

*This issue of the newsletter is devoted to "getting a diagnosis." Receiving a proper diagnosis is the starting point for understanding troubling symptoms, causes, treatment, and prognosis. Early diagnosis can result in early treatment that may slow the progression of the disease.*

## What is it Like to Live in Purgatory?

By Richard Taylor, Ph.D.

My admittedly ignorant understanding of purgatory (I am neither a theologian nor a Catholic) is that reasonably good people who have done some bad things in their lives spend an indeterminate amount of time living between heaven and hell. The living conditions get progressively worse depending on how bad they were and how long they are being retained in purgatory. They have no idea when they will find out if they are going up or down. The decision is not theirs to make.

Welcome to my purgatory: the time between knowing I might have Alzheimer's and the time I knew for sure I had Alzheimer's disease.

We hadn't been together since last Christmas. On the way to the airport, my daughter leaned over and whispered into my spouse's ear, "There is something wrong with Dad." I had noticed that I was increasingly more forgetful. Nothing out of the ordinary, I thought, just more of it. I felt a little more distant from everyone, but that comes and goes in all of us. I just wasn't as involved in the world as I used to be. I chalked that up to aging.

A month later, while at my General Practitioner's for my annual check up, I mentioned my daughter's comment and my own observations of

myself. "Don't worry," he said, "We have a medication for people with Alzheimer's."

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***"Welcome to my purgatory: the time between knowing I might have Alzheimer's and the time I knew for sure I had Alzheimer's disease."***

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"ALZHEIMERS? No way! I'm too young. I take good care of myself. I don't eat meat. I think good thoughts at least once every day. I perform random acts of kindness! I am friendly with stray dogs and cats, although I don't actually take them home with me."

Off to the neurologist for a year's worth of testing, a year in purgatory. I read books, checked dozens of internet sites, made frequent trips to my local Alzheimer's Association chapter and checked out a dozen depressing videos of individuals in the later stages of the disease.

Living in purgatory was getting worse. Then, finally, THE day arrived. "Dr. Taylor, you have dementia with Alzheimer's syndrome." What he said after that no one in my family can remember!

Now I realize that purgatory is better than my real life alternative (to live with Alzheimer's). I have moved out of purgatory and back into the world of the living, and am learning to live with and in Alzheimer's disease.

...

*It has been a year since Richard Taylor first shared his experience with Alzheimer's from "the inside out." Excerpts from his essay, "What is it Like to Live in Purgatory?" poignantly describe how he felt while he was waiting for a diagnosis. We appreciate Richard's willingness to share his very personal insights and observations as he travels through the "strange land" of Alzheimer's. For the full text of Richard's essay, please see our website [www.alztx.org](http://www.alztx.org) and the Spring 2005 issue of "The Alzheimer's Care Quarterly."*

### What's Inside:

#### Getting a Diagnosis

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## Step 1: Physical Examination

By James S. Goodwin, M.D.

An examination by a physician is called a “History and Physical.” The “history” is the talking part - questions about possible symptoms, when they occurred, what they were like, and how they affected you. The “physical” is the actual examination.

For the first visit for evaluation of possible dementia, I probably spend 70% of the time on the history, 10% on the physical, and 20% answering questions and explaining what comes next. The most important thing to bring is another person who can contribute to the history. This could be a spouse, relative or close friend. Often, the spouse or friend of someone with memory problems will give a much fuller picture of when the problem first started and how it has progressed.

The next most important thing to bring is the right attitude. People who cope best with early dementia are those who can talk about it openly, in essence, treat it as a disability, similar to a physical ailment that produces disabilities.

During the examination, the physician will usually perform some type of brief cognitive testing, as well as a full neurological and focused physical exam. Depending on the physician, the patient may also see one or more other health professionals during the same initial visit, for example, a nurse practitioner who would obtain comprehensive information issues such as social support. Eventually, most patients will receive extensive cognitive testing, anywhere from two to four hours of question and answer testing and problem solving.

It is usually at the second and subsequent visits, after the results of the blood tests and imaging studies, that the physician is in a position to discuss the results of the initial assessment.

*Dr. James S. Goodwin is the George and Cynthia Mitchell Distinguished Chair of Geriatric Medicine and Director of the Sealy Center on Aging at UTMB.*



### Save The Date . . .

...for the Chapter’s inaugural spring gala, *A Waltz Down Memory Lane*, to be held the evening of **March 10, 2005**. You will be transported to a bygone era of elegance as you dine in The La Fontaine Ballroom of the Warwick Hotel and dance the night away to the sounds of **The Artie Shaw Orchestra** featuring Dick Johnson.

This very special evening honors **Ginger and Deane Kanaly**, two long-standing friends and benefactors of the Alzheimer’s Association. Event Co-Chairmen are **Shirley Flowers** and **Allene Skalla**. The Honorary Chairman will be **Walter Zivley**. **Jerry Hart** of Hart Galleries will serve as Auctioneer.

Individual tickets are \$200. Tables start at \$2,000. For more information, contact Maria at 713-266-6400, ext. 123.

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## Mission Statement

To eliminate Alzheimer’s disease through the advancement of research and to enhance care and support for individuals, their families, and caregivers.

## Step 2: The Value of the Neurologic Examination

By Paul Schulz, M.D.

A neurologist is specialized in the accurate diagnosis of disorders that present with symptoms such as those that might indicate dementia. The neurologic history and physical examination are critical for the process of determining whether dementia is present. Moreover, if there is evidence for it, then the history and physical help neurologists in accurately identifying the etiology or cause of the symptoms. Diagnostic procedures are also very helpful in diagnosing dementia and the type present: these include neuropsychological tests of memory and cognition, tests of blood and cerebrospinal fluid, identification of Apolipoprotein E gene alleles, and brain scans (such as MRI, CT, or PET).

Some persons with memory loss or other signs of dementia have a potentially reversible condition that mimics dementia, such as metabolic problems, depression, delirium, drug or alcohol intoxication, thyroid problems, vitamin deficiencies, hydrocephalus, or brain infections.

There are also many different types of dementia that may require different treatments, including Lewy Body Disease, Vascular Dementia, Frontotemporal Degeneration, Parkinson's and Huntington's Disease, stroke, traumatic brain injury, or Multiple Sclerosis. As a result of this variety, and the differences involved in treating them, it is important to accurately determine the type of dementia that is present.

Prompt and accurate diagnosis also enables people to take immediate action to learn about and anticipate changes that accompany their disease and make appropriate plans for the future. Moreover, treatments work best when begun early in the disease.

• • •

*Dr. Schulz is a behavioral neurologist at the Cognitive Disorders Clinic of the Baylor College of Medicine at the Methodist Hospital. See below for contact information.*

### DIAGNOSIS / ASSESSMENT FACILITIES

**Alzheimer's Disease Center  
Baylor College of Medicine**  
6550 Fannin, #1801  
Houston, TX 77030  
713-798-6660

**Geriatric Medicine Associates  
Baylor College of Medicine**  
6550 Fannin – Suite SM-1153  
Houston, TX 77030  
713-798-3967

**The Geriatric Center  
Harris County Hospital  
District  
Baylor College of Medicine  
Quentin Mease Hospital**  
3601 MacGregor Way  
Houston, TX 77004  
A-G: 713-873-4886  
H-Z: 713-873-3785

**University of Texas Mental  
Sciences Institute**  
1300 Moursund  
Houston, TX 77030-3497  
713-500-2525

**Geriatric Services at UTMB  
(Galveston)**  
Contact UTMB Geriatric  
Service Line at 1-888-887-6800  
Two geriatric assessment centers:  
**In Galveston -**  
400 Harborside Drive, Suite 125  
Galveston, TX 77555-1128  
409-772-1948 or 1-888-887-6800  
**In Texas City -**  
519 Ninth Avenue  
Texas City, TX 77590  
409-948-8862

**Cognitive Disorders Clinic of  
the Baylor College of  
Medicine at the Methodist  
Hospital**  
6550 Fannin  
Smith Tower, 18th Floor  
Houston, TX 77030  
713-798-8986

***If you are a Veteran, contact:***  
**Cognitive Disorders Clinic at  
the Michael E. DeBakey VA  
Medical Center**  
2002 Holcombe, MS 127  
Houston, TX 77030  
713-794-7201



**FUNDING OUR MISSION**

**Fifth Annual Houston AWARE Family Portrait Luncheon**



*Keynote speaker Joanne Koenig-Coste (right) with AWARE President Carol McDonald, brought laughter and tears to the 450 luncheon guests with her approach to caregiving. Her book, *Learning to Speak Alzheimer's*, teaches one to emotionally care for loved ones with dementia.*



*Luncheon co-chairs, Cathy Frank (right) and Camille Patton, did an outstanding job organizing the beautiful event at the Houstonian. **Many thanks to all of the generous underwriters of the luncheon and especially to the luncheon honoree and major underwriter, The Ellwood Foundation!***



*The Chapter's first men's event, "A Well Done Roast," raised nearly \$75,000. Honorees Mark (top left) and Jack Dulworth are seen with hosts Leo Linbeck III (bottom left) and Leo Linbeck Jr. The Linbecks led the roasting, joined by: Robert H. Allen, Lee Cutrone, Pete DeLongchamps, John W. Fain II, Barry Lewis, Walter Murphy, Welcome Wilson Sr., and Walter Zivley.*

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**Terriers Take Tea**

Alzheimer's Association mascot Judy will host a Doggy Tea on March 5 in Beaumont for all canine supporters. The schnauzer soiree is sponsored by the Pilot Club of Beaumont and underwritten by PETCO.



The Tea will take place from 9 a.m.-1 p.m. at the Beaumont PETCO. Mastiffs and miniatures alike can attend for a fee of \$10 and will receive a bandana featuring the Alzheimer's Association logo and the names of event sponsors. Our four-footed friends will be able to put their best paws forward in a series of contests. May the best man's-best-friend win!

For more information, call Debi Brozak at 409-833-1613. The Beaumont Doggy Tea promises to be a howling good time!

**Thanks to the 2005 Houston Marathon Runners**

Many thanks to the 71 dedicated runners who "ran for a reason" in this year's annual HP Houston Marathon to raise funds for the Alzheimer's Association. Visit our website, [www.alztex.org](http://www.alztex.org), for all the highlights and participants.



**Thank You 2004 Education Conference Supporters**

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Supporters of the Alzheimer's Association put on their walking shoes in September, October, and November and participated in nine Memory Walks in Southeast Texas. With new walks in Katy and Galveston, we had a record number of walkers. Over 2,250 dedicated participants and hundreds of doggies braved the heat and rain to raise funds to support the 70,000 individuals with Alzheimer's in Southeast Texas.

Date	Walk Location	Number of Walkers	Amount Raised	Chairs
September 18	Katy	250 people 30 dogs	\$10,225	Amanda Bailey and Jennie Smith
October 9	Tomball	220 people 47 dogs	\$21,000	Jackie Barnes
October 16	Baytown	150 people	\$18,025	Judy Wheat and Nancy Mann
October 16 & 23	Hilltop Lakes and Centerville in Leon County	100 people	\$5,000	Jean Bottoms and Bill Johnston
October 30	Sugar Land	1250 people 85 dogs	\$170,200	Susan and Bob Hargarther, Honorary Chair: Dee Koch, Junior Chair: Alycia Curtis, Doggie Chair: Judy
November 6	Galveston	75 people	\$8,500	Mari Berend and Alice Williams
November 20	Beaumont	150 people	\$23,000	Melinda Weeks



*Houston/Ft. Bend County Memory Walk*



*(Left to right) Melinda Weeks, Debi Brozak, Mayor Evelyn Lord, Joe and Linda Domino at the Beaumont Memory Walk*

**Memory Walk Sponsors**

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**Friends of Memory Walk:**

The Bozeman Foundation · Epoch Assisted Living · Steve & Julie Ewbank · Dee Koch · Parkway Place · Jan & Michael Schiff

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## Step 3: Psychometric Exam

By Matthew Nance, Ph.D

A diagnosis of Alzheimer's disease requires the presence of cognitive impairment in two or more areas including memory, attention, orientation, language, spatial abilities, and motor skills. Observations of cognitive problems by patients and family members are helpful in documenting cognitive deficiencies, yet observations should be followed by a formal assessment. Formal testing often begins with a cognitive screening in the physician's office, and may be followed by a comprehensive neuropsychological evaluation.

The Mini-Mental State Exam (MMSE) is the most widely used instrument for screening cognitive functioning. The MMSE is brief, and can be administered as part of a routine physician visit. The MMSE assists the physician in deciding whether a comprehensive neuropsychological evaluation is appropriate.

A neuropsychological evaluation is a time-intensive procedure, usually conducted by a licensed psychologist with specialty training in brain functioning. The evaluation requires three to four hours of the patient's time.

During the evaluation, a "psychometrician," an individual trained in the administration and scoring of numerous psychological tests, will administer as many as 20 to 30 tasks, that require anywhere from three to twenty minutes to complete. The results of individual tests are then compared with normative data derived from groups of individuals who are

similar to the patient with respect to age, education, and other variables. By measuring an individual's performance on numerous tasks, and comparing the obtained scores to normative data, the neuropsychologist can classify cognitive abilities along a continuum from normal to impaired. The neuropsychologist also can make inferences about brain function based on the processes a patient uses to complete a task.

A neuropsychological evaluation is usually conducted at the request of the consulting physician. The evaluation not only assists with making accurate diagnoses, but is helpful in making decisions about medications, monitoring the progression of disease, and identifying behavioral changes that may affect quality of life. Most patients can benefit from having a re-evaluation on an annual basis.

Some anxiety before undergoing this procedure is not uncommon, and may be alleviated by having a family member accompany the patient, taking occasional breaks in testing, and communicating concerns and questions with the consulting neuropsychologist before testing begins.

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*Matthew Nance, Ph.D. is a clinical neuropsychologist in private practice in the Texas Medical Center, Houston, Texas. He is a consulting neuropsychologist for the Alzheimer's Disease Research Center at Baylor College of Medicine. His email is mnan@swbell.net.*

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## Step 4: An Alzheimer's Disease Diagnosis: What Does it Mean?

By Mary M. Kenan, Psy.D.

Alzheimer's is a treatable condition. Effective therapies are available for those with mild to moderate symptoms and those with advanced AD. Establish realistic expectations. Current treatments are intended to stabilize the symptoms of AD, not "reverse" the existing symptoms or halt the disease from progressing. How do you know if the medication is working? If you are no better or worse at checkup. If you do experience some changes in thinking or day-to-day functioning, don't assume your medication isn't helping. You can't know how you would be doing if you weren't on treatment. Stopping the medication is risky. Even if you restart treatment, you may not get the same degree of benefit you had before. Remember, you must be on an effective dose for the medication to work.

Your response to treatment, age, general health, and severity of symptoms at the time of diagnosis may influence how your diagnosis affects you, but aren't predictive. If you are diagnosed with mild AD late in life, are in good health, and respond well to treatment, you may never experience a significant decline or need to depend wholly on others. Why?

AD medications do not extend your lifespan, but they do extend quality of life.

"Dementia" is a category, not a diagnosis. Alzheimer's disease is the most common cause of a dementia. Dementias are categorized as progressive, structural, toxic/metabolic, or infectious because many different medical and psychiatric conditions can cause a dementia that may be misdiagnosed as AD. To determine the cause, a clinician engages in the process of "differential diagnosis", meaning he/she considers all possible causes for the presenting symptoms then chooses the most likely diagnosis from conditions with similar features.

A diagnosis of AD means you have a chronic health condition that warrants routine evaluation and ongoing treatment. Early diagnosis is an opportunity to become educated and make certain lifestyle changes to balance independence with safety and well-being. There is much life after diagnosis. Be proactive and informed.

*Mary M. Kenan is a clinical psychologist with the Alzheimer's Disease Center at Baylor College of Medicine. See pg. 3 for contact information.*

### Education Calendar

#### February

**Partnering with Your Doctor Workshop**  
**Thursday, February 24, 2005**  
 6:30 p.m.-8:30 p.m.  
 Silverado Senior Living  
 1221 7<sup>th</sup> St.; Sugar Land, TX 77478

#### March

**Lectures by Baroness Susan Greenfield**  
 Britain's foremost neuroscientist, and professor at Oxford University

"Does Alzheimer's Disease Have a Future?"  
 Tuesday, March 8, 2005  
 9:00 a.m. to 10:30 a.m. (open to the public)  
 McGovern Museum of Health & Medical Science  
 1515 Hermann Dr. at Crawford  
 Houston, TX 77004

"Neurodegenerative Nature of Alzheimer's"  
 12:00 noon to 1:30 p.m.  
 Baylor College of Medicine, Cullen Auditorium  
 One Baylor Plaza, Houston, TX 77030  
 Target Audience: Healthcare Professionals

#### Lunch and Learn Presentation\*

"Navigating through the Medicaid Maze"  
 Wednesday, March 16, 2005  
 12:00 noon to 1:00 p.m.  
 McGovern Museum of Health & Medical Science  
 1515 Hermann Dr. at Crawford  
 Houston, TX 77004

Target Audience: Healthcare Professionals

#### April

##### Memory Lecture Series

Tuesday, April 12, 2005 - "Mild Cognitive Impairment: Fact and Fiction"

Tuesday, April 19, 2005 - "What to Expect: Understanding Cognitive Changes Associated with Mild Cognitive Impairment"

Tuesday, April 26, 2005 - "Living with Mild Cognitive Impairment: Effective Treatment and Strategies"

7:00 p.m. to 9:00 p.m.  
 McGovern Museum of Health & Medical Science  
 1515 Hermann Dr., Houston, TX 77004

#### May

##### Lunch and Learn Presentation\*

"Brain Stimulation: Environment and Experience"  
 Wednesday, May 18, 2005  
 12:00 noon to 1:00 p.m.  
 McGovern Museum of Health & Medical Science  
 1515 Hermann Dr., Houston, TX 77004

Target Audience: Healthcare Professionals

##### Basic Dementia/Respite Care Training

May 17-May 31, 2005  
 6:00 p.m. to 9:00 p.m.  
 Triumph North Houston Hospital  
 2407 I-45 N. at Little York, Houston, TX 77076

#### June

##### Enhancing Communication Skills with Residents, Staff and Families

June 14, 2005  
 6:30 p.m.-8:30 p.m.  
 Hearthstone at Braeswood  
 2555 South Braeswood, Houston, TX 77025

Target Audience: Experienced Staff

\* \$5 donation requested for Lunch and Learn



### **Best Wishes**

*Goodbye to Development Manager Alexis Eaton, and good luck as she departs to begin a new endeavor! Alexis has coordinated Memory Walk and served as staff liaison to AWARE for nearly four years, and will be deeply missed.*

### **Joint Initiative with Baylor for Mild Cognitive Impairment**

The Alzheimer's Association in collaboration with Baylor's Alzheimer's Disease Center is planning a six-week series to provide educational and practical information for people with mild cognitive impairment (MCI). Topics will include: nutrition, brain health, stress management, alternative therapies, memory enhancement techniques, and more. Call 713-266-6400 for more information.

### **A Call to Volunteers**

As the Association continues to grow, so does our need to find extra helping hands. We need volunteers at many levels. If you have a few hours a week to spare, WE NEED YOU! You can take on a special project, listen to callers and give referrals on the Helpline, help in the office with data entry, assist with fund-raisers and health fairs, or become part of our Speaker's Bureau. Make plans to join our team by calling 713-266-6400.

### **Financial Help is a Phone Call Away!**

The Chapter offers financial help to low and moderate income families. Call 713-266-6400 for Alzheimer's or dementia related needs.

### *Save the Date!*

#### **Swing Into Action**

Save **May 9** on your calendar for the annual **Beaumont Golf Tournament** at Belle Oaks Golf Course. For more information call Debi Brozak at 409-833-1613.

#### **Austin Conference**

"Alzheimer's Care: Innovation and Practice for Everyday Life," sponsored by the Texas Department of State Health Services (TDSH), will cover the latest research, diagnosis, treatment and care, June 16 -18. To register, call the TDSH: 1-800-242-3399.

#### **Conference for Caregivers**

"The Science, Spirit and Sensitivity of Dementia Care" is set for June 23, 2005 from 9:00 a.m. to 2:00 p.m. More details to be announced.

#### **On Our Website:**

Information & Referral · Education & Training Opportunities · Support Groups · Advocacy · The Latest Research · Research Studies Needing Participants · Newsletter Archives

**Visit: [www.alztex.org](http://www.alztex.org)**