

# alzheimer's association

## houston and southeast texas chapter

### What is it Like to Have Alzheimer's?

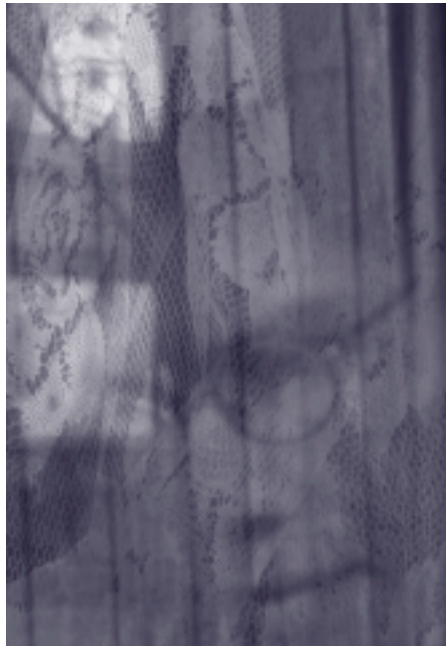
Winter 2004

By Richard Taylor, Ph.D.

What is it like to drive your car from Houston to Anchorage? It depends on the type of the car, the age of the car, how well you kept it up, where you are in your trip, if others are helping you with the drive, if you have enough gas or access to a gas credit card, if you have accepted the fact you must drive to Anchorage, and whether or not you are afraid of arriving in Anchorage.

I was diagnosed with dementia of the Alzheimer's type about two years ago. I imagined, maybe hoped, that some day I would wake up and a heavy velvet curtain would have fallen during the night. I would wake up to a world where I could see shapes but not enough details to know what or who they were, sort of like Plato's flickering shadows on the wall produced by the fire in the cave.

Instead, right now, I am sitting in my grandmother's living room looking at the world through her lace curtains. From time to time, a gentle wind blows them and the patterns through which I see the world change. There are large knots in the curtains and I cannot see



*Seeing the world through the "lace curtain" of Alzheimer's.*

through them. There is a web of lace connecting them to each other around which I can sometimes see. However, this entire filter keeps shifting unpredictably in the wind.

Sometimes I am clear in my vision and my memory, sometimes I am disconnected but aware of memories, other

times I am completely unaware of what lies on the other side of the knot. As the wind picks up it is increasingly frustrating to understand all that is going on around me because access to the pieces and remembering what they mean keeps flickering on and off, on and off.

Thanks in large part to my family caregivers, I am still functioning in the non-Alzheimer's world. I drive, I learn (although I seem to forget much of what I learn), I teach, I love, I mostly understand – but not all the time, and not always the way others do. It is a constant effort to look around the webs and have to put effort into understanding and doing things that came naturally only a few months ago (cooking, reading, driving to a new store, remembering the recent past). Some activities hide beyond the knots and rarely have clarity (arithmetic, reading a watch, remembering what I just read). It is not a lot of fun, but it is doable.

Individuals have a cold, have cancer, and have the measles. Alzheimer's has

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#### Editor's Note:

*This article is the first of a series of articles authored by Richard Taylor, Ph.D. who was diagnosed with Early-Onset Alzheimer's approximately two years ago. Over the next several months, Richard's articles will be posted on our website, a new one appearing every two weeks. Be sure to bookmark our website [www.alztex.org](http://www.alztex.org) in your "favorites" file so you can access Richard's latest essay.*

#### Wishing Our "Purple People" .... Bon Voyage!

The familiar "purple people" have already retired and are enjoying a well-deserved rest. Starting in February 2004, we'll have a whole new look. The Association's new logo will be used both nationally and locally.



HELPLINE:

713-266-6400 ext. 9

24/7 1-800-272-3900

# Research

## Service Dogs for People with Alzheimer's Disease

(Excerpt from October 5, 2003 article by ISRAEL 21c staff)

Polly may look like a regular collie dog - but in fact, she represents a revolution. Polly is the first dog to be trained as a guide dog and companion for people suffering from early-onset Alzheimer's disease, the result of four long years of patient work by a team comprised of an Israeli social worker and a professional dog trainer. She is the first dog in the world to be trained specifically to improve the quality of life for Alzheimer's patients. Yehuda, 62, depends on Polly as a safety net when his memory fails him. Polly accompanies Yehuda wherever he goes, as she has done for the past year. She knows his routines and his habits. If he becomes confused or disoriented, all he has to do is utter the word, "Home," and Polly leads him back to his house.

The concept of an Alzheimer's guide dog began when social worker Daphna Golan-Shemesh was introduced to professional dog trainer Yariv Ben Yosef. "We sat in a room and talked about what we did and immediately a light bulb went off over our heads," recounts Ben-Yosef. "It was clear to us that Daphna's expertise in Alzheimer's and my expertise with dogs could result in something new. We asked ourselves why couldn't we train dogs to help these people, not just as therapy dogs - but as real practical daily assistance." Ben Yosef is confident that Alzheimer's dogs will someday be as common as guide dogs for the blind.

The goal of the Alzheimer's patient guide dog project is an attempt to make the patient's life easier, and in turn, make the life of the rest of his family more manageable.

"Unfortunately, this is a population that gets lost frequently, and as a result, they experience terrible isolation, frustration, anger and a sense of helplessness," explains

Golan-Shemesh. "They find themselves prisoners in their home and completely dependent on other people to allow them to go outside. The problem is that the Alzheimer's patient looks like everyone else. So when you talk to him in the street you can't tell he is sick because he can communicate logically. But as he wanders, and as he gets increasingly lost, and dehydrated, he can panic, and then his cognitive function drops, and it becomes a vicious circle, that sometimes, sadly ends in death."

Alzheimer's dogs don't resemble guide dogs for the blind. The main task of the service dog for an Alzheimer's patient is to bring him home when the order "HOME" is given. If the patient forgets to say the order, and is so lost that he strays too far from the house or wanders into an unfamiliar area, the worried family can activate an electronic device that is installed on the dog's collar and works with a GPS navigation system. In addition, a special tone that can be heard by the dog can be sounded if the pair is not more than 50 kilometers from the house, and the tone also signals the dog to lead his patient home.

After Yehuda and Polly became a success, Ben Yosef and Golan Shemesh joined forces with the Israeli Alzheimer's Association to promote the project. It is now being unveiled to Alzheimer's groups and dog training organizations around the world, and the reception has been enthusiastic.



## Are Two or More Siblings In Your Family Living With Alzheimer's Disease?

If two or more siblings in your family are living with Alzheimer's disease (AD) or severe memory loss, please consider participating in the AD Genetics Study. Families like yours may hold the key to this important research. This is a nationwide study to find genes that play a role in late-life AD and understand how they work. Help to discover more about what causes AD and how we might prevent it for future generations.

*For more information about the study and to learn about volunteering, please contact:*

Toll-free: 1-800-526-2839

E-mail: [alzstudy@iupui.edu](mailto:alzstudy@iupui.edu)

Website: [www.ncrad.org](http://www.ncrad.org)

## Clinical Trial at UT

The University of Texas-Houston is now recruiting patients in a phase II randomized, double-blind, parallel-design clinical trial to determine whether oral IFN-alpha will prevent cognitive decline in individuals with Alzheimer's disease. Eligible subjects include males and females, fifty years old or older with dementia of the Alzheimer's Type for at least one year.



*For more information contact:*

Staley A. Brod  
MD Principal Investigator -  
713-500-7046

Lucie Lambert  
Assistant to Dr. Brod  
713-500-7050  
Email: [Staley.A.Brod@uth.tmc.edu](mailto:Staley.A.Brod@uth.tmc.edu)

# Service Delivery



## AWARE Assistance Programs

Thanks to the ongoing generous support of Houston AWARE, a women's auxiliary of the Chapter, our two financial assistance programs have been fully funded for another year. These two programs, the Carol and Don C. McDonald Emergency Assistance Program and the AWARE Care Assistance Program (formerly known as Family Assistance), have been revised for the coming year due to major reductions in dementia care funding in Texas.

The 2003 Texas Legislative session, in order to balance the state budget, made drastic cuts to social programs serving seniors, including those providing needed benefits to persons with Alzheimer's disease. The CARE program (Community Alzheimer's Resources and Education), funded as part of the Department of Human Services, was eliminated at the end of August 2003. As a result, demand for financial assistance programs across the nonprofit sector has increased. This has forced social service organizations to focus on the most needy and to focus on assistance during life crisis points.

In response to these financial challenges, the Chapter has modified the AWARE assistance programs. These programs are available to persons with dementia who live within the Chapter's 27 county service area. The financial eligibility criteria for the Care Assistance Program have been modified as follows: individuals

can earn no more than \$1496/month, couples can earn no more than \$2000, and recipients must have less than \$7500 in liquid assets. This program can provide up to \$800 in direct financial assistance.

The waiting list for these programs will be prioritized based on financial need. Qualified participants must receive care consultation services designed to assist the family in the care planning process. For further information and to learn more about these programs, please contact Grace Jackson at 713-266-6400, ext. 140, or by email at [grace.jackson@alz.org](mailto:grace.jackson@alz.org).

## Alzheimer's Recreation Training and Service (ARTS)

The Alzheimer's Association Houston and Southeast Texas Chapter has been awarded a grant from the Harris County Area Agency on Aging to pilot an activity program, starting in January 2004, that promotes the highest level of functioning for individuals in the early to early-middle stages of Alzheimer's. Participants will have an opportunity to utilize their skills through volunteerism, educational seminars, and social activities during this monthly program. If you are interested in participating and/or learning more about this exciting new initiative, please contact Grace Jackson at: [grace.jackson@alz.org](mailto:grace.jackson@alz.org) or 713-266-6400 ext.140.

## New in Beaumont

### *Enjoying a Morning Out*

The Morning Out Club is a partnership between the Alzheimer's Association's Beaumont office and Trinity Methodist Church. This is a new weekly program, starting in mid to late January, for individuals in the early stage of Alzheimer's or a related disorder. In addition to a morning off, care partners are offered monthly support groups and educational programs. Goals for this exciting new collaborative program are as follows:

- Encourage independence and stimulate cognitive skills
- Provide a safe and supportive environment with opportunity for socialization
- Reduce care partner stress
- Meet spiritual needs of program participants

*For more information about The Morning Out Club or to register, contact:*

Kim Anderson, Director of Christian Education and Program Ministries  
Trinity United Methodist Church  
3430 Harrison Avenue  
Beaumont, TX 77706  
409-892-8121 ext. 123

The chapter is grateful to Trinity Methodist Church and The H.E. and Kate Dishman Foundation for their support of the Morning Out Club.

### HELPLINE:

**713-266-6400 ext. 9**  
**24/7 1-800-272-3900**

# Funding Our Mission



*George Foundation Awards \$31,000 Grant for Outreach in Fort Bend County. Richard Elbein, CEO and Ann Schmitt, President Elect receive a check from Dee Koch, George Foundation Grants Officer (right).*

## Turn your Clunker into Cash!

Through a partnership with Car Program, L.L.C., the Chapter can now accept donations of used automobiles. Through this partnership, Car Program will pick up your car, sell it, and then donate 70% of the proceeds to the Chapter. Your car must be in working order and its value must exceed the cost of towing. If you would like to donate a used vehicle to the Chapter, contact Maria Magee at 713-266-6400, ext. 123.



*The Alzheimer's Association is proud to participate in the Youth In Philanthropy program with Hightower High School. Thank you to Hightower, the Fort Bend Chamber of Commerce, and the George Foundation for making this partnership possible.*



*(left to right) CEO Richard Elbein, Board member Nancy Carlisle and Beaumont Advisory Board member Linda Domino at the Beaumont Memory Walk.*



Thank you to our foundation and corporate funders:

***The George Foundation***  
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Thank you to our Education Conference Underwriters:

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Our continuing thanks to:

***St. Luke's Episcopal Health System***  
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## Record-Breaking Success

Supporters of the Alzheimer's Association put on their walking shoes in September, October, and November and participated in six Memory Walks in Southeast Texas to raise funds for our chapter.

- A record-breaking crowd of over 1100 people raised an astonishing \$157,000 at the sixth annual Houston/Ft. Bend Memory Walk honoring Helen and Roy Cordes. Kudos to Memory Walk chair Kathy Rose and her daughter Kristine, Junior Chair!
- On September 27, over 125 people participated in the second annual Northwest Houston Memory Walk held at the Texas Sports Medicine Center in Tomball.

## Houston AWARE Family Portrait Luncheon 2003

Featured speaker, Lady Henrietta Spencer-Churchill, impressed the group of 450 luncheon attendees who gathered for the fourth annual Houston AWARE Family Portrait Luncheon on November 17. Her presentation on "Saving Memories" incorporated her interior design expertise with the history of her family. Luncheon chairs, Cindi Blakely and Betty Newton, exceeded their goal – raising over \$257,000 to provide care assistance and emergency respite aid to families in our twenty-seven county service area. Many thanks to all of the generous underwriters of the luncheon and especially to the major underwriter, **The Ellwood Foundation!**



(Left to Right) Luncheon committee members Kay Hedges, Co-Chairs, Betty Newton and Cindi Blakely, Nancy Burrow, AWARE President, Betty Conner, and Jeanne Moses.

- Leon County supporters led by support group leader, Bill Johnston, hosted a Memory Walk at Highland Lakes on October 4.
- The Baytown Pilot Club held their most successful Memory Walk ever on October 18, raising over \$19,000!
- The Bryan/College Station Memory Walk & Run on November 8 went off without a hitch thanks to Chairman, Debbie Scott, and raised over \$10,000!

- Braving chilly conditions, over 160 supporters walked in the Southeast Texas Memory Walk at the Crockett Street Entertainment District in Beaumont on November 8. Chairs Tammy Novak and Jim Vincent led an outstanding committee and raised over \$22,000!

Special thanks to our National Memory Walk 2003 sponsors: Creative Memories and GE Financial Long Term Care Insurance. At the Houston /Ft. Bend Memory Walk, GE agents, led by GE Champion Rebecca Ponder, raised over \$10,000! Hats off to all our sponsors for their ongoing support and participation!

# Legal/Advocacy



The Alzheimer's Association, as part of our core programs, is involved with advocacy. Advocacy is defined as speaking up for the needs and rights of individuals with Alzheimer's disease and their families. Advocacy can take many forms: local action, such as speaking out about community-based care; improving nursing homes and other residential settings; expanding funding for public programs serving people with dementia; working with bureaucrats to improve the health-care delivery system for people with dementia and lobbying state and federal legislators to improve funding for dementia care and research, and to tighten laws requiring dementia care training. These are just a few of the many opportunities available when you become involved in Alzheimer's Advocacy.

If you are willing to become involved in some small or large way – from sending an email, writing a letter, or making a phone call, to planning a visit to your elected officials or participating in a planned day at the state capital – we need your help! Please join us by adding your voice to the thousands of others across our state. Give us your name, address, phone, and email. We are looking for advocates at every level of involvement.

Contact **Grace Jackson** at **713-266-6400 ext. 140**, or via email at **grace.jackson@alz.org** to help speak up for those who cannot.

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## THE FORGETTING: A Portrait of Alzheimer's

On January 21, 2004, at 8:00 p.m., HoustonPBS Channel 8, along with Public Broadcasting Service stations throughout the country, will air *The Forgetting: A Portrait of Alzheimer's*, based on the critically acclaimed book of the same name by David Shenk.

The centerpiece of this special production is a 90-minute documentary offering an all-encompassing look at a disease that 95% of Americans feel is a serious national problem. The primetime national broadcast will weave together powerful portraits of families with the science of this challenging disease, its imprint on human history and the current quest to find a cure. Following this powerful portrait of Alzheimer's will be a localized half-hour show airing at 9:30 p.m. designed to answer practical questions and point audiences to valuable community resources.

Increase Understanding, Reduce Fear,  
Diminish Isolation

- Nearly five million Americans currently suffer from Alzheimer's disease, which can last up to 20 years.
- The 10-15 million caregivers in this country are often driven into "exhaustion, depression and bankruptcy."
- Alzheimer's is poised to reach epidemic proportions in 2011 when the first of America's 78 million Baby Boomers turn 65.

From the PBS special, *The Forgetting: A Portrait of Alzheimer's*



Area professionals featured in local Alzheimer's program, from left to right: Psychologist Robert E. Reichlin, Ph.D., Attorney Gina D. Patterson, Rachelle Doody, M.D., Ph.D., Director of the Alzheimer's Disease Research Center, Baylor College of Medicine, and The Reverend Dr. Helen W. Appelberg, Visiting Scholar at UTMB, Sealy Center.

Throughout the evening, telephone volunteers will be on hand in the Channel 8 studios to answer questions and direct callers to local resources. Viewers will also be able to request resource packets developed especially for the Houston area. This informative documentary will be broadcast on **Channel 8 from 8:00 -10:30 p.m. on Wednesday, January 21, 2004**. For additional information or to view a short video clip, visit the Association's website at **www.alztex.org**.

# VIEWPOINT

## The Heart of the Matter

By Robert E. Reichlin, Ph.D.

We all know that Alzheimer's is a disease- it's a brain disease, chronic, progressive, terminal. It happens inside someone's head. There are amyloid plaques, neurofibrillary tangles, neuronal death.

But is AD really about the brain? Or, putting it another way- is that the best way to characterize this disease?

I ask this because I think that AD, while a brain disease, is really about the heart, not the brain. I say this fully knowing that in the highly medicalized approach that we take toward AD, it seems unlikely that the disease could be about something else. But, that's the funny thing about AD. Just when you think you understand what's happening, something unexpected occurs.

Think for a moment about treatment. What are our treatments for AD? Well, we have a number of medications that seem to provide support for a failing neurotransmitter system. We can treat other, non-cognitive illnesses in support of good health as well as psychological reactions to the disease... But, that's it. That's it as far as medicine can take us.

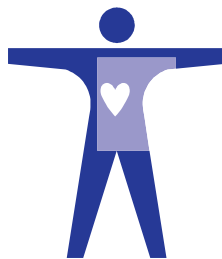
Yet, we all know there is another kind of treatment, treatment that is called caring. Caring isn't about the brain, it's about the heart. Our caring supports the personhood of the person, our caring provides a social context for the maintenance of self in the face of growing losses. Our caring preserves our sense of self in the face of our experiences of helplessness and heart-break as carers.

Caring is not about control. There is no behavioral management of Alzheimer's disease. We don't manage people's behavior. Honestly now, have you ever tried to manage a child's behavior? Why would we ever imagine we can manage an adult's? We can restrict people's behavior, however.

And, we do that sometimes to take care of ourselves rather than the person with the disease. Caring is about optimal responsiveness – doing the right thing at the right time.

Alzheimer's is about the heart, not the brain. When a person with this illness talks of overcoming stigma, of fearlessly acknowledging their difficulties, of refusing to give in – that's a matter of the heart, not the brain. What is most destructive to a person with AD? To be treated as if he or she was no longer a person, an adult. Tom Kitwood described such behaviors as a malignant social psychology that undermines the person's sense of viability and selfhood. To extend the metaphor just a little bit further, we could call such behavior – heartless.

Alzheimer's is about the heart, not the brain. It is your care, your contributions of love, time, energy, hope, and money that resonates with those afflicted with AD. Caring isn't sexy, you can't get grant money for it. But, when all is said and done, caring is what we human beings give to those who we love and respect.



## Mission Statement

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

## EDUCATION CALENDAR 2004

The following educational programs have been designed for specific target audiences. Please check our website [www.alztex.org](http://www.alztex.org) or call **713-266-6400** for more details.

**January 28, 2004, (12:00 noon to 2:00 p.m.)**

Brown Bag Presentation

### Current Trends in Person-Centered Dementia Care

Target Audience: Health care professionals

**February 7, 2004, (1:00 p.m. to 3:00 p.m.)**

Community Workshops in 7 locations

### Partnering With Your Doctor

Target Audience: Diagnosed individuals and their care partners

**February 11, 2004, (10:00 a.m. to 12:00 noon)**

### Alzheimer's: More Than Memory Loss

Target Audience: Recently diagnosed persons and their care partners.

**February 17-26, 2004, (6:00 p.m. to 9:00 p.m.)**

### Basic Dementia Care Training and Hands-On Instruction

Target Audience: Respite aides, in-home care staff, personal care attendants, family care partners, etc.

**February 24, 2004, (9:30 a.m. to 11:00 a.m.)**

### Houston AWARE Education Seminar

St. Martin's Episcopal Church

Target Audience: General public

**March 17, 2004, (12:00 noon to 2:00 p.m.)**

Brown Bag Presentation

### What the Future Holds for Medicare and Medicaid

Target Audience: Family care partners and health care professionals

**April 13, 2004**

Houston AWARE Annual Membership Coffee

**April 14, 2004, (10:00 a.m. to 12:00 noon)**

### Alzheimer's: More Than Memory Loss

Target Audience: Recently diagnosed persons and their care partners

## Partnering with your Doctor

*A Workshop for Persons with Memory Problems and Their Care Partners.*

Have you ever come away from an appointment with your doctor wanting more time to get your questions answered, or have you felt rushed, or been unsure of what was said?

A nationwide survey, commissioned by the Alzheimer's Association in May of 2001, revealed that although 88% of physicians believed they were providing the necessary advice and recommendations to care partners, only 33% of the care partners surveyed felt that they were receiving the information they needed from their primary care physicians.

If you, or someone you care for has memory problems, developing a partnership with your physician and improving communication skills can result in increased knowledge of the situation and less stress. This can help you make informed decisions about care and services.

The Alzheimer's Association Houston and Southeast Texas Chapter will be introducing a new, two-hour workshop *Partnering with Your Doctor: A Workshop for*

*Persons with Memory Problems and Their Care Partners.* Starting in February, this workshop will be offered free as one of the chapter's ongoing education classes.

Workshop participants will learn eight strategies to make the best use of time with their doctors. The goal of the Alzheimer's Association is to improve and enhance how patients, care partners, and physicians relate in the care setting. The workshop will help patients and care partners:

- Improve communication with their doctors
- Improve how the patient and care partner work together
- Get organized and prepared for doctors' visits
- Reduce their stress levels
- Ensure the best health care possible for their loved ones

If you are interested in attending this two-hour workshop, check out our website [www.alztex.org](http://www.alztex.org) for specific times and locations. On Saturday, February 7, 2004 this new workshop will be offered at multiple sites in Houston and surrounding areas.

713-266-6400 or 800-272-3900(24/7)

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## alzheimer's association

**houston and southeast texas chapter**

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