As another year comes to a close, we can note some exciting progress that has been made with people with Alzheimer’s disease or a related disorder speaking out and making their feelings, experiences, wisdom, and needs both heard and affirmed. *Perspectives* has reported on web sites, conferences, personal testimonies, written resources, and many national and international advances in empowering people with Alzheimer’s to have a voice in shaping their quality of life and connecting with one another.

One of the most recent examples of this exciting trend is a conference held on October 27th at the Skirball Auditorium in Los Angeles. Richard Bozanich and Jay Smith met in a support group for people with dementia in August, 2006. They had read an article in *Perspectives* about the 5th annual conference by and for people with Alzheimer’s in New York and inspired by the prospect of such an event, asked themselves why they couldn’t put together a conference of their own in Los Angeles. Over a year later and as a result of much collaborative planning with the California Southland Chapter of the Alzheimer’s Association, Richard and Jay realized a dream and the extraordinary outcome of some very hard work.

The conference sold out its capacity to seat 350 people and planners note that a few hundred people had to be turned away from both local and distant regions. The audience included over 200 people with dementia as well as professionals, family members and those interested in learning more about the issues.

Richard and Jay cast a broad net in being inclusive of people with all forms of dementia including Mild Cognitive Impairment (MCI) Frontotemporal Dementia (FTD), atypical dementias, and the “worried well” with the belief that there is more common ground than differences between these groups. They noted that at times, some conference attendees without dementia still struggled with the belief that people with dementia could really be speaking about their condition with clarity and conviction. Speakers defied the old prevailing stereotypes that people with dementia have little insight into their symptoms.

The conference had a series of breakout sessions that allowed for a diverse array of (continued on page 2)
Early Memory Loss Forum  
(continued from page 1)

topics and issues to be discussed. Breakout sessions included communication and relationships; complementary therapies; current and future treatments; legal and financial issues; living with early memory loss; partnering with your doctor; redefining early-stage dementia; and stimulating the brain.

In her illuminating article on the conference, Gabrielle Strobel of Alzforum provides some paraphrased samples of quotes from the conference participants on a wide range of issues. Participants spoke of challenges in receiving an accurate diagnosis and how frustrating it can be to try to communicate with one’s doctor. They discussed how they coped with the diagnosis once it was given, and how family and friends could assist in helping everyone to cope more effectively. Patience and acceptance were common themes. To read this article and the selected quotes from some of the conference participants, see the excellent Alzforum website at http://www.alzforum.org/new/detailprint.asp?id=1675.

During the conference, the National Alzheimer’s Association held a brief Town Hall Forum (see page 7 for more information about these Forums) facilitated by Mike Splaine, Director of the Association’s State Policy and Advocacy Programs. Conference participants were able to voice their opinions and concerns on a number of topics. Richard and Jay both observed that many people were able to voice their thoughts and “feel as if they still mattered.” Richard states, “A lot of people got up who never had a voice before.”

The conference also hosted Story Corps, a national oral history project. Through its Memory Loss Initiative, Story Corps aims to collect stories from persons with memory loss to be archived at the Library of Congress’ American Folklore Center. See http://www.storycorps.net for this wonderful program. A number of conference participants were afforded the opportunity to do interviews with Story Corp during the conference.

The Early Memory Loss Forum included an overarching message of a call to action for people with Alzheimer’s disease or a related disorder to advocate for more services, funding for research, and for more programs designed to meet the needs of people in the earlier stages of a dementia. We are truly heartened that Perspectives newsletter and the work of the New York City Chapter of the Alzheimer’s Association could play a role in inspiring Richard and Jay. We hope that in turn, their extraordinary actions will inspire other readers to make their voices heard and to collaborate when possible with regional Alzheimer’s organizations to “live your life and plan for the future.”
The Dementia Trinity.... Sacred and Inviolate

Dangerous times my ‘dementia days’, especially when I link a sacred concept of the Christian faith with my meandering thoughts and stumbling ways. Yet it seems so natural to me, so supportive, so comforting, and so true so to do. Three in one, one in three. No longer alone. The persons of my Dementia Trinity: My Love and partner for all time; those who are and will care for me; and me.

No place here for selfishness or grandstanding. When one hurts we all hurt. When one succeeds we all rejoice. Frustrations and joys bind us as surely as fetters of iron.

Sadly we so often experience disunity in this blending of love and care. This escalates as we respond for our own protection and pride. Then we each hurt and feel less than we truly are. The ‘three in one’ breaks into its three parts with each of us is the poorer for it.

The World needs unity, Alzheimer’s International shows unity, you and I living with dementia yearn for unity - with self and with one another. Perhaps my concept of ‘The Dementia Trinity’ may hold a feeling of sacredness amongst us all as we move our lives forward together.

Brian McLaughlin
Invercargill, New Zealand

Dementia Guide From Health Scotland

Facing Dementia is a helpful booklet written for persons diagnosed with Alzheimer’s disease or a related disorder. Published by Health Scotland, this booklet covers important topics including understanding your diagnosis and symptoms, and how to develop effective coping strategies. It also reviews methods for seeking emotional and practical support, as well as legal and financial planning. Each of the nine sections of the booklet give clear and concise information that is summarized by helpful suggestions and practical tips.

Facing Dementia aims to help readers understand more about their dementia and about how to cope with the effects it may have on your life. It also discusses where you can turn to for help now and in the future. The content of this publication is pertinent to individuals with dementia all around the world and is not specific to the region of Scotland with the exception of resource and helpline referral numbers. To access this publication, click on the web site as listed below. If you do not have access to the internet, give the web site to someone who does and ask them to print out a copy of the booklet for you!

Cold-Weather Tips

In many parts of the world the upcoming winter months pose significant challenges for staying warm and healthy. The National Institute on Aging (NIA) has an informative 12-page publication called *Stay Safe in Cold Weather* that offers older adults tips on staying warm and avoiding a dangerous condition called “hypothermia.”

Hypothermia occurs when a person’s body temperature drops dangerously low because of exposure to cold. Low body temperature can contribute to a number of serious health conditions that can be fatal, including heart attack, kidney problems, or liver damage. People with memory loss must take extra precautions to avoid circumstances that could lead to hypothermia. Becoming lost or disoriented while outdoors alone in very cold weather could lead to hypothermia. Also, some people may forget to dress warmly enough or forget to turn up the home thermostat to a comfortable temperature and become dangerously cold without realizing it.

*Stay Safe in Cold Weather* provides a description of hypothermia and its warning signs, how to prevent the condition in the home or outdoors, and case examples of people at risk. To obtain a copy, check the following web site and download the PDF. You can also obtain a copy of the booklet free of charge by calling the NIA at 1-800-222-2225.

http://www.nia.nih.gov/HealthInformation/Publications/staysafe/

Brainstorming

We asked people with Alzheimer’s:

**Do you have any tips to share for managing and enjoying the holidays?**

Here are some of the answers:

“I used to write a note in each Christmas card, but that’s too hard now. This year, I’m writing one letter to everyone that I’ll make copies of and send out. I used to think they were less personal, but now I realize it’s a lot easier!”

“My husband and I decided that I do better in smaller groups rather than the huge family gathering. We’re going to have a series of smaller events this year so we can spend special time with each section of our large family.”

“Avoid shopping malls! I got separated from my wife for a few minutes and it felt like I was lost for hours!”

“Eat a lot! No matter how bad my memory is, I still enjoy a good meal. I have a sweet tooth, so this is a great time of year!”

“I can’t manage shopping anymore so I asked my daughter to go with me. We wrote a list and did it all in one day. Couldn’t have done it without her.”

“Sometimes I just sit back and watch. My wife likes things just so and it used to bother me that I couldn’t be more helpful. But now, I keep her company while she bustles around. She seems happier to just do things her way and I’m less stressed.”

“Do something for someone less fortunate than you are.”

“Keep it simple and focus on what’s most important – when you stop and think about it, there’s a lot to be grateful for.”


**Question**

What is the difference between early stage and early onset Alzheimer's disease (AD)?

**Answer**

Early-stage AD refers to the beginning stages of AD when disability is mild. People with early-stage AD have troubles with memory and other areas of thinking, but are still able to function independently or with limited assistance. Age is not a factor in early-stage AD and a person can be of any age and have early-stage AD. Since physicians are learning to detect the symptoms of AD earlier and earlier in their course, many people receive an initial diagnosis of early-stage AD and may remain in the early stages for a number of years.

Unlike early-stage AD, early onset AD is defined by the age at which the onset of symptoms occurs. Any person diagnosed with Alzheimer's before the age of 65 is called early onset. People with early-onset AD sometimes have a genetic variant of the disease that runs in families and results in the onset of symptoms much younger in life. Both groups, however, have the hallmark brain plaques and tangles of AD, and the course and rate of progression of AD are not necessarily different across the two groups. Rate of progression and experience of symptoms can vary considerably within all age groups. People with early-onset AD do have distinct challenges. Many have to retire early from productive careers, or struggle to try to raise children who may still live at home. It can be harder to find a peer group for support, and many people in their 30s, 40s or 50s with AD find themselves in support groups or other activities with people many years older. Some communities have developed special early-onset programs for younger individuals and families to try to meet their unique needs.

I've lost my sense of smell. Is that a part of Alzheimer's disease (AD)?

Some decrease in smell is a normal part of aging. With the onset of Alzheimer's, however, the loss of smell is often more significant. Our sense of smell is regulated by a part of the brain called the olfactory bulb. The olfactory bulb is located next to the hippocampus, a region of the brain where we process memory. The hippocampus and surrounding region is usually the first area to be affected by AD and accounts for the primary symptom of memory loss. Scientists think the olfactory bulb may also be affected in the very earliest stages of AD. As such, the ability to detect and to identify smells can be diminished.

Some researchers have examined whether the loss of smell can be one of the earliest signs of changes in the brain that may suggest AD. It is very important to realize, however, that loss of smell can be attributed to many other circumstances. Chronic sinus problems and smoking can also reduce one's sense of smell. Reduced smell can also lead to reduced taste, and it is important to maintain a healthy diet and season food as needed to maintain appetite and interest in eating.
Alzheimer’s Association
Town Hall Forums

Town Hall Forum, Chicago, Illinois

In recent years, the National Alzheimer’s Association has been working towards greater inclusion of the perspectives of persons with Alzheimer’s in the workings of the organization. Long established as an organization to serve care partners and professionals, the Association and its many chapters across the country have also made important advances in working to provide more direct services to those living with Alzheimer’s disease (AD). This has included establishing a National Advisory Committee of people with AD to consult with the organization on pertinent issues and more recently, a series of live Town Hall meetings for people living with early-stage Alzheimer’s to voice their needs and concerns to the Association.

During these Town Hall meetings that are starting to be staged around the country, participants with Alzheimer’s or a related disorder have the chance to voice their opinions on a variety of topics and share their experiences living with symptoms. As a result, the perspectives of those affected by Alzheimer’s will have an opportunity to be voiced and heard by the public as well as staff and of the National Alzheimer’s Association.

Meetings are free-of-charge and usually run as a half-day event. Participants have the opportunity to talk about a number of topics including:

- Diagnosis
- Coping
- Maintaining relationships
- Access to resources
- Stigma
- Treatment and medication
- Clinical trials and research
- Legal issues
- Community involvement including volunteering and advocacy

Call your local chapter of the Alzheimer’s Association to see if a Town Hall meeting is being scheduled in your area.

For those who may not be able to get to a Town Hall meeting, The Alzheimer’s Association has also established a web site where people with dementia and their families can participate in a kind of Town Hall meeting online. The web site has a section where you can share your opinions about the topics listed above and also has a message board and chat room where you can talk with others with Alzheimer’s or a related dementia.

If you are not comfortable using a computer, work with a friend or family member who can go on the computer with you and help you express your opinions. Perspectives raised in these meetings and on this Web site will help the Alzheimer’s Association learn how to best serve people living with early-stage dementia, so make your voice heard!

http://www.alz.org/townhall/overview.asp
RESEARCH UPDATES

Alzhemed Clinical Trials End

For the past few years, we have kept readers updated as to the status of the drug Alzhemed. Alzhemed held promise for being able to lower levels of the damaging amyloid protein that deposits in the brain of persons with Alzheimer’s disease (AD). After much debate, data analysis, and controversy, Neurochem (the company that makes Alzhemed) recently announced that it is halting development and further testing of the drug because it failed to produce statistically significant improvement or slowing of progression in persons with AD. Due to the public’s apparent demand for the drug, however, Neurochem has stated that it plans to start a new company that will market the drug as a nutritional supplement. Because it is a natural product, the compound can be sold as a nutritional supplement without the need to establish safety or effectiveness, but it cannot claim to be therapeutic (meaning it cannot claim to have a known beneficial effect on AD). Alzhemed also goes by the names “trimiprosate”, “3-amino-1-propanesulfonic acid”, or “homotaurine”, but it is not yet clear what the supplement’s name will be when it goes on the market next year.

While this step will make the compound widely available through health food stores and like distribution sites, it is always wise to give careful consideration to any use of supplements especially when a therapeutic benefit is not clear. Consult with your doctor and keep your health care team up-to-date on any decisions you make concerning unregulated or unsupervised use of supplements.

Although it is stopping further testing of Alzhemed, Neurochem plans to speed up development of another similar compound, NRM-8499, in the hopes that it may produce more promising results.

Survey Findings from ADI

Alzheimer’s Disease International (ADI) recently announced the results of a survey that explored the needs, challenges, and gaps in services experienced by persons with mild-to-moderate AD and care partners in the US, Canada, France, Germany, Spain, and Brazil. Over 100 persons with AD and over 100 care partners participated in the brief phone survey. Survey results fell into three themes: quality of life; access to information and services; and views on AD treatment.

Most persons with AD reported an ability to enjoy life and had a positive relationship with their care partner and friends. Care partners reported both burden and considerable satisfaction and reward in their caregiving responsibilities. Most persons with AD and the care partners reported that their physician was the primary source of information. Newspapers and magazines for persons with AD and the internet (for caregivers) ranked second. Families in European countries tended to make better use of their Alzheimer’s Association support services than those in the US. Survey findings suggest that families are not taking full advantage of services that may be available in their communities.

Concerning treatment, more than 70% of persons with AD who were surveyed are satisfied to some degree with their treatment and feel that the medicine they are taking is helping with their symptoms.
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