



Summer 2003



# Texas Alzheimer's News

A collaborative effort of the Texas Council on Alzheimer's Disease and Related Disorders  
and the Alzheimer's Association Coalition of Texas

## Health Care and the Information Age *The Changing Face of the Doctor-Patient Relationship*

Calling Dr. Welby!

Times have changed when it comes to visiting the doctor. Remember when you saw your doctor but once a year for your physical? He checked your vital signs, told you the numbers looked good, maybe to lose a few pounds, and then told you he would see you in a year. Chances are you may not have asked many questions. The doctor said you were fine and that is all you needed to know. Your role was the recipient of care.

With the advent of the World Wide Web, the hoards of health promotion books and magazines, the ever-present phone in radio shows, the growing trend of virtual doctors, and now mobile technology, consumers are inundated with health information. Descriptions and treatment options for a myriad of diseases from A through Z are literally at your fingertips. This increased access to health

information has changed the face of the doctor-patient relationship.

Traditionally, the physician was the sole source of medical information. He or she took the lead and the patient followed. Today, health care is a team effort. The team may include other doctors, nurses, physician assistants, pharmacists, occupational, physical and/or speech therapists, and must include the patient. Innovations in technology have led to a much better informed consumer, which in turn has redefined the patient's responsibility in the management of his or her health. Some have described this evolution as the rise of the health care consumer and person-centered decision-making, advocating that the power of information in the hands of consumers enables them to make more informed health decisions when visiting or consulting with their doctor.

### *Panacea or problem?*

Proponents of the more informed health care consumer assert that the single most important way to stay healthy is to become an active member of your own health care team. The multitude of resources now available has allowed individuals to become more proactive in their health care, particularly in terms of learning about their specific condition and treatment

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options. As the responsibility for learning about the disease and current developments in treatment has become more shared between patients and their doctor, a deeper level of doctor-patient interaction is possible. Patients are far more likely to approach their doctor with information and questions, and negotiate treatments, rather than taking a passive role. Information can be very empowering.

Those more skeptical of the diffusion of innovation may compare the Internet and its huge repository of rapidly accessible information to early descriptions of television as the vast wasteland. Concerns range from the integrity of information presented to problems with self-diagnosis and self-medication. The most documented concern is that information gleaned from the Internet is not always accurate. To date, protocols for evaluation of the information have been highly individual. There are, however, a number of guidelines available to help discern whether the information is valid and reliable. A partial listing of Web sites to help evaluate the validity and reliability of Internet information is listed at the end of this article.

There is also concern that a patient may convince himself that he has a particular disease because he has experienced many of the symptoms listed under said disease. This may be further compounded by the patient's plan to self-medicate based on his own diagnosis. Calling Dr. Welby, we need your able assistance!

The relative pros and cons of health care and the Information Age continue to be debated. What is evident is that new technology and faster access to information have transformed the role consumers play in their own health care. Becoming more informed and taking an active role in decisions made about your care is **your right** and **your responsibility**.

Here are three things to keep in mind when searching the Internet for health information. Make sure:

- The information is valid, reliable, and intended for educational purposes only,
- It does not replace the advice and expertise of your doctor/health care team, and
- It helps you to become a more active participant in your own health care.



## Web Sites to Help Evaluate Validity and Reliability of Internet Information

One way to get good health care is to find and use quality health information and take an active role in all of the decisions made about your care. Below is a partial listing of Web sites intended to help the consumer evaluate the validity and reliability of Internet information.

<http://healthweb.org/eval.cfm>

Links to Web resources and references to articles that will assist in the evaluative process.

[www.lawpublish.com/ftchealt.html](http://www.lawpublish.com/ftchealt.html)

Full-text reproduction of the Federal Trade Commission's "Fast Facts for Consumers: Health Claims: Separating Fact from Fiction."

<http://hitiweb.mitrettek.org/docs/policy.html>

Policy paper titled "Criteria for Assessing the Quality of Health Information on the Internet." Presents set of seven criteria developed for use in evaluating the quality of health information provided on the Internet.

[www.librarysmart.com/working/LSPublic/01\\_evaluate.asp](http://www.librarysmart.com/working/LSPublic/01_evaluate.asp)

Tools to evaluate information for reliability and accuracy.

# Best Practices

## Making the Most of Your Doctor Visits

The patient is a vital member of the health care team. Integral to being an effective team member is establishing a partnership with your primary care doctor.

Here are some tips to help you and your doctor become partners in improving your health care.

**1. Be Prepared.** Take these items with you when you visit your doctor:

- ◆ A list of all the medications you are currently using and/or you can take your medications with you in a large sealable plastic bag. Your list should include when and how often you take the medications and their strength. Be sure to mention any herbal products, vitamins, or over-the-counter medicines you are using. Your doctor can determine whether there are possible interactions. It's a good idea to carry a list of your medications with you at all times, along with your doctor's name, address and phone number.
- ◆ Your updated medical history. If you have had any recent X-rays or medical tests,

ask that the results be sent to your doctor prior to your visit.

- ◆ A list of any recent symptoms you may have experienced. You may want to jot these down on a calendar.
- ◆ Your top three questions or concerns.

**2. Give Information.** You know important things about your symptoms and your health history. Tell your doctor what you think he or she needs to know. Bring the items listed above and talk about your biggest concerns first. By giving information, this will help you get information.

**3. Get Information.** This is the reason for your visit. Here is what you need to do:

- ◆ **Ask questions.** Your doctor may think that you understand everything that is said during the visit if you do not ask questions. You may also find it helpful to jot down some questions before your visit. Here are some examples of questions you may want to ask:
  - What's wrong with me?
  - What treatment do you recommend?
  - What medicines are you giving me? What are they for? Are there any side effects?
  - When should I come back for a follow-up visit?
  - When is the best time to call you with any questions?

◆ **Take Notes.** Write down the answers to questions you ask. Jot down any instructions. You may want to bring a family member or friend to the office visit. He or she can take notes for you.

◆ **Take Information Home.** Ask for pamphlets or brochures that may help explain your condition. Ask for written instructions.

◆ **Clarify and Confirm.** If you do not understand something, ask your doctor to explain it. You may want to repeat what you think he has said in your own words to confirm your understanding.

**4. Follow-up.** Once you leave the doctor's office, call:

- If you have questions.
- If your symptoms get worse.
- If you have problems with your medication.
- If you had tests and the doctor has not called with the results, within a reasonable amount of time.
- To schedule appointments for recommended tests and referrals to specialists.

Maintaining a good doctor-patient relationship with open communication is an important part of good health care. Remember to ask questions and share your point of view. You are, after all, a very important member of the health care team.

# Outcomes of the 78<sup>th</sup> Texas Legislative Session

by Sarah Jackson

The 78<sup>th</sup> Legislative Session began with many new faces. David Dewhurst was sworn in as Lieutenant Governor and the House of Representatives elected Tom Craddick as Speaker of the House. In addition, there were a large number of first time legislators. Comptroller Carol Keeton Strayhorn announced a \$9.9 billion budget deficit in January. Advocates for a variety of causes fought hard to keep programs funded. The end result, after Governor Rick Perry assigned Federal Aid funds, has led to the following changes in long-term care:

- Community Care entitlement programs, also known as Primary Home Care, will cut client services by 15% in 2005.
- Community Care waiver programs, also known as Community Based Services (CBA), will have no new slots available to future clients and a lower total number of clients will be served through attrition by the end of 2005.
- Medicaid Providers, including physicians, hospitals and nursing homes, will have rate cuts from 2.5% to 5%.
- A variety of state funded programs were cut. The most devastating to individuals

with Alzheimer's disease and their caregivers includes respite care services and the Community Alzheimer's Resources and Education Program (CARE). With the exception of the San Antonio and Harlingen areas, which were funded for one more year, all other CARE programs will cease to exist as of September 1, 2003.

Alzheimer's advocates worked hard to pass HB 776 that requires one hour of annual training in dementia care for nurses and nursing assistants who work in nursing facilities. That bill will take effect September 1, 2003.

HB 2292 will require a major consolidation of Health and Human Service Agencies. The current 11 agencies will merge to form four new agencies. The Health and Human Services Commission (HHSC) will remain an oversight agency and take over the responsibilities of eligibility services currently handled by the Department of Human Services. The four new agencies will be:

- ◆ Department of Aging and Disability Services
- ◆ Department of State Health Services
- ◆ Department of Family and Protective Services

- ◆ Department of Assistive and Rehabilitative Services

HHSC is required to deliver a transition plan to the Governor and Legislative Budget Board on December 1, 2003. The Commission is required to conduct hearings on the plan before it is adopted. Effective dates regarding transfer of functions and other key activities will be established in the transition plan.

For more information on the consolidation process and when individuals may provide public comment, visit the Health and Human Services Commission Web site at:

[hhscx.hhsc.state.tx.us/cons/trans\\_home.html](http://hhscx.hhsc.state.tx.us/cons/trans_home.html).

*Sarah Jackson is Public Policy Director for the Alzheimer's Association Coalition of Texas.*



## **Prescription Drug Proposals Under Medicare** **Article from the National Alzheimer's Association**

At the end of June, both the U.S. House and Senate passed legislation to provide a Medicare drug benefit. In crafting prescription drug legislation, Congress is operating with the constraint of a \$400 billion limit over 10 years. This overall budget constraint has led to a delay in implementation. Neither the House nor the Senate bill provide access to a prescription drug benefit until 2006, placing consumer reliance on discount cards until the actual drug benefit becomes available in 2006.

In addition, the budget limit will allow the new program to cover only about one-quarter of prescription drug costs for Medicare beneficiaries (estimated to be \$1.8 trillion between 2005 and 2014.) Because of this limit, there are coverage gaps in both bills.

To compare the two bills, below are four scenarios of drug coverage for beneficiaries with different drug costs. The two middle cost scenarios could be particularly relevant for persons with Alzheimer's disease. Average annual drug costs for people with Alzheimer's disease are estimated to be approximately \$3000 (Johns Hopkins University). A \$4500 cost scenario is also given as an estimate of drug costs if a new therapeutic treatment, costing \$125/month, came on the market.

<b>Annual Drug Cost</b>	<b>\$1500</b>	<b>\$3000</b>	<b>\$4500</b>	<b>\$12,000</b>
<b>Senate Bill</b>				
Deductible	\$275	\$275	\$275	\$275
Premium	\$420	\$420	\$420	\$420
Beneficiary's Share of Initial Coverage	\$613	\$1363	\$2113	\$2113
Gap in Coverage	—	—	—	\$1312
Beneficiary's Share of Catastrophic Costs	—	—	—	\$619
<b>Total Cost to Beneficiary</b>	<b>\$1308</b>	<b>\$2058</b>	<b>\$2808</b>	<b>\$4379</b>
<b>House Bill</b>				
Deductible	\$250	\$250	\$250	\$250
Premium	\$420	\$420	\$420	\$420
Beneficiary's Share of Initial Coverage	\$250	\$350	\$350	\$350
Gap in Coverage	—	\$1000	\$2500	\$2900
<b>Total Cost to Beneficiary</b>	<b>\$920</b>	<b>\$2020</b>	<b>\$3520</b>	<b>\$3920</b>

\$3000 is average cost for person with Alzheimer's disease

\$4500 is projected average cost for person with Alzheimer's disease with new Alzheimer's treatment

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The Henry J. Kaiser Family Foundation has created a “benefit calculator” to determine coverage under the House and Senate bills. To estimate your drug costs using their calculator, go to:

[www.kaisernetwork.org/static/kncalc.cfm](http://www.kaisernetwork.org/static/kncalc.cfm).

The following outlines some differences in the House and Senate bills:

**Senate Version:**

- ◆ Prohibits low-income Medicare beneficiaries who are also on full Medicaid – the so-called “dual-eligibles” – from participating in the new Medicare drug benefit. States would remain responsible, under current law, for providing drug coverage through the Medicaid program to these Medicare beneficiaries.
- ◆ Provides a fall-back provision whereby the government would provide coverage in absence of a private plan.
- ◆ Maintains traditional fee-for-service Medicare.

**House Version:**

- ◆ Provides drug benefits to the Medicaid “dual-eligibles” through Medicare.
- ◆ Does not include a guaranteed federal “fallback” with a defined benefit and defined premium to ensure that a drug benefit will be delivered in areas of the country where private plan options do not

exist.

- ◆ Requires traditional Medicare fee-for-service to compete against private plans based on price beginning in 2010.

The next step in the congressional process is for a Conference Committee, composed of both Senators and Representatives, to reconcile differences in the two bills.



**Memory Walks  
Across Texas**

It’s almost fall and that means Alzheimer’s Association chapters and regions are busy planning their annual Memory Walk events. Each year thousands of individuals participate in this event across the state and the nation, helping to raise funds for vital research and community services. Memory Walk is the Association’s premier national event to increase public awareness and raise funds for Alzheimer’s disease. Listed below are some of the scheduled events. For information on Memory Walks in your area, please contact the Alzheimer’s Association closest to you.

**Greater Austin Walk**  
Saturday, September 20  
Auditorium Shores  
8:30 am

**Temple Walk**  
Saturday, September 27  
Old Raquet Club  
8:30 am

**Dallas Memory Walk**  
Saturday, November 1  
Dallas Zoo

Ellis County Memory Walk  
Saturday, September 13  
Lions Park Nature Trail,  
Waxahachie

**Denton County Memory Walk**  
Saturday, September 20  
Lewisville Senior Activities  
Center

**Sherman Memory Walk**  
Saturday, September 27  
Fairview Park, Sherman

**Cooke County Memory Walk**  
Saturday, October 4  
Heritage Park Depot Days  
Celebration, Gainesville

**Fannin County Memory Walk**  
Saturday, October 4  
Town Square, Davy Crockett  
Days Celebration, Honey Grove

**Gunter Memory Walk**  
Saturday, October 11  
Hilltop Haven Christian Care  
Center

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**McKinney Memory Walk**  
Saturday, October 25  
Kingsley Place at Stonebridge  
Ranch

**Houston Memory Walk**  
Saturday, October 25  
AMC Theaters, Sugar Land

**Memory Walk on the Trinity**  
Saturday, September 13  
Trinity Park Shelter, Ft. Worth  
Registration – 8:00 am  
Walk – 9:00 am

**Memory Walk – Wichita  
Falls**  
Saturday, September 13  
MPEC – 1000 5<sup>th</sup> Street  
Registration – 8:00 am  
Walk – 9:00 am

**Memory Walk – Arlington**  
Saturday, September 20  
Sonny Bryan’s Pavilion @ the  
Ballpark  
Registration – 8:00 am  
Walk – 9:00 am

**Memory Walk on the Brazos**  
Saturday, October 4  
Silverado Ranch, Weatherford  
Registration – 8:00 am  
Walk – 9:00 am

**Memory Walk – Abilene**  
Saturday, October 11  
Nelson Park  
Registration – 8:00 am  
Walk – 9:00 am

## Alzheimer’s Association Chapters and Regions in Texas

**Capital of Texas Chapter**  
3420 Executive Center Drive  
Austin, TX 78731  
1.800.367.2132 or 512.241.0420

**Greater Dallas Chapter**  
7610 Stemmons, Suite 600  
Dallas, TX 75247-4288  
1.800.515.8201 or 1.214.827.0062

**Denton Region**  
PO Box 310919  
Denton, TX 76203-0919  
940.565.3450

**Sherman Region**  
1117 Gallagher, Suite 210  
Sherman, TX 75090  
903.813.3506

**Houston and Southeast Texas  
Chapter**  
3903 West Holcombe Blvd.  
Houston, TX 77025  
1.800.266.8744 or 713.266.6400

**Beaumont Region**  
440 North 18<sup>th</sup>  
Beaumont, TX 77707  
1.800.449.1613 or 409.833.1613

**North Central Texas Chapter  
Fort Worth Region**  
101 Summit Avenue  
Ft. Worth, TX 76102  
1.800.471.4422 or 817.336.4949

**Abilene Region**  
1926 Campus Court  
Abilene, TX 79601  
1.888.511.4132 or 915.672.2907

**Heart of Texas Region**  
3708 West Waco Drive  
Waco, TX 76710  
1.866.753.7722 or 254.753.7722

**Wichita Falls Region**  
901 Indiana, Suite 350  
Wichita Falls, TX 76301  
1.877.322.6259 or 940.767.8800

**STAR Chapter  
El Paso Region**  
4400 N. Mesa, Suite 9  
El Paso, TX 79902  
1.877.544.1799

**Amarillo Region**  
2200 West 7<sup>th</sup> Street  
Amarillo, TX 79106  
1.800.687.8693 or 806.372.8693

**Harlingen Region**  
1000 Camelot Drive  
Harlingen, TX 78550  
1.800.509.9590 or 956.440.0636

**Midland Region**  
4400 N. Big Spring #C-32  
Midland, TX 79705  
1.800.682.1174 or 915.570.9191

**Nacogdoches Region**  
PO Box 630636  
Nacogdoches, TX 75963  
1.800.246.7888 or 936.569.1325

**San Antonio Region**  
7400 Louis Pasteur  
San Antonio, TX 78229  
1.800.523.2007 or 210.822.6449

## In Tribute

Long time Alzheimer's Council member, Grapevine physician, colleague and friend, Dr. Minnie Lee Lancaster passed away on April 15. She died at home after suffering a heart attack while preparing to go to work. She was 79.

Born to Methodist missionary parents in the Belgian Congo, Dr. Lancaster lived a life of service to her community, her church, and her family. She was raised in Bay City, graduated from the University of Texas at Austin, and completed her medical studies at the University of Texas Medical Branch in Galveston, where she met her husband, Dr. Ed Lancaster. In 1953, the Lancasters moved to Grapevine, where they had been practicing medicine for 50 years. Dr. Minnie Lee, as she was affectionately referred to by Grapevine residents, was determined to give her community a state-of-the-art hospital...and her vision was realized. Her death came just months before dedication ceremonies for the new six-story Ed and Minnie Lee Lancaster Patient Tower at Baylor Medical Center in Grapevine. The tower will be the central feature of a hospital that grew from a small clinic started by the Lancasters in the 1960s to its current status as a regional medical center.

Dr. Lancaster is remembered for her ability to relate well to her patients, spending time with them and getting to know each person so she could better help them. She was said to have practiced medicine throughout her career with intelligence and compassion. These traits were evident in her work on behalf of people with Alzheimer's disease, during her tenure on the Texas Council on Alzheimer's Disease and Related Disorders. You could rely on Dr. Lancaster to bring discussions down to earth, infusing the practical into the vision. She was a tireless advocate for the thousands of Texas families affected by Alzheimer's disease.

Dr. Lancaster was also recognized as a strong spiritual leader, having served her church in many capacities, traveling on several missions, and participating in numerous prayer teams. The evening before her death, she hosted a women's ministry group at her home.

Dr. Lancaster was a devoted wife, mother and grandmother. In the last five months of her life, she suffered two profound losses, with the passing of two of her five children.

Dr. Minnie Lee will be remembered for her vision, her pragmatism, her cheerfulness, her exemplary service to her church and community, and her devotion to her family. As Mayor William D. Tate, who delivered the eulogy at her funeral attended by some 850 family and friends, so aptly expressed, "You rarely see all those qualities in one package." We will miss you, Dr. Minnie Lee.



***About the Texas Council  
on Alzheimer's Disease  
and Related Disorders***

The Council was created by legislative mandate in 1987 to serve as the state's advocate for persons with Alzheimer's disease and those who care for them. Members are appointed by the Governor, the Lieutenant Governor, and the Speaker of the House to coordinate statewide research and education efforts, and to disseminate information on services and related activities available for persons with Alzheimer's disease to the medical and academic communities, family and professional caregivers, and the public.



***About the Alzheimer's  
Association Coalition of  
Texas (AACT)***

The Coalition represents the five chapters and 12 regional offices of the Alzheimer's Association in Texas. The Alzheimer's Association is a national voluntary health organization founded in 1980 to provide information and services, including a telephone help line, family support groups, educational programs, a lending library, the Safe Return program for wanderers, in-service training, and multicultural outreach programs. The mission of the Coalition is to advocate for the improved quality of life for Texans affected by Alzheimer's disease and related disorders.

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**Editor**

Elaine Braslow, MEd  
800.242.3399 or 512.458.7534

For more information on Alzheimer's disease, to be placed on the newsletter mailing list, or to change your mailing address, please call 800.242.3399. There is no cost to subscribe. Newsletters are also posted on the Internet at [www.tdh.state.tx.us/alzheimers/alz.htm](http://www.tdh.state.tx.us/alzheimers/alz.htm).

Viewpoints expressed in this newsletter do not necessarily reflect those of the Texas Council on Alzheimer's Disease and Related Disorders or the Alzheimer's Association Coalition of Texas.