Overview of the Medical-Scientific Advisory Committee

The mission of the Alzheimer’s Association is to eliminate Alzheimer’s disease through the advancement of research, to provide and enhance care and support for all affected, and to reduce the risk of dementia through the promotion of brain health. The Desert Southwest Chapter has traditionally focused on providing services, resources, and education to families struggling with the disease in Arizona and Southern Nevada. The Chapter’s core programs include Helpline/Information and Referral, Family Care Consultation, Support Groups, Education, and Safe Return, serving over 10,000 community members last year. The Chapter is also involved in local and national advocacy in public policy on behalf of persons with dementia.

The Medical-Scientific Advisory Committee (MED-SAC) was redeveloped in July 2004 by co-chairs Dr. Wallace Reed and Dr. Marwan Sabbagh, to enhance the Desert Southwest Chapter’s capacity to live its mission with respect to building greater awareness of and support for research in Arizona and Southern Nevada.

Membership for the MED-SAC consists of health care practitioners and scientists who concentrate or have interest in the care, management, and research of Alzheimer’s disease and related disorders. Membership will include physicians, psychologists, nurses, and scientists. MED-SAC’s objectives include:

1. Promote clinical and other research pertaining to Alzheimer’s disease that is occurring in our communities.
2. Inform the community of the partnership between the Alzheimer’s Association Desert Southwest Chapter and individual scientific institutions.
3. Develop a newsletter specifically targeting the medical community. Establish a column in the Chapter’s newsletter to update the community-at-large on the latest scientific and medical progress locally and nationally. Create additional communication and educational opportunities, including through the Chapter’s website.

We are pleased to share this inaugural issue of the MED-SAC newsletter for the health care community with you. Our intent is to briefly provide information and resources that primary care physicians and other health care providers can quickly use when working with families struggling with Alzheimer’s disease. We would welcome your comments and questions.

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A Very Special Thank You

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Resource Guide
www.alzdsw.org
www.alz.org
www.alzheimers.org/adcdir.htm#arizona
www.nia.nih.gov

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Dietrick A. Stephan, Ph.D.
This article gives an overview of four critical issues associated with the treatment of behavior problems in persons suffering from dementia. Behavior problems are common with this patient population, and physicians and other health care providers are often called upon to help with the treatment of such problems. Unfortunately, we often see psychoactive medications used as the first and only treatment alternative, even though such medications have considerable challenges and pitfalls. As an alternative, we advocate behavioral and environmental approaches to treating behavior problems that have been proven successful even in the most challenging cases. Minimally, we believe that whenever these treatment alternatives are used, medication dosages can be significantly diminished, or even eliminated.

**MEDICAL PROBLEMS / PAIN.** When sick or in pain, people with dementia often exhibit increased confusion and exacerbated behavior problems. Such behavior changes may include initiation/exacerbation of: physical restlessness, emotional lability/volatility, resistance to care and aggression, problematic vocalizing, and/or psychosis. Since persons with moderate or greater dementia may not be able to verbalize their symptoms, acute medical conditions often go undetected and untreated, with associated problem behaviors being attributed to their dementia. Such patients are more likely to receive tranquilizing medications than pain medications, even when pain is the primary culprit. Physicians and other health professionals should always assess for acute medical problems, including pain, when caring for dementia patients who exhibit sudden changes in behavior.

**COMFORT.** Dementia care is comfort care. When dementia patients are physically, emotionally, and socially comfortable, they tend to function at their best both cognitively and behaviorally. Conversely, uncomfortable patients are much more likely to hit, yell, and act agitated. Since persons with moderate or greater dementia cannot always verbalize their discomfort, their comfort needs are often misunderstood or ignored by caregivers. Caregivers and professionals need to be sensitive to all aspects of patient comfort and aggressively anticipate and preemptively address comfort needs like pain, hunger, thirst, positioning, and continence care, as well social interactions and general emotional well-being.

**UNMET NEEDS.** A different way of looking at the comfort issue is to equate behavior problems with unmet needs. Persons with dementia are said to use behaviors as a means of expressing the presence of some sort of need. Failure to meet their needs causes increases in discomfort and agitation, as well as increases in co-morbid conditions and acute hospital visits. “Needs” can either be physical (e.g., health, illness, functional, and other physiological needs), and/or affective (e.g., environmental stress, sensory stimulation, meaningful human contact). Being sensitive to, and addressing patients’ needs, should significantly reduce problematic behaviors.

**CAREGIVING TECHNIQUES AND APPROACHES.** Caregiving for persons with dementia is not intuitive and often goes against human nature. It is quite natural in our society for people to correct or confront statements/actions that are erroneous. Yet such reactions by caregivers towards dementia patients are non-therapeutic and tend to trigger upsets and exacerbate problem behaviors. In this regard, the skills and attitude/demeanor of caregivers are critical factors in how persons with dementia behave. Poor hands-on caregiving techniques trigger resistive and aggressive behaviors, as do abrupt and/or rushed caregiver approaches. Caregivers need training. Plus we advocate using a “soft approach” to caregiving, which emphasizes soft/gentle/respectful voice tones, facial expressions, body language, attitudes, and physical touch. Along with that, we teach caregivers to not focus attention on upsets and, instead, back off and/or meaningfully engage/disturb patients during upsets. Using good caregiving techniques and approaches can significantly diminish or eliminate many problematic behaviors.

These are just a few of the many critical issues used in the nonpharmacological treatment of dementia-related behavior problems. For more information, Dr. Martin can be contacted through the Desert Southwest Chapter of the Alzheimer’s Association.
The Alzheimer’s Disease and Cognitive Disorders Division at Barrow Neurological Institute (BNI) has established programs to address some of the medical, scientific and psycho-social issues related to AD and other neurodegenerative disorders associated with neurobehavioral symptoms. The BNI is one of the several institutions that participate in the Alzheimer’s Disease Research Consortium that also includes the Banner Health System, Mayo Clinic, Sun Health, University of Arizona, and the VA Hospital in Tucson.

Our clinical program at BNI includes investigations that employ diagnostic protocols to distinguish AD from other conditions such as normal pressure hydrocephalus, strokes, multiple sclerosis, traumatic brain injury, and Parkinson’s disease, and examines autopsy brain materials to verify the type, distribution and extent of brain damage that may help explain the evolution of cognitive and behavioral changes in various neurologic conditions. We intend to establish strong collaboration with Sun Health as we pursue programs on retrieving autopsy CNS materials. A dedicated laboratory for animal and human experiments complements the clinic.

Clinical trials are studies designed to determine the safety, tolerability and efficacy of newer treatment modalities that may include novel pharmacologic agents, modifications of older treatment modalities, surgical intervention like shunting excess brain fluid, and in certain cases, combination of medical and surgical measures. We are currently involved in trials that utilize certain acetylcholinesterase inhibitors and neuroprotective agents to treat some of the symptoms of Alzheimer’s disease. A standardized diagnostic and treatment protocol that includes the use of a programmable valve for normal pressure hydrocephalus is awaiting IRB approval. Study participants will be encouraged to have at least a brain autopsy in order to gain a better understanding of such a treatable form of dementia.

A major focus of our clinical efforts is to characterize the clinical features of AD among Hispanics and other minorities, and identify risk factors that may influence disease development among different ethnic groups. We also have certain programs dedicated to providing free diagnostic evaluation and treatment for qualified Hispanics with AD. Such investigations may allow us to assess the safety, tolerability and efficacy of a particular drug such as Donepezil hydrochloride, a central acting acetylcholinesterase inhibitor, among target populations, and permit us to substantiate ethnic related alterations in metabolism, clinical response and toxicity.

An integral part of our program is the development of a strong human and animal research laboratory that will correlate clinical features of various forms of cognitive disorders with the type, distribution and degree of CNS damage as well as characterize the neuropathological and metabolic changes in the microcellular environment of experimental animals such as the acetylcholinesterase knock out mouse model and the triple transgenic mouse model for AD.

For additional information please call Catherine Young, Clinical Research Coordinator, at 602-406-3719 or Lee Nowak, Research Laboratory Coordinator, at 602-406-3334.
**Notice:** The World’s Leading Forum on Dementia Research

The 10th International Conference on Alzheimer’s Disease and Related Disorders
Presented by the Alzheimer’s Association, July 15–20, 2006, Madrid, Spain

This is the world’s leading forum on dementia research. As a part of the Alzheimer’s Association research program, the International Conference serves as a catalyst for generating new knowledge about dementia and fostering a vital, collegial research community.

More than 5,000 researchers will share groundbreaking information and resources on the etiology, pathology and treatment of Alzheimer’s disease and related disorders. The program will include 135 invited speakers, who are respected leaders and new voices in their disciplines, and more than 2,000 oral and poster presentations on current research. Continuing medical education credits will be available.

For more information, contact our Conference Services team at icad@alz.org or call +1.312.335.5790.

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**What Can the Desert Southwest Chapter Do for You?**

We offer 5 core programs and services to our constituents in Arizona and Southern Nevada:

- 24-Hour Help Line: 1-800-272-3900
- Family Care Consultations
- Support Groups for Patients and for Caregivers
- Educational Programs for Patients, Caregivers and Professionals
- Safe Return®, an Award-Winning Registration Program for Patients Who May Wander

Please call us for information: 602-528-0545
Or visit our web site: www.alzidsw.org
1028 East McDowell Rd., Phoenix AZ 85006