DIMENSIONS

AGING & ALZHEIMER'S UPDATE

Published by the University of Washington Alzheimer's Disease Research Center

23RD ANNUAL ALZHEIMER'S DISEASE RESEARCH CENTER PUBLIC FORUM

Alzheimer's Care in the 21st Century

By Elizabeth Sharpe

Caring for someone with Alzheimer's disease (AD) is a difficult, often overwhelming responsibility. Caregivers often feel alone and unsure of how to handle what happens as their loved one enters advanced stages of this progressive, degenerative disease.

Featured speakers Dr. Linda Teri and Dr. Murray Raskind addressed recent advances in care for Alzheimer's Disease at the 23rd Annual Public Forum on June 18, 2008, which airs on UWTV. Teri is professor and vice-chair of the UW Department of Psychosocial and Community Health as well as director of the Northwest Research Group on Aging. Raskind is professor and vice-chair of the UW Department of Psychiatry and Behavioral Sciences as well as director of the UW ADRC. The Forum, which has been held every year since the ADRC was first founded, offers the public a chance to hear about new evidence-based treatment being used for AD and a chance to raise concerns about the disease.

Alzheimer's disease affects nearly seven million older adults, and that number is expected to grow significantly as the U.S. population ages. The disease is characterized by an individual's loss of memory and language, lapses in judgment, and changes in personality, as well as behavior. Probably the most difficult for both caregivers and care recipients are disturbing behaviors, such as irritability, agitation, anxiety, depression, outbursts of anger, aggression, sleep disruption, and uncooperativeness with necessary care like dressing or eating. These behavioral problems increase as cognitive abilities decrease, explains Teri. Only 8% of people with mild cognitive impairment average three or more behavioral problems while 88% of people with severe cognitive impairment have three or more behavioral problems.

Speakers (left to right): Murray A. Raskind, MD, Linda Teri, PhD, and Rebecca Logsdon, PhD

Alzheimer's Care in the 21st Century: The 23rd Annual ADRC Public Forum, will be broadcast on UWTV. Exact date and time will be posted on the ADRC website at www.uwadrc.org. The program will also be available as video on demand at www.uwtv.org and www.researchchannel.org.

UW ADRC has been funded by the National Institute on Aging since 1985 to facilitate cutting edge research on causes and treatments of Alzheimer's disease and other dementias. In particular, the UW ADRC focuses on research to enhance the clinical care of patients with AD and their caregivers, and to provide community and professional education about AD, dementia, and caregiving.

Treatment is necessary, as the behavioral problems may harm others as well as compromise care. Plus, the untreated behavior may contribute to disability as well as increase rates of brain decline. Agitation and anxiety, along with other distressing behaviors that become chronic and may be harmful, are traditionally treated with drugs. The ideal approach, said Raskind, would be to treat the abnormality in the brain the same way people with diabetes are treated—identify what chemical is lacking in the body and then

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supply it. But the biology behind the brain has not been understood well enough to find that single mechanism that causes agitation, for example, if there is only one, Raskind adds. So instead, drugs used to treat agitation are the same drugs found effective for other kinds of "mental" disorders such as schizophrenia and insomnia.

The problem, Raskind explains, is that these drugs haven't been tremendously effective in older adults with AD. In fact, studies done using randomized placebo-controlled trials found they were little more effective than a placebo (a placebo is also called a sugar pill because it isn't really a drug at all).

Puzzling over this disappointing data, Raskind's research team wondered why a drug works to treat agitation in a patient with schizophrenia but doesn't work to treat agitation in a patient with Alzheimer's disease. If the same drug doesn't work for both, then what exactly is different about the brain of a person who has AD?

Through a series of studies, they found a possible answer. Alzheimer's disease damages or destroys brain cells called neurons. So, one suspected cause of agitation is the increased production of a neurochemical called norepinephrine by remaining neurons. The brain reaction to this neurochemical is a little like adrenaline surging through the body during a stressful event—it fires up the person's alertness, explains Raskind. If there are too many continuous "fires," then the person becomes agitated.

Raskind's team tested a commonly used drug for hypertension called prazosin that also blocks the brain's ability to respond to norepinephrine. Would it work to decrease agitation in people with AD, they wondered? In an eight-week-long initial placebo-controlled trial on twenty-one people with suspected AD and frequent agitation, the individuals taking the drug showed significant improvement when compared to the individuals taking the placebo. Although these results were promising, Raskind cautioned that more studies are needed, as are volunteers to participate in the studies.

Although behavioral disturbances have historically been treated with drugs, other approaches becoming more common today are non-pharmacological—or non-drug—approaches to care. Increasing evidence shows that psychosocial interventions are effective. According to Teri, these interventions improve the quality of life for the person with dementia and the quality of life for the caregiver, too. More and more, this is the first type of intervention that should be used, before drugs are even considered, agrees Raskind.

Behavioral disturbances place enormous stress on the person with AD but also on the person's caregiver. It's when these behaviors seem "out of control" that the caregiver feels incapable of handling care for a loved one.

The caregiver often places the person in an institution, such as in a nursing home or in an assisted living facility. The goal of her work, Teri said, is to help give caregivers skills to deal with situations that often feel hopeless, decrease the burden of care, and delay the need to place the loved one in a care facility.

Building skills so that caregivers can deal with problem behaviors on their own is key to the protocols Teri has developed. These skills include communicating clearly and with compassion, increasing the number of interactions or events that are pleasurable, maximizing

Pictured above:
Partcipants of the Forum audience at Kane Hall, University of Washington; Katherine Segura and Faith Martian from the Western and Central Chapter of the Alzheimer's Association, and at bottom; Anita Ranta, Cathy Blackburn, and Amy Moore of the UW ADRC.

cognitive function with environmental supports and regular exercise, and problem-solving to prevent or stop the chain reaction that sets off problem behaviors.

In controlled clinical trials, Teri reported significant results of non-pharmacologic interventions. Depression in both the person with dementia and the caregiver improved. The physical activity of the person with dementia increased while physical frailty decreased, and the number of people with dementia who were institutionalized because of behavioral problems decreased.

But Teri cautions the protocols have limitations, too. They take significant commitment, time, and patience to make them work. The protocols can't just work in the clinic; they have to be able to work in the home. Even though Teri and her colleagues are working to develop manuals and to lead trainings to broaden access, learning these protocols still requires specialized training.

Ultimately, Teri and Raskind, as well as the other research teams at the ADRC, are working to develop strategies and techniques to overcome the disabilities that prevent people with Alzheimer's disease to enjoy life and to chip away at the burden that caregivers often feel.

So even with the disease looming ever more on the horizon, caregivers and the cared for can still get through difficult times, knowing there are options out there to help.

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To find out more or to participate in research studies, contact the study director directly.

For research study of prazosin for agitation in dementia, contact Lucy Wang, MD. Ph. 206-277-5089 or by email: lucy.wang@va.gov.

For non-drug research studies related to issues in dementia (NITE-AD Study, Memory Care & Wellness Study, and Early Stage Memory Loss Study), contact Amy Moore, Ph. 206-616-5550 or toll-free at 1-866-292-4464.

To Our Readers...

As of August 1, 2008, we have stepped down from co-directing the Education and Information Transfer Core of the UW ADRC. We have passed the baton to our very capable colleagues at the ADRC. We made the decision because of our increasing involvement in administrative responsibilities in our home department within the School of Nursing, and because of the growing demands of our behavioral and psychosocial research studies.

We remain very committed to educating both professionals and families about psychosocial interventions to improve the lives of individuals with cognitive impairment and their caregivers, and we look forward to continuing our involvement with community partners and colleagues around the country as we expand our translational research efforts.

Sincerely,

Linda Teri, PhD, Director
Rebecca Logsdon, PhD, Co-Director
Training and Information Transfer Core, UW ADRC

Future contact information for DIMENSIONS:
Andrew David, 206-768-5098 or Andrew.David@va.gov

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1-800-317-5382 or wamble@u.washington.edu

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www.uwadrc.org

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Dimensions is published by the Alzheimer's Disease Research Center. The Center is affiliated with the University of Washington's Division of Gerontology and Geriatric Medicine, the Institute of Aging, the Veterans Administration GRECC units, the Division on Aging in the Department of Psychiatry and Behavioral Sciences, the Northwest Geriatric Education Center, the Geriatric and Family Services Clinic at UW Medical Center, and the Friends of Alzheimer's Disease Research. The Center is funded by the National Institute on Aging.

The University of Washington ADRC Support Fund is used to help support new junior faculty investigators with strong credentials in the field of Alzheimer's disease research and also to enhance the research infrastructure of the ADRC.

For more information regarding the Alzheimer's Disease Research Center Program Support Fund, please contact Victoria Hoyt, ADRC Program Coordinator, at 206-764-2749, or toll-free at 1-800-329-8387, ext. 6-2749 or by e-mail at Victoria.Hoyt@va.gov.

Checks should be made out to ADRC and addressed to: VAPSHCS (S-116-MIRECC), Attn: Viki Hoyt, 660 S. Columbian Way, Seattle, WA 98108.

ADRC PROFILE

Meet Ellen Steinbart

"I help provide a link between families and science," says Ellen Steinbart, a research nurse at the Alzheimer's Disease Research Center (ADRC).

Steinbart works with Thomas Bird, MD, and Gerard Schellenberg, PhD, who lead the Genetics Core of the ADRC. This research team is looking for genetic changes to explain dementia in families.

When family members have questions about Alzheimer's disease and genetics, Steinbart is often the first point of contact. She takes information on their family history and draws a family tree. For families appropriate for the genetic research, she obtains blood samples and medical records.

Some of the families she's kept in touch with for 22 years, back to when she first started working at the Center.

Steinbart carefully opens one of the family trees she's created, eight-and-a-half-by-eleven-inch sheets of paper taped together and folded over and over to fit into a manila folder.

This family tree is one of many filed away in folders that are filled with information on hundreds of families with a wide range of ethnic ancestry taking part in research studies. The folders squeeze into nondescript metal file cabinets that stretch down the hall and around each cubicle corner.

Steinbart has tracked eight generations of this particular family. Squares designate males and circles represent females. Many of the shapes are filled in, darkened, indicating individuals diagnosed with Alzheimer's disease.

The family is one of a small group of families being studied who trace their ancestors to adjacent villages in the Volga River region in Russia.

Steinbart knows the history of these Germans well.

In the 1700s, Catherine the Great, a German, married the Russian tsar. When he died, she became the Empress of Russia. She was bothered by the Tatars moving into a stretch of land around the Volga River. So in the 1760s, Catherine the Great recruited German farmers to come and settle in the Volga River region of Russia. Catherine thought the farmers would help stabilize the region, Steinbart explains.

In the late 1800s and early 1900s, when the situation in Russia changed, some of these families began emigrating to the U.S.

It was a group of these descendants that helped lead to an exciting discovery back in 1995.

A rare genetic mutation--the Presenilin 2 gene--was identified as the cause of Alzheimer's disease in that family line. (See Dimensions, Fall 1995 "ADRC researchers identify gene that causes familial Alzheimer's disease.")

Perhaps it's no coincidence that Steinbart's career has come full circle, from her initial interests in history and German as an undergraduate student at Macalester in St. Paul, Minn. Her sophomore year abroad was spent in Vienna, studying German and volunteering in a hospital in the city.

After graduating, she moved to New York to get her nursing degree at Cornell University. Then she got her master's degree in nursing at the University of Washington School of Nursing, which brought her to Seattle. It was an ad in the newspaper that told her of the job at the ADRC.

Bird asked her to take family histories and the research team began to study the Volga-German families among the other groups involved in research studies at the ADRC.

"It felt like it (the job) was meant to be," said Steinbart.

When she's not working, Steinbart is weeding her small flower and

Continued on next page ➜

Alzheimer's Disease Research Center, University of Washington
and VA Puget Sound Health Care System

Genetic Studies of Dementia

The Genetics Program of the Alzheimer's Disease Research Center at the University of Washington and the VA Puget Sound Health Care System is studying the role of genetics in dementia. It seeks to identify the genes responsible for various forms of dementia. Families are being sought with two or more living affected individuals. Participation could involve an interview, examination, review of medical records and a blood sample.

For further information, please contact Ellen Steinbart, RN at 206-764-2112 or toll free 800-745-4511.

vegetable garden or reading. She's been with the same book club for the past fifteen years, and sometimes they travel together.

Pictures of Steinbart's two grown daughters hang on a bulletin board. So, perhaps what Steinbart likes best about her job comes as no surprise.

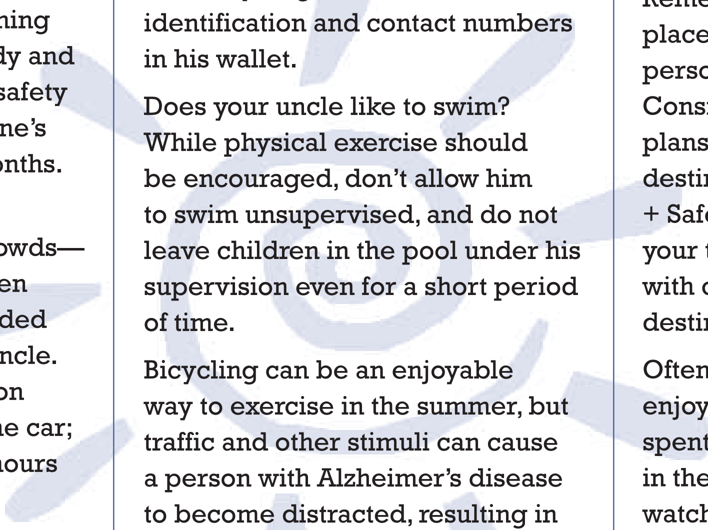
I really enjoy working with the families," said Steinbart. "They've been very generous people to share with us what's going on in their families, to give us an opportunity to try and learn more about Alzheimer's and come up with answers."

The hope is to find the genes responsible for dementia, which in turn "gives researchers an opportunity to create some kind of treatment or prevention," says Steinbart.

Sometimes people just want information and don't want to participate in the studies. That's fine, too, she says. "We try to be a resource for families. Sometimes it's hard to find information on genetics and Alzheimer's disease. So we do a lot of sharing."

To find out more about research on Alzheimer's disease and genetics, call Ellen Steinbart at (206) 764-2112 or toll-free at 1-800-745-4511. ❖

Q&A Fair weather fun!



Question: My uncle who has Alzheimer's disease is coming to visit this summer. What activities can the family enjoy together to help make his stay pleasurable?

Answer: Good for you! Sharing time with a family member with Alzheimer's can be very rewarding—and also a challenge. Combining activities to stimulate the body and mind, while always keeping safety in mind, can enhance everyone's enjoyment of the summer months. Here are a few tips.

Remember that noise and crowds—such as parades, festivals, even picnics in the park on a crowded day—may overwhelm your uncle. Consider watching parades on television or in the quiet of the car; picnic during less crowded hours and days.

Backyard BBQ's and fireworks can spark happy memories of childhood but can be a fire and safety hazard for your loved one who may not remember the proper use for such items. Never allow unsupervised access to open flames and hot surfaces.

Attending a ballgame may be something your uncle has always enjoyed. Again, large crowds can be overwhelming, so make sure to identify someone in your group ahead of time to be your uncle's designated "buddy." Make sure this person always accompanies him to the restroom and the concession stand and stays with him until he returns to his seat. In large crowds the risk of being separated is great and can happen very quickly. It's always a good idea to have identification and contact numbers in his wallet.

Does your uncle like to swim? While physical exercise should be encouraged, don't allow him to swim unsupervised, and do not leave children in the pool under his supervision even for a short period of time.

Bicycling can be an enjoyable way to exercise in the summer, but traffic and other stimuli can cause a person with Alzheimer's disease to become distracted, resulting in an accident or wandering. Look for trails designated for pedestrians and cyclists. Accompany him on the ride or ask a trusted companion to go with him. Helmets are a must!

Gardening can be a pleasurable and relaxing activity but keep an eye on sharp gardening shears or tools and closely monitor their use. Use fertilizers that are not harmful if swallowed accidentally and ensure that the plants in the garden are not poisonous.

Family reunions can cause anxiety as the family member struggles to recall names and faces. Let your hosts know ahead of time so they can arrange for a quiet place for him to retreat to if necessary.

Many families plan vacations and trips during the summer time. Remember that new and unfamiliar places can be confusing for the person with Alzheimer's disease. Consider simplifying travel plans or traveling to a familiar destination. Alert the Medic Alert + Safe Return registration line of your travel plans and provide them with contact information for your destination.

Often people with Alzheimer's just enjoy watching. Peaceful moments spent sitting on a comfortable chair in the yard beside a familiar face, watching children play, enjoying flowers, trees, and the breeze can bring satisfaction to you and your loved one.

Adapted from the Alzheimer's Association website (www.alz.org/co/in_my_community_13328.asp). ❖

Alzheimer's Association 24-hour Helpline:
1-800-272-3900
Medic Alert + Safe Return Enrollment Line:
1-888-572-8566
Medic Alert + Safe Return Incident Line:
1-800-625-3780

Recognizing and responding to pain in loved ones with dementia

By Elizabeth Sharpe

When her 90-year-old mother Ruth says, "I hurt," her daughter Emily worries. It is Mother's Day and her mother has fallen not once but twice. She asks Ruth where, where is the pain? Ruth rubs the outside of her leg. She can't explain, can't explain how bad the pain is, or even that it's really her hip that hurts. Twenty-four hours later, Ruth can't move and the paramedics rush to take her to ER. The doctor gives Ruth medicine for the pain, for the severe bone degeneration aggravated by the falls.

Emily has cared for Ruth for the last eight years. Then two years ago, Ruth had a stroke. That's when Ruth's cognition and ability to explain started going downhill and her day-to-day pain became more and more difficult to pinpoint, in words anyways. In addition to shingles on the right side of her face and along her scalp, Ruth had an ulcer-type sore on her ankle that took three months to heal.

Emily wants to help Ruth feel better, to relieve the pain, but Ruth often has difficulty explaining what hurts or how much it hurts. She gets confused about where the pain is coming from. When one of Ruth's eyes was swollen shut from the shingles, Emily took Ruth in to see the doctor. Ruth told the doctor the eye didn't hurt. "It itches," she said instead. Even so, Emily is sure the hurt is real. She can sometimes tell when her mother is in pain, even when Ruth doesn't say anything, just by "reading" Ruth's face.

This caregiver's experience in trying to recognize and respond to a loved one in pain is not unique. Nearly 4.5 million Americans have dementia and much of that number includes Alzheimer's disease, a disease that progressively debilitates both cognition and language.

With increasing difficulty to communicate through words, a person with dementia has more and more trouble articulating pain or level of pain, too. Yet, most pain assessment tools rely on self-reporting. For example, a question like the following would be difficult for a person with dementia: Given a scale of 1 and 10, with 10 being excruciating or unbearable, how would you rate the pain you experienced after this morning's fall? In order to respond accurately, the person must be able to understand the rating system, recall the event that caused the pain in a specific time frame, as well as interpret the feeling in the body as a "painful event."

Without a more reliable system of evaluation, many cases remain under diagnosed or under treated. In fact, research studies have shown that people with dementia are less likely to receive treatment than their cognitively-intact peers, despite similar pain-related conditions.

Pain can adversely impact the quality of life of a person's day-to-day life, their ability to take care of daily tasks and to remain mobile. Untreated pain can lead to a number of conditions detrimental to health: depression, sleep disturbance, impaired functional abilities and cognitive function and diminished socialization. Lack of treatment may also magnify problems that lead to more health care and as a result, further costs.

To ameliorate the pain their loved ones may feel, caregivers should go beyond words. Caregivers like Ruth's daughter take a more comprehensive approach to identifying pain in loved ones and in managing their pain. This approach may include the following steps:

1. Assume pain is present if the person suffers from injury, a surgical procedure, is diagnosed with another disease, or a physical examination confirms pain is present.

2. Establish what "normal" behavior is for this person. How does this person act in usual activities and in his or her regular environment? Then monitor for changes in behavior that may be associated with pain using the common behavioral indicators (see table on facing page). Take note of behaviors during movement as well as during rest.

3. Remember that nonverbal cues and behavioral changes are common, but some people demonstrate little or no specific behavior associated with severe pain. Still other people may present with signs of agitation or disruptive or aggressive behaviors.

4. Practice regular non-drug interventions for pain management. These interventions target behavior disturbances for pain as well as discomfort in general, "unmet needs" such as thirst or uncomfortable clothing. The symptoms or behaviors may be identical in

both situations, according to A. Lyn Snow and John Shuster in the November 2006 issue of the *Journal of Clinical Psychology*. According to the authors, non-drug interventions include "reduced or increased environmental stimulation (which may include noise, activity, physical materials, changes in routine or in the environment); soothing and supportive verbal communication; soothing and supportive touch; physical exercise and movement; sensory stimulation (which include activities that arouse smell, taste, or touch); music therapy; and therapeutic massage."

5. Analgesic interventions may be necessary in conjunction with non-drug therapy if non-pharmacological interventions are not successful or if physical examination or observation indicates the presence of pain. If medication appears to provide relief, pain may be the likely cause of the loved one's distress. Even so, be vigilant for potential side effects or further changes in behavior.

Without a doubt, perception of pain is a personal, subjective experience, based on factors as varied as age, endurance, and even past memories and experiences. Trial and error seems to be more the norm than the exception, and with such a vulnerable population, sometimes no single prescription can ameliorate the pain. But with patience and attentiveness, caregivers can surely make a difference.

Researchers have found that each person's behavior is idiosyncratic; behaviors can vary from individual to individual. Various tools or approaches exist to determine pain in persons with dementia. One such tool is the American Geriatrics Society's guidelines for persistent pain in older adults. It cites common pain behaviors in cognitively impaired elderly persons.

Facial expressions
- Slight frown, sad or frightened face
- Grimacing, wrinkled forehead, closed or tightened eyes
- Any distorted expression
- Rapid blinking

Verbalizations, vocalizations
- Sighing, moaning, groaning
- Grunting, chanting, calling out
- Noisy breathing
- Asking for help
- Verbally abusive

Body movements
- Rigid, tense body posture, guarding
- Fidgeting
- Increased pacing, rocking
- Restricted movement
- Gait or mobility changes

Changes in interpersonal interactions
- Aggressive, combative, resisting care
- Decreased social interactions
- Socially inappropriate, disruptive
- Withdrawn

Changes in activity patterns or routines
- Refusing food, appetite change
- Increase in rest periods
- Sleep, rest pattern changes
- Sudden cessation of common routines
- Increased wandering

Mental status changes
- Crying or tears
- Increased confusion
- Irritability or distress

But note, too, that some patients demonstrate little or no specific behavior associated with severe pain. ❖

References:

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Snow, A.L. & Shuster, J.L., Jr. (2006). Assessment and treatment of persistent pain in person with cognitive and communicative impairment. *Journal of Clinical Psychology, 62*(11): 1379-1387.

AGS Panel on Persistent Pain in Older Persons (2002). The management of persistent pain in older persons. *Journal of the American Geriatrics Society, 50*(s6), 205-224.

SEEKING VOLUNTEERS

Reducing Amyloid in Alzheimer's Disease

University of Washington / VA Puget Sound Health Care System
206-764-2069 or 1-800-317-5382

Researchers are participating in a new nationwide study that will test an experimental treatment to target the source of the Alzheimer's disease (AD). The experimental drug may block a critical pathway in AD that causes damage to the nerve cells in the brain.

Participants will receive either the active study drug or placebo (inactive pill). All participants will be monitored carefully by a team of doctors and nurses at the research clinic throughout the study. You are eligible to participate if you are:

- Are age 50 or older and have mild to moderate AD
- Have not suffered from serious or unstable diseases within the past three months
- Do not have Type 1 or Type 2 diabetes
- Have a reliable caregiver

People of all racial or ethnic backgrounds are encouraged to participate.

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MARK YOUR CALENDAR!

3rd Annual African American Caregiver Forum:

Affirming the Legacy of Love

Saturday, October 25, 2008
9:00 am to 2:00 pm
Northwest African American Museum
2300 S. Massachusetts St., Seattle
Attendance and luncheon are free.

The forum provides an opportunity to learn about Alzheimer's disease, share with each other, and connect with resources. Mark Snowden, MD, MPH, will deliver a medical keynote address. Dr. Snowden is medical director for geriatric psychiatry services at Harborview Medical Center. His research focuses on delivery of evidence-based mental health services to community-dwelling older adults and nursing home residents.

Caring for a loved one with AD is a family affair. Be sure to tell friends and family who would like to attend! *Register online at www.alzwa.org/102508eventreg.htm or call 206-529-3894 to register by phone. Register early – space is limited!*

The Alzheimer's Association Memory Walk™

The Memory Walk™ is the nation's largest event to raise awareness and funds for Alzheimer's care, support and research. Held annually in over 600 communities across the country, this inspiring event calls on volunteers of all ages to become champions in the fight against Alzheimer's disease. Since 1989, Memory Walk has raised more than $230 million dollars. Money raised at Memory Walk supports programs, services, and research in local communities to help people and families living with Alzheimer's disease.

Saturday, August 23, 2008
South Sound - Annie Wright School, Tacoma
Saturday, September 6, 2008
North Sound - Skagit Transit Station, Mount Vernon
Sunday, September 14, 2008
Sand Point Magnuson Park, Seattle
Saturday, September 20, 2008
Olympic Peninsula - Waterfront Park, Silverdale

To register and for more information visit our website: www.alzwa.org

Alzheimer Society of Washington

22nd Annual Fall Conference: Look at the Gifts in Dementia Care

Friday, October 17, 2008 - 8:30 am to 4:30 pm
Christ the King Center in Bellingham. Pre-registration required. 6 CEU's available.

Featured speakers: Geri Hall, PhD; Elaine Peskind, MD; Jolene Brackey, BA; and Gail & John Goeller, MS.

For information and registration please call 360-671-3316 or 800-493-3959. Visit our website: www.alzsociety.org.