC facilities' caregiving "cultures" and dining milieus can improve eating behaviors, make mealtimes easier, and prevent unintended weight loss and health problems. The keys, they say, are developing strong, positive relationships with individual residents and retooling dining approaches to better address individuals' needs.

"Mealtime is a time when people have the greatest opportunity to do something that is familiar, comfortable, and noninvasive, and it should be a chance for them to have real success," says Anna Ortigara, RN, MS, vice president of the Campaign for Culture Change at Life Services Network. a 450-member association of senior-care providers in Illinois. "We need to make sure we are setting up situations in which residents can do as much as possible for themselves, and we need to pay attention to steps they can take to be successful."

Get to Know the Person

Although the physical and social dining environments are critical, building positive relationships with residents and their families and understanding individuals' needs and preferences are paramount, says dementia-care expert Geri Richards Hall, PhD, ARNP, CS, FAAN, clinical professor at the University of Iowa College of Nursing and volunteer professional consultant to the online support group of the Alzheimer's Disease

Research Center (ADRC) at Washington University in St. Louis.

"The cardinal rule is 'Know thy patient,'" Dr. Hall says. "Food represents quality of life, and for many people with dementia in long-term care, it represents one of the few things they can enjoy. Therefore, it's important that they have what they want and need. Even people with end-stage dementia tell you what they want, either verbally or non-verbally."

Dr. Hall and other experts say that caregivers should work with families and get to know the resident's physical and cognitive status as well as the

changes that are occurring as the disease progresses. Getting to know the individual helps the caregiver find ways to support the resident in managing each step of the mealtime experience.

"When people with dementia are not able to manage dining well, some may get frustrated or upset or very anxious, while others may withdraw," says Ortigara, who has worked in dementia care and training since the early 1980s and was director of Residential Care Services at the Rush Alzheimer's Disease Center (ADC) in Chicago. "They may be telling us that they simply can't manage this situation. As the disease advances, people are less and less able to communicate verbally and will communicate more and

more through their behaviors."

"We have to think about how we as the staff are communicating with the person," Ortigara continues. "For example, are we friendly, warm, easygoing, and non-demanding? Are we sending clear messages? Are we giving them good, orienting information to the setting and task? Are we looking directly at the person, making sure the person sees us and calling him or her by



name? Are we speaking slowly and asking simple, very clear, one-choice questions like 'Mary, would you like some more milk?'"

Customize the Menu

Just as they get to know LTC residents as people and understand their ability to manage the mechanics of eating, direct caregivers should become familiar with the individual's food preferences. Learning what the person will and won't eat can take time and patience, and is a process of trial and error. It can also require being open to new strategies that help ensure adequate calorie intake and permitting residents in the later stages of dementia to eat what they want, not what the staff thinks they should have.

Jan Dougherty, RN, MS, Dementia Program director at Hospice of the Valley in Phoenix, Arizona, asserts that eating and mealtimes should be resident-directed, regardless of the stage of dementia. She works closely with nursing facilities in the Phoenix region and has written standards of care for nursing homes that serve people with moderate to advanced dementia.

"We all have these myths about what people should eat, how they should eat, and when they should eat," she says. "Even profoundly demented people can still direct their care based on their behavior. When they're readily accepting ice cream, they're directing us to give them more ice cream. When they're spitting out their peas, they're saying 'No more peas.' . . . We need to customize dining for every person because we all have different needs and different desires."

The ADA echoes this sentiment in its position paper on liberalization of the diet prescription in long-term care. "Dementia syndromes may impair self-feeding, alter appetite, and increase energy needs. Nutrition restrictions may make food less appetizing, resulting in diminished intake and weight loss," the position paper states. "Overly restrictive diets, such as those low in cholesterol/fat, salt, and sugar, may take much of the enjoyment out of eating. . . . The use of a more liberalized approach produces several benefits, including better intake, lower incidence of unintended weight loss, more consistent blood glucose levels, and, perhaps most important, quality of life for the residents."

Nancy Lerner, RN, BSN, MSN, CDONA/LTC, director of nursing

at Copper Ridge, a nonprofit dementia-care facility in Sykesville, Maryland, that is affiliated with the Johns Hopkins University ADC, suggests that LTC facilities adopt a variety of strategies to encourage residents with mid- to late-stage dementia to eat. Strategies used at Copper Ridge include, for example, baking bread and cookies daily to stimulate residents' sense of smell and appetites, and

"...a more liberalized approach produces several benefits, including better intake, lower incidence of unintended weight loss...and, perhaps most important, quality of life for the residents."

offering sharply flavored foods, such as marinara sauce over eggs.

The Copper Ridge staff also offers calorie-rich foods like "super cookies" and enhances most foods served with ingredients such as extra protein, fruit, dry milk, cream, half and half, ice cream, butter, peanut butter, and brown sugar.

"We basically add value to whatever foods they're eating," notes Lerner. "And, if we can give people a simple carbohydrate and they'll eat it, we'll let them eat it because they need the extra calories."

Make Food Readily Available

In addition to encouraging people to eat what they want, some LTC facilities have helped maintain residents' weight by making food available to residents when they want to eat instead of only at mealtimes. In this way, they maximize food intake whenever the person is receptive to eating. Vermillion Cliffs, a 46-bed Alzheimer's and dementia

care skilled nursing unit at the nonprofit Beatitudes Campus continuing care retirement community in Phoenix, Arizona, has adopted an innovative approach to eating and mealtimes, achieving positive outcomes for both residents and the staff.

At Vermillion Cliffs, the staff makes high-calorie, protein-dense foods available to residents around the clock, and food is viewed

as an important part of the caregiving culture. For example, rather than waking everyone to get ready for breakfast at a scheduled time, breakfast is served from 4:30 a.m. through mid-morning, so residents can eat when ready. Breakfast rolls, bran muffins, yogurt, fruit, sandwiches, and other finger foods are available 24/7 from a food cart in a central area, and all staff, from nurses and

and all staff, from nurses and nursing assistants to activities staff and housekeepers, offer residents food throughout the day.

The positive outcomes are significant. Vermillion Cliffs Unit Director Tena Alonzo, MA, reports that 73 percent of the residents maintain a stable weight or gain weight, and less than 5 percent lose significant weight, compared with about 50 percent who lost significant weight in the past. Other outcomes include decreased "sundowning" syndrome, fewer behavioral challenges, improved sleep, decreased use of sleeping pills, and almost no staff turnover.

Alonzo attributes these outcomes to a shift in the facility's caregiving culture and extensive, ongoing training that began 8 years ago. She says they wanted to make the dining experience more pleasurable and easier, despite the many challenges of the disease.

"We stopped looking at what was a balanced meal and started giving people food that they want, when they want it. We're taking our cues from the people we serve," Alonzo says.

Dougherty, who has worked with the Vermillion Cliffs dementia care team for several years, adds that the unit's staff caregivers spend a lot of time getting to know their residents and respect what individuals are telling them behaviorally.

"The whole philosophy is that it's not about us—it's about this person. The team is there to support the individual, and they work with the family to help them understand that this is a quality-of-life issue," she says.

Empower Frontline Caregivers

Improving residents' eating behaviors and preventing weight loss also involves a strong commitment to the staff, dementia-care experts suggest. Consistent assignments to individual residents have the potential to improve eating behaviors because caregivers are able to build relationships with the residents and get to know their behaviors and food preferences. Likewise, staff who assist with eating should be given data about their assigned residents' weight and other health factors, and empowered to use techniques that work for individuals, experts say.

Consistent assignments and empowering frontline caregivers can benefit residents and dramatically reduce staff turnover. Ongoing, interdisciplinary staff training can also make a difference by helping caregivers learn about behavioral interventions and understand nutrition risks, dietary needs, and other issues during the various stages of AD and other dementias.

Common Mealtime and Eating-Related Challenges

Many factors and barriers influence food and fluid intake among LTC residents with AD and related dementias. These factors, which evolve during the course of the disease include, for example:

- Physical issues, such as dysphagia (chewing or swallowing problems); loss of physical control; seating or positioning problems resulting from poor balance, coordination, strength, or endurance; mouth sores or gum disease; poorly fitting dentures; dry mouth or excessive salivation; and vision impairment.
- Cognitive and behavioral issues, such as decreased recognition of hunger or thirst, decreased perceptions of smell and taste, loss of the ability to manipulate objects such as utensils, inability to recognize eating utensils or food, forgetting to eat, rejecting certain foods, attempting to swallow before chewing, eating inedible objects, loss of impulse control, and wandering or having difficulty sitting down for meals.
- Communication impairments, such as the inability to express one's needs or desires.
- Factors in the dining environment, such as too many people and excessive activity in the dining room, noise from overhead paging and music, poor lighting, and confusing table settings.
- Food and menu-related issues, such as food not being available when residents want to eat, having too many food choices at one time, unfamiliar or inappropriate menu choices, diets that are too restrictive, and poor food quality.
- Staffing issues, such as frequent rotations or insufficient or inconsistent feeding support, lack of training in identifying the needs of residents at different stages of dementia, and the inability of mealtime staff to establish relationships that meet residents' individual needs.

"Each organization has to create a work environment in which staff turnover is minimized," Ortigara says. "Consistent assignments and reducing staff rotation can eliminate many eating difficulties because the staff really know the person—for example, that you've got to go slower when feeding Bill, that John doesn't like vegetables, that if you give Mary a little bit of sweets first she eats better. It's not about one strategy, it's about relationships."

Alonzo believes that Vermillion Cliffs' positive resident outcomes and near-zero staff turnover have resulted in part from empowering certified nursing assistants (CNAs). "We give the CNAs what they need to make the resident feel comfortable. It may or may not have to do with eating, but it often does because that's central to keeping people comfortable."

Dementia-care experts acknowledge that CNAs and other caregivers often feel restricted in how, what, and when they can serve residents because of nursing home regulations or physicians' therapeutic diet prescriptions. However, they point out that many of the regulations were

written in the 1970s and 1980s, when there were fewer dementia residents in long-term care. Today, caregivers are beginning to understand the need to be creative to ensure that nutritional and quality-of-life needs are met.

The ADA's position paper states, "Nutrition care for the resident is both driven and hindered by the regulatory environment. On one hand, regulations speak of physician-prescribed therapeutic diets, and, on the other, they speak of resident rights. Both regulations



and ethics demand that facilities meet the nutritional needs of residents while maintaining their dignity and quality of life."

"Many facilities are afraid of being cited for breaking the rules," comments Geri Richards Hall. "If you're nearing the end of your life and you have endstage dementia, and you want to eat chocolate cookies, does broccoli really make sense?"

She recommends working with physicians to plan feeding approaches to meet the individual's needs and desires

while ensuring quality of care and heeding the regulations.

Lerner says that the staff at Copper Ridge is encouraged to use creative feeding techniques and to exchange problem-solving ideas with their peers. "Generally, people have to be less afraid of assessing residents' individual needs, taking the time to figure out what can get them to eat, and then care-planning those strategies," says Lerner. "If you give aides the freedom to experiment, to talk together, and to try something different, then they know it's OK if the end result is getting someone to eat."

Rethink the Mealtime Experience

Ensuring that LTC residents consume adequate food and fluid can also require assessing—and often changing—the dining room experience. As stated in the Alzheimer's Association's Dementia Care Practice Recommendations for Assisted Living Residences and Nursing Homes (2005), "A positive social environment can promote the ability of residents to eat and drink. . . . Residents should have a pleasant, familiar dining environment free of distractions to maximize their ability to eat and drink."

Ortigara recommends that LTC administrators and caregivers begin to assess the dining experience in their facilities by asking some basic questions such as:

- What are mealtimes like here? Does the dining room experience look and feel "normal," or does it feel like a big, confusing institution?
- Do mealtimes provide an opportunity for the person with dementia to be successful?

- Are mealtimes pleasantly social? Are residents eating with people they like, or are they distracted or agitated by others with them?
- How is the staff approaching residents at mealtime? Are they engaging them and calling them by name?
- Does the dining room environment support people's remaining abilities and allow them to feel success during the dining experience?
- And finally, is this a place where I would want to eat my meals for the rest of my life?

LTC administrators and caregivers should try to make mealtimes easier and less confusing for residents. For example, depending on the resident's stage of dementia, facilities might limit menu choices, have residents make menu choices before coming to the dining room, serve meals as soon as individual residents are seated, serve only one course or food at a time, offer finger foods, and give residents adequate time to eat.

To promote independent eating, residents should be cued both verbally and visually. The caregiver can offer one-step instructions, remind the resident to chew and swallow, and demonstrate eating tasks, for instance. Simple steps, such as pre-opening milk cartons, not wrapping silverware in napkins, and cutting foods into bite-sized pieces can also help.

Environmental changes can also help maximize residents' ability to eat and drink. These changes can include minimizing movement of people around the room, eliminating distracting noise such as overhead paging and music,

improving lighting, using boldly colored plates and cups, using placemats to define the resident's eating space, not placing unneeded items such as garnishes on plates, and removing used or unneeded utensils and other items from tables, for instance.

Some facilities have also created smaller, non-institutional dining rooms to reduce distractions and seat residents according to their eating abilities and dining needs. For example, at Vermillion Cliffs, residents who are easily distracted dine with three or four others in a small dining room or in other locations, sometimes with their families. At Copper Ridge, groups of 20 assisted-living residents with similar capabilities dine in kitchen areas in their "houses."

Ortigara recommends that administrators observe dining from the residents' perspective. "Every administrator should eat one meal in the dining room where people with dementia are eating, and they should be served exactly like the residents are served to

understand what it's like to eat meals in this room," she suggests.

Dougherty agrees, concluding that, "We need to get administrators and caregivers to think about how to make the best dining experience we can for people with dementia and to really focus on the dining experience that's right for this person. We can't have a one-size-fits-all model."

For More Information

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Next Issue: Caregiver Tips for Dining at Home

Photos on pages 1, 5, and 6 courtesy of the U.S. Department of Agriculture.



A new Spanish booklet—*Guía de la Enfermedad de Alzheimer, La información que usted necesita saber*—is the latest addition to the ADEAR Center's collection of Spanish-language resources. Based on the English *Alzheimer's Disease Fact Sheet*, this new 20-page booklet provides basic information on causes, symptoms, diagnosis, treatment, research, clinical trials, and resources for caregivers.

In addition, two newly-updated Spanish booklets are available:

- Guía para Quienes Cuidan Personas con la Enfermedad de Alzheimer (Tips for Caregivers of People with Alzheimer's Disease)
- Protección en el Hogar para las Personas con la Enfermedad de Alzheimer (Home Safety for People with Alzheimer's Disease)

Copies are available by contacting the ADEAR Center at 1-800-438-4380 or by visiting the ADEAR website at www.alzheimers.nia.nih.gov. You can also use the order form on the back of the newsletter.



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://chid.nih.gov, by following the link at www.alzheimers.nia.nih.gov or by following the National Library of Medicine's link to CHID at www.nlm.nih.gov/medlineplus/databases.html.

Dementia Care

Teaching Dementia Care: Skill and Understanding. 2005

Mace, N.L., Coons, D.H., Weaverdyck, S.E.

Available from The Johns Hopkins University Press, 2715 North Charles Street, Baltimore, MD 21218. Phone: 410-516-6900; Website: www.press.jhu.edu. PRICE: \$65.00 hardcover; \$29.95 paperback.

This 360 page manual is a comprehensive, useful tool for staff members of nursing homes, assisted living facilities, adult day-care centers, and other venues that require staff to be well-prepared on the practices of adult dementia caregiving. The author, Nancy L. Mace, is a co-author of the wellknown AD guide, The 36-hour Day, and the editor of Dementia Care. The manual is segmented into three main sections and further sectioned into individual lesson plans. The first part discusses how educators and administrators can get started teaching caregivers. This section introduces caregiving background and its evolution, what it takes to teach adult students, and effective teaching methods. Part Two includes lesson plans that can be used in their entirety or adapted to fit the individual needs of the class or group. Lesson plans focus on:

 facilitating function by treating excess disability and stress,

- applying skills in activities of daily living,
- helping the person by enriching communication,
- caring for the person by meeting emotional needs,
- helping the person by addressing mood,
- restoring enjoyment through activities, and
- thinking through challenging behaviors.

Part Three provides information for educators, including how to use assessment tools and how to efficiently chart information. The author uses an upbeat and humorous writing style to make her book accessible and friendly, and less like a textbook.

Assisted Living Design

Humanistic Design of Assisted Living. 2005

Marsden, J.P.

Available from The Johns Hopkins University Press, 2715 North Charles Street, Baltimore, MD 21218. Phone: 410-516-6900. Website: www. press.jhu.edu. PRICE: \$49.95.

The guidelines for humanistic design of assisted living in this book are based on input from consumers and research focused on assisted living facilities. This book will be particularly helpful to gerontologists, architects, designers, landscape architects, housing providers, and nursing home and assisted living administrators.

Concepts of humanistic design are discussed, including data from research-based information. Six themes are introduced, including familiar housing cues, protective enclosure, caring cues, human scale, usability, and naturalness. The author then writes about how to apply these themes to guidelines for building exteriors, interior entries, and common shared spaces. Marsden includes successful design strategies and examples of unsuccessful designs. Tables depict more than 90 specific design recommendations that can also serve as design checklists. His 100-page book closes with a summary of the similarities and differences between the architectural needs of older people and the needs of the average family. Many of these design tactics can be translated to nursing homes and housing for elderly independent living.

Detecting Memory Loss

Memory Loss: When to Seek Help. 2005

Available from Mayo Clinic Health Information. 200 First Street, SW, Rochester, MN 55905. Phone: 1-800-291-1128. Website: www.mayoclinic. com/health/memory-loss/HQ00094. PRICE: FREE online access.

This Mayo Clinic online fact sheet highlights some ways to identify signs of memory loss. Although age-related memory loss is considered normal, significant gaps in day-to-day memory should be viewed seriously. The fact sheet discusses the differences between types of memory loss, and the signs and symptoms of dementia. It encourages readers to seek professional help to determine the possible causes of memory loss.

Art Therapy

When Words Have Lost Their Meaning: Alzheimer's Patients Communicate Through Art. 2005

Abraham, R.

Available from Greenwood Publishing Group, Inc., 88 Post Road West, Westport, CT 06881. Phone: 1-800-225-5800; Website: www. greeenwood.com. PRICE: \$49.95.

Abraham is a therapist who believes that caregivers can use art to help people with AD express thought, emotion, and communicate in a productive and positive way when words fail them as the disease progresses. In her 190-page book, she discusses the relationship between the therapeutic nature of art and the cognitive abilities of patients with various stages of AD. She stresses that patients are able to communicate even though speaking may no longer be an option. She suggests that creating art helps caregivers and others avoid labeling patients as prematurely uncommunicative. In this book, Abraham describes:

- a background of AD stages and cognitive and behavioral changes in the patient,
- art therapy contributions to the patient and caregiver,
- a guide to practicing art therapy,
- theoretical perspectives on art and AD.
- three case studies discussing the impact of art therapy, and
- opportunities to promote art

therapy for AD patients.

Abraham writes and discusses her theories clearly, in a straightforward style. Abraham's mother had AD and she applied art therapy techniques, thus she can provide empathy and emotional context from personal experience. She also includes over 70 pieces of artwork with captions and information regarding the artists' illness and history.

Children and Dementia

Getting to Know Ruben Plotnick

Rosenbluth, R., author, Manning, M., illustrator

Available from Flashlight Press, 3709 13th Avenue, Brooklyn, NY 11218. Phone: 1-800-888-4741; Website: www.ipgbook.com. PRICE: \$15.95.

A children's hardcover book for ages 5-9, Getting to Know Ruben Plotnick is about a boy named David whose "Grandma Rosie" has dementia. Sometimes, David's Grandma forgets his name and talks to her husband who died years ago. When the most popular kid in school—Ruben Plotnick, the title character—comes to David's house to play, David worries that his Grandma Rosie's antics will embarrass him, particularly when she is known for waltzing spontaneously. Will Ruben make fun of her behavior and tell the rest of the school? Will David end up embarrassed in front of his playmates? This sensitive and clever story deals with school-age embarrassment and what dementia looks like from a child's perspective. It teaches young children not to judge a book by its cover and has a few surprises at the end. All 15 pages of this book are well-illustrated by Maurie J. Manning and have

colorful drawings of both people and scenes. Roz Rosenbluth is best known for her fiction in *Cricket* and *Highlights* magazines for children.

Personal AD Stories

Into the Mist: When Someone You Love Has Alzheimer's Disease

Uetz, D., Lindsay, A.

Available from Barnes and Noble, Inc., Customer Service Department, 122 Fifth Avenue, Second Floor, New York, NY 10011. Phone: 1-800-843-2665; Website: www.barnesandnoble. com. PRICE: \$19.39 paperback.

Into the Mist takes the reader on a journey through the lives of three AD patients and their families. The author, Deborah Uetz, drew inspiration from her experiences with her father who had AD and has since died. She starts with three patients' stories, Jack, Frank, and Shirley. The stories are told through their daughters during the early, middle, and late-stages of the disease. This book will help families understand the almost imperceptible way dementia progresses, which is likened to that of a mist or fog. The second part provides information about how families can cope with the psychological aspects of AD, including making difficult choices, assessing communication difficulties, and dealing with behavior problems. Uetz then writes about the stages of AD and provides resource information on Medicare, Medicaid, long-term care, insurance and geriatric care management, and drug treatments. The book also includes a section on commonly asked questions with helpful, straightforward answers.

Clinical Trials and Studies Update

People with AD, those with mild cognitive impairment (MCI), or those with a family history of AD, as well as healthy people, can help scientists learn more about the brain and AD. Participating in a clinical trial or study helps researchers identify effective AD prevention and treatment strategies. The NIA and its partners fund a number of studies exploring a variety of potential approaches. If you or someone you know would like to participate in one of these studies, please contact the ADEAR Center: 1-800-438-4380, or visit <u>www.nia.nih.gov/</u> Alzheimers/ResearchInformation.

Anti-Oxidant & Other ADCS Trials

The latest Alzheimer's Disease Cooperative Study clinical trial is the Anti-Oxidant Study, which is investigating the use of oral antioxidant supplements in slowing AD progression. The anti-oxidant regimens being studied are 1) a combination of vitamin E, vitamin C, and alpha-lipoic acid, and 2) coenzyme Q. Biomarkers in blood and cerebrospinal fluid are being examined for changes after 16 weeks of anti-oxidant therapy. Currently, 15 sites are actively seeking volunteers between the ages of 60 and 85 with mild to moderate AD. A total of 75 participants are needed.

Participants are also needed for these ADCS clinical trials:

 VALID (VALproate in Dementia)—to demonstrate whether valproate therapy slows the progression of AD or

- delays the emergence of agitation and/or psychosis in outpatients with probable AD who have not experienced agitation and psychosis in their illness.
- HUPERZINE A—to determine
 whether treatment with huper zine A, a natural cholinesterase
 inhibitor derived from a Chinese
 herb, slows decline in people
 with AD.

These studies are sponsored by NIA and the ADCS at sites across the country.

The Alzheimer's Disease Neuroimaging Initiative (ADNI)

The Alzheimer's Disease Neuro-imaging Initiative (ADNI) is a major, 5-year clinical study seeking a total of 800 older adults to participate. The study is aimed at identifying markers of memory decline and AD and will use brain imaging (MRI and PET scans) and biomarkers in blood and cerebrospinal fluid to measure progression of MCI and early AD. Scientists hope that brain and biological changes can be detected, allowing the effectiveness of drugs to be evaluated at the earliest possible time.

The project was begun by the National Institute on Aging (NIA) and is supported by more than a dozen other federal agencies and private-sector companies and organizations. Investigators at 58 local study sites across the U.S. and Canada are asking people ages 55 to 90 to become a part of this landmark research.

Genetics Study Makes Headway Toward 1,000 Family Goal

The AD Genetics Study is collecting genetic material from individuals in families with two or more living brothers or sisters who have lateonset AD. This valuable resource will allow geneticists to speed up the discovery of additional AD risk factor genes to advance understanding of the early biological steps leading to AD, and to pinpoint targets for drug development and other strategies.

As of June 2006, researchers for the AD Genetics Study had identified 922 families for participation in the study. Of these, 650 families are actively enrolled in the study at the National Cell Repository for AD (NCRAD). Researchers anticipate hitting the 1,000-family mark this year. Even after meeting this goal, recruitment of new families will continue.

Eligible families must have at least two living siblings who developed AD after age 60 and one other living family member age 50 or older who may have memory loss or age 60 or older with no memory loss.

The study is also seeking volunteers to serve as "controls"—spouses, friends, and other interested people age 60 or older without memory impairment who are not biologically related to participating family members.

Families who may meet the eligibility criteria for this study can contact NCRAD at 1-800-526-2839 for more information.



August 24

Performance of Play "Augusta's File," about Dr. Alois Alzheimer's patient and the discovery of AD, Irvine, CA

Contact:

University of California, Irvine 1113 Gillespie Neuroscience Research Facility Irvine, CA 92697-4540 Telephone: 949-824-3251 E-mail: kbailey@uci.edu

September 1-4

National Arab American Medical Association 28th National Medical Convention, Dearborn, MI

Contact:

National Arab American Medical Association 801 South Adams Road, Suite 208 Birmingham, MI 48009 Telephone: 248-646-3661 Fax: 248-646-0617

E-mail: naama@naama.com Website: <u>www.naama.com</u>

September 6-8

5th International Conference on Frontotemporal Dementias, San Francisco, CA

Contact:

UCSF Office of Continuing Medical Education UCSF Box 0742, LH-450 San Francisco, CA 94143-0742 Telephone: 415-476-4251 E-mail: info@ocme.ucsf.edu

Website: www.cme.ucsf.edu

September 10-16

Annual American Association of Neuropathologists/International Congress of Neuropathologists Meeting, San Francisco, CA

Contact:

ICN2006 Registration 1837 16th St NW Washington DC 20009 Fax: 202-478-1743

E-mail: register@icn2006.org Website: <u>www.icn2006.org</u>

September 10-14

6th International Congress of Neuropsychiatry, Sydney, Australia

Contact:

ICMS Australasia Pty Ltd E-mail: info@inacongress2006.com Website: <u>www.inacongress2006.com</u>

September 11-14

Alzheimer's Association Dementia Care Conference, Atlanta, GA

Contact:

Alzheimer's Association 225 North Michigan Avenue

Floor 17

Chicago, IL 60601

Telephone: 312-335-5790

E-mail: careconference@alz.org Website: <u>www.alz.org/careconference</u>

September 27-October 1

American Academy of Family Physicians Scientific Assembly 2006, Washington, DC

Contact:

American Academy of Family Physicians

Attn: Registration Services 11400 Tomahawk Creek Parkway Leawood, KS 66211-2672 Telephone: 1-800-274-2237

Fax: 913-906-6075 E-mail: fp@aafp.org Website: <u>www.aafp.org</u>

September 28-29

6th Annual Leonard Berg Symposium, St. Louis, MO

Contact:

Tom Meuser, PhD Washington University at St. Louis School of Medicine St. Louis, MO 63108 Telephone: 314-286-2882 E-mail: meusert@wustl.edu

Website: http://alzheimer.wustl.edu

October 8-11

Annual American Neurological Association Meeting, Chicago, IL

Contact:

American Neurological Association 5841 Cedar Lake Road, Suite 204 Minneapolis, MN 55416

Minneapolis, MN 55416 Telephone: 952-545-6284

Fax: 952-545-6073

E-mail: Julieratzloff@llmsi.com

Website:

www.aneuroa.org/annual-meeting

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| Guía para Quienes Cuidan Personas con la Enfermedad de Alzheimer (Caregiver Guide) |
| Protección en el Hogar para las Personas con la Enfermedad de Alzheimer (Home Safety booklet) |
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