

early-onset connections

Oklahoma and Arkansas Chapter
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Los Angeles: People With Memory Loss Speak for Themselves

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Editor's note: Richard Bozanich and Jay Smith met in a support group in 2006 in California and were talking about an early stage conference put on by the NY City Chapter of the Alzheimer's Association. One commented "why don't we do such a conference here" and they did! The Early Memory Loss Forum "Living Our Lives Planning Our Future" held October 27, 2007 was the result. Read about this amazing conference where over 200 people with early Alzheimer's and other dementias gathered to remind us all that they are still here and can speak for themselves!

On October 27 in Los Angeles, an unusual conference marked a paradigm shift in the Alzheimer's disease movement, or so its organizers hope and vow. Put together jointly by Richard Bozanich (see ARF Q&A: <http://www.alzforum.org/eFAD/profiles/bozanich1.asp>) and Jay Smith, two men with early-stage memory loss, the day-long gathering drew a mixed crowd of people with early-stage dementia, their friends and caregivers, people who are at risk of developing AD, and professionals in the field.

The purpose of the conference was not to have

professionals speak to caregivers, as is typically the case, but to give voice to people in the early stages themselves. This combination made for an intense mix of sharing experiences, frustrations, and efforts to transcend the suffering, but also a loud call to action. The day began and ended with a rallying cry to stop being "polite," to step up the pace and urgency of advocacy for more research funding, better medical care, and for more programs designed for people at early stages of dementia. "You are the moral voice to bring word about the disease, and about the need for change," Michael Splaine, who directs advocacy programs at the Alzheimer's Association, told the audience. The conference title is "Living Our Lives, Planning Our Futures".

The event took place at the Skirball Cultural Center, a meeting venue nestled into the hills of Los Angeles' Bel Air neighborhood. The conference sold out weeks ago, and the organizers had to turn away scores of people who called, e-mailed, and otherwise pleaded to be let in. Mailed-in prepayments had to be returned to comply with fire regulations, and in the morning there was a standby line of people vying for last-minute seats. A week of dramatic fires in the LA area did not deter patients and partners from *see "LA" pg. 5*

Safe Return[®] and MedicAlert[®] form alliance

In a move to significantly improve the safety of individuals with Alzheimer's or related dementia, MedicAlert and the Alzheimer's Association have formed an alliance to offer MedicAlert[®] + Alzheimer's Association Safe Return. This is a live, 24-hour emergency response service for wandering and medical emergencies.

When a person with dementia wanders or becomes lost, his or her information and photo is provided to local law enforcement. When a person is found, a citizen or law official calls the 800-number on the identification product and the individual's family or caregivers are contacted. The nearest Alzheimer's Association office provides information and support during search and rescue efforts. In addition, should medical attention be required, access to a personal health record is immediately available.

Who is MedicAlert?

MedicAlert, a non profit organization, is driven by its mission to

protect and save lives by providing identification and medical information in emergencies. MedicAlert has been in business for over 50 years and is distinguished by its 24-hour emergency response center staffed by professionally trained agents. As a trusted third party custodian of comprehensive personal health information, the MedicAlert staff can provide critical medical information to first responders 24 hours a day throughout the country. MedicAlert has earned the trust of over 4 million members and the healthcare community worldwide.

Current enrollees in safe return were sent a letter October 30, 2007 outlining their options under the new alliance. They can do nothing, they can update their personal health record and opt into the new program, and be subject to the annual renewal fee next year, or they can create their personal health history and order new jewelry and be subject to the renewal fee next year. The cost of new jewelry is \$12.90. Caregivers are also eligible for the new program and jewelry.

see "MedicAlert pg. 2

From JoAnn's Desk



**Are you confused, too?
Early-onset, early stage, which is which?**

For five years now we have had an early-onset program here at the Oklahoma and Arkansas chapter, and we are still defining it, and distinguishing it from early stage. The confusion stems in part from the fact that early-onset and early stage sound alike. We have had early stage programs and services through out the chapter network for 10-15 years. It has been only recently that many others have started to work with early-onset people, and often they were placed in early stage groups, assuming that their needs were the same as older early stage folks.

Over the past 3-5 years many of these early stage people have also been early-onset (disease occurring before age 65), and they have been among our most vocal advocates for support for the person with the disease, and services for themselves. As these early-onset individuals have become more visible, especially with the increased media attention to Alzheimer's the past six months, the assumption has been that the terms early stage and early-onset are synonymous. **This is not true.** With more and more younger people being diagnosed, and at very early stages in the disease process, the difference in needs and services desired are becoming more apparent. The recent early stage Town Hall meetings in California and Chicago have called attention to this confusion, as did many of the

presentations at the Dementia Care conference in Chicago in late August. During September, I was privileged to present a paper on early-onset issues and programs with Kate Maslow, Jeffrey Carpenter and Mike Slain from the national offices in Chicago and Washington, DC at two regional workshops for the ADDGS (Alzheimer's disease Demonstration Grants to States) grantees, sponsored by AoA and the Alzheimer's Association. As we talked together at these meetings, it seems the best way to avoid this recurring confusion between the two terms is to change the terminology we use for early-onset. Both Jeff and Mike are beginning to use the term **Younger-onset** (occurring before age 65) in their discussions and we plan to follow suit beginning in 2008. It is our hope that at the beginning of the year we will also see a link on the National Association website home page to services and programs specific to persons with Younger-onset Alzheimer's disease.

Many chapters have tried to assimilate early stage, early-onset individuals into groups of older early stage people. Sometimes this works, but often times it does not, because the life stage of these younger people is very different and so are their needs. The young person feels like he/she is in a group with their parents, not their peers.

Differentiation between early stage and Younger-onset is important for understanding people and their needs, for clear communication, for developing useful programs and services, to advocate for relevant public policies and to conduct meaningful research.

We believe that using different words will help to reduce and ultimately eliminate the confusion between early stage and Younger-onset. Join us in making this transition in 2008.

(MedicAlert from pg. 1)

What is the cost for the new MedicAlert + Safe Return product?

New enrollment will be \$49.95 and the annual renewal fee is \$25. Companion caregiver jewelry can be purchased for \$25 with an annual renewal fee of \$25.

To enroll a person with Alzheimer's disease in MedicAlert + Safe Return, update a current enrollment with a member's medical information or learn more about the program, contact the Alzheimer's Association at 1.800.272.3900, your local chapter or MedicAlert at 1.888.577.8566. You may enroll a person or update a member's medical information

online at www.alz.org/SafeReturn or www.medicalert.org.

Where will I be able to learn more about MedicAlert + Safe Return?

You can learn more about MedicAlert + Safe Return by contacting: Alzheimer's Association at 800-272-3900 or www.alz.org or Medic Alert at 888.572.8566 or www.medicalert.org

Stay Connected

If you have moved and have a new mailing address, phone number and/or email address, please let JoAnn Webster, Early-onset Coordinator, know of this change. We want to stay connected with you and by providing us up-to-date information we can make sure you have the information you need. joann.webster@alz.org or 918-481-7746.

(“LA” cont. from pg. 1)

filling the auditorium to its maximum capacity of 350 people. The proceedings were taped and will be shown at Alzheimer’s Association events in towns around the country.

Bozanich and Smith had the idea for the conference and created the program over the past 14 months notwithstanding their cognitive impairment. The California Southland Chapter of the Alzheimer’s Association provided fundraising, logistic, and planning support. The chapter’s president and CEO, Peter Braun, noted that the conference marks a “transformational moment” in the AD movement. Traditionally, people used to be diagnosed further into the disease. They relied on impassioned caregivers and the Alzheimer’s Association to speak for them. They tended to be hidden from view and could not participate actively in efforts to raise awareness and advocate. At the conference, both the tone and the language were different from those days. To cite but one example: people with early-stage dementia resent the term “caregiver.” They prefer “care partner” because, for the most part, they can still take care of themselves very well, thank you.

“More than 200 of you in here are living with dementia. This is the largest gathering of people with dementia in our country,” Braun greeted the crowd. “Our network of agencies, universities, and institutions has come to hear your voice.” And speak they did. Bozanich and Smith’s introductory invitation to make the voice of early-stage dementia heard drew a standing ovation, and throughout the day patients stood and made their points. Defying the commonly held notion that people with dementia have no insight into what’s wrong with them, those assembled at this conference clearly articulated their impairment. They talked about how it forced them out of work and turned their lives upside down. Diagnostic uncertainty was a recurrent theme throughout the day. People repeatedly spoke of the burden of living in a grey zone of failing abilities but without a diagnosis.

Here are some paraphrased samples to reflect the range of what they said:

“I was aware I was slipping at work. I could not contribute ideas at meetings anymore. I went into my office and just stood there, not knowing where to start, even though I knew there was a lot to do. I thought it was stress, so shifted to a simpler position but could not learn its tasks. I felt scared. One day I called in sick and never went back. From there it was a long and bumpy road to diagnosis.”

“I had eight diagnoses in 18 months. Time after time, doctors said ‘It could be...,’ ‘It could develop into...,’ ‘You have a risk for...’ It was very difficult to live with this vague information.”

“As long as I had a diagnosis of mild cognitive impairment, my doctor did not give me medications. I needed to be diagnosed with AD to get them.”

“Compensating for my subtle impairments fatigued me so much, I ended up spending two days in bed after what used to be routine business trips. I had to retire and start a long search for diagnosis.”

Many speakers shared how they coped with the diagnosis:

“I accepted it right away. I reassessed my life and priorities, began to plan and accommodate, and made some commitments about judgment.”

“At first I was in a dark phase. Then advocacy became important. I met people in a similar situation who have become a family of sorts. I will not lead a stigmatized life.”

“I joined a memory club, participate in research studies, took up ceramics, and put in a 600-gallon pond in our backyard. I take care of my mother, who has AD and lives with us. I try to focus on the positive and the beauty of each day.”

“We moved into a smaller house. We simplified our life. I gave up handling our finances. I try to adopt routines of exercise and healthy living, and I found an unexpected spiritual gift in recognizing where I am in life and living fully what I have left.”

Speakers also advised family, friends, professionals on how to help:

“Be patient. It makes a world of difference.”

“Accept it. We go through a tunnel of denial at first. When we come out the other end and have found acceptance, accept along with us. Don’t make us insist and explain that we do have a problem.”

“Getting here took me two hours. That’s no biggie for me. But I do want to be able to reach events without having to ask for a ride.” Getting a diagnosis can mean the eventual loss of one’s driver’s license. Support groups and other events should plan to be within reach of public transportation.

Throughout the day, people voiced frustration with doctors, especially when their doctors were uncomfortable telling them candidly that they are not able anymore to think the way they used to, or when doctors simply told them to come back a year later. (It’s worth adding, however, that the approach to diagnosis varies with the individual. Some people don’t want their doctors to force them to face a problem they prefer to avoid or deny. A conference like this tends to draw, and highlight, a self-selected group of proactive personalities who deliberately choose openness.) Related concerns revolved around a fragmented health care system ill-equipped to support people in the aftermath of a diagnosis that implies major life changes. Furthermore, people called on all presidential candidates to explain how they plan for an upcoming epidemic of dementia as the baby boom generation ages. Others called on Congress to pass legislation to ensure that people do not face insurance or employment discrimination if they choose genetic testing for AD.

The program featured a medical update by Gary Small of University of California, Los Angeles, as well as a lecture by David Shenk, author of *The Forgetting* (Random House, 2003). Shenk rallied the audience to get angry about a national lack of adequate funding, and to use their still-vigorous faces and voices to demand more resources. In two breakout sessions, the program offered workshops on eight different topics. (Full disclosure: this reporter moderated workshops on the topic of Current and Future Treatments.) The conference had an advisory committee of 52 members of various local institutions, who are working with the Alzheimer’s Association to build programs for people with early-stage dementia in Southern California. A different kind of follow-up might come, as well: crews from PBS and HBO were on-site to film and interview people with early-stage dementia. —

Gabrielle Strobel.

Email Connections for Kids and Chapter Staff

If you have children ages 11-16 who would like to email their peers, please contact JoAnn Webster. Send her names, ages and email addresses to: joann.webster@alz.org or call 918-481-7746.

If you would like to have a peer group for Chapter Staff working with early-onset/young-onset families, please also contact JoAnn.

Useful Resources

- National Alzheimer's Association: www.alz.org;
- Find your local chapter, the early-onset Message Board and Clinical Trials. Check out the new design and information on this site.
- Oklahoma and Arkansas Chapter: www.alz.org
- and click on the map for your state. 24-hour Helpline: 1-800-272-3900 or 918-481-7741.
- CareFinder: www.alz.org/carefinder/index.asp. A new website to assist in finding good care, coordinating care, planning, and resources in the community.
- Nedy Meds: www.nedymeds.com. A useful website for finding financial assistance for getting prescription medications.
- DASN International www.dasninternational.org. Dementia Advocacy and Support Network for persons with dementia.