FULL CIRCLE
A Unique Conference for People with Early-Stage Dementia

By Paulette Michaud, LCSW
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It was such a wonderful day! On November 12th, 41 people with early-stage dementia gathered at our New York City office for an all-day event that focused on ways to live their best. For the first time, people with early-stage dementia from as far as Long Island, Upstate New York, and Connecticut were brought to a conference without their caregivers to learn and to share their thoughts and experiences about living life to the fullest.

The day began with a warm welcome from Jed Levine, Executive Vice President and Director of Programs & Services, who noted that the New York City Chapter has come “Full Circle” from 10 years ago when we held our first early-stage conference (that included caregivers). Jed was followed by our keynote speaker, Lisa Snyder, Director of the Quality of Life Programs at the University of California, San Diego’s Shiley-Marcos Alzheimer’s Research Center. Lisa has worked with people with early-stage dementia and their families for over 20 years and is the author of the new book Living Your Best with Early-Stage Alzheimer’s.

The audience listened intently as Lisa talked about the three areas of well-being: 1) Cognitive or mental well-being that results from being involved in meaningful activities and adopting positive and adaptive attitudes; 2) Physical well-being that relies on good eating habits, exercise, and adequate sleep; 3) Emotional well-being that results from feeling a sense of purpose and value. Lisa encouraged considerable audience participation and she was not disappointed! The room came alive as people enthusiastically shared their thoughts and experiences about “living your best.” Erica Goldberg (from the Chapter office) was an invaluable scribe for the session so that participants had a written handout with the session material and their discussion contributions to take home with them. One participant later said, “I loved when we were all together talking about how we live our lives. I felt reassured being with so many other people like myself…it was really stimulating.”

Lou-Ellen Barkan, our President and CEO, shared her thoughts with the participants during a delicious lunch that was followed by two excellent afternoon workshops. “Let’s All Be Advocates” was led by (continued on page 2)
FULL CIRCLE
(continued from page 1)

Lauren Tiede and Paulette Michaud. Once again, the voices of our early-stage participants rang loudly. They wrote a letter to their congressmen asking for increased dementia research funding (see page 3). It was wonderful to hear the participants become impassioned advocates.

The second workshop given by Jed Levine focused on “Medications & Alternative Therapies.” Jed provided information about available medications for symptom management and talked about alternative approaches to healthy living that can improve quality of life. Everyone agreed that there are many things each of us can do to maintain a healthy lifestyle, in spite of having an early-stage diagnosis.

The day ended with a wrap-up session in which everyone heartily agreed that we have to hold a conference just for persons with early-stage dementia each year. As one participant commented, “I would like to have more of this. Everything we did today was very valuable.” We can assure them that their voices will be heard!

During the FULL CIRCLE plenary session with Lisa Snyder, participants responded to a series of questions throughout the discussion. The following are two of the questions and the audience responses:

What attitudes help you to live your best?
• “Try to be positive towards other besides just yourself.”
• “Liking the world, liking what’s around me, reaching out, it’s easy and it can be rewarding.”
• “Best thing I learned is to let it go. If I can’t remember something, just let it go and do it with ease.”
• “Good humor.”
• “Making your expectations of yourself and other people reasonable.”
• “Forgive those that make you upset because they have something insensitive to say about your condition. Then they can learn.”
• “Central Park. I spend hours in the park. It is complete bliss. Appreciating beauty and nature.”
• “There are so many people in this world who have it worse off than I do and I am very fortunate.”

Has anything positive come out of Alzheimer’s?
• “I was very serious and studious my whole life. But dementia changed my whole personality. I have a new sense of humor. I tell terrible jokes. But I have one trip here, so I’m going to go out laughing!”
• “Finding a wonderful support group with a gifted leader. I have a greater sense of community.”
• “After joining Paulette’s group, I find that my brain is exercising in a way I never would have expected.”
• “Aside from all the nice new people I met in the group, I also forgot about all the people I didn’t like!”
November 12, 2010

Dear Representative,

We write to you as people living with mild cognitive impairment or an early-stage memory disorder. There are 41 of us, your constituents from 14 districts, gathered today at the Alzheimer’s Association, New York City Chapter for the 10th Annual Early-Stage Persons Forum. We implore you to remember the words we have written below that express our deep commitment to advocating for increased funding for Alzheimer’s disease research. We ask that you keep us in the forefront of your mind come voting day.

“We want more funding!”

“We are still viable and able human beings who function and are able to vote.”

“Remember...we can vote you out!”

“If you want our support, you have to support us.”

“What if this were happening to you and your family?”

“We need more funding to provide better programs and services.”

“We need people to become more educated, and we need more classes in universities and medical schools that will teach people about Alzheimer’s disease, and how to help us.”

“The mind you save may be your own!”

“We need you to lower the age criteria for people who want to participate in clinical trials and research studies.”

“Remember – people with Alzheimer's disease and their families represent a huge block of voters.”

“Baby boomers are aging and many are developing Alzheimer's....you can no longer pretend this is not happening!”

“You have to do more work to get rid of the stigma that's attached to this illness.”

“And finally.......PLEASE WAKE UP TO OUR CAUSE!!!”

While we have a lot of demands, we would like to thank you for your work and votes to pass the Compassionate Allowances Initiative. It has greatly benefited a lot of us who are living with early-onset dementia.

Thank you, Representative, for reading this letter. We appreciate your attention to this very important matter. We trust that you'll remember our words going forward as you vote on bills that will benefit all of us affected by this illness.

Sincerely,
(All of the conference participants signed the letter.)
Understanding Common Non-Alzheimer’s Dementias

The term “dementia” covers over 70 different conditions that can result in changes in thinking abilities, behavior, and personality. The most common dementia is Alzheimer’s disease, accounting for between 60-70% of all cases. Other significant causes of dementia, however, may not be as commonly acknowledged including Lewy Body dementia and Frontotemporal dementia. Individuals living with these dementias share many of the same concerns facing people with Alzheimer’s, but are also dealing with unique symptoms and challenges that warrant particular attention.

Lewy Body Dementias

Lewy Body Dementia is one of the most common types of progressive dementia, affecting an estimated 1.5 million individuals and their families in the United States. Lewy Body Dementia (LBD) is an umbrella term for two related diagnoses: Parkinson’s disease dementia and dementia with Lewy bodies.

The earliest symptoms of these two dementias differ slightly, but ultimately, both result in the same set of challenges including: problems with visuospatial abilities (judging distance and depth), attention, and executive functioning (organization and planning). Fluctuations in confusion and alertness are also common, as are slower and more rigid movements. Some individuals develop a Parkinson’s-like tremor. Unlike in Alzheimer’s, visuospatial problems can be significant, and may occur before problems with memory or language. A person with DLB might sit down on the edge of chairs, fall, trip on stairs, misjudge distances while driving, or have difficulty drawing or writing. Visual hallucinations are also common.

Steve first noticed the onset of his symptoms while driving. He says, “I couldn’t figure out where I was going. I remembered how to get to places, the street names, and the addresses. My memory was fine, but it’s like I couldn’t see right - It’s a bit like being in a fishbowl. Everything looks a little off.”

Because some LBD symptoms can resemble other more commonly known diseases like Alzheimer’s and Parkinson’s, only 30-50% of persons with LBD are accurately diagnosed. Early and accurate diagnosis is important because some drugs commonly prescribed to treat Alzheimer’s symptoms can cause severe side-effects in persons with LBD, while other Alzheimer’s medications may be helpful.

People with LBD often need to make modifications to their environments to improve functioning and safety. Helpful interventions include: reducing clutter; taking extreme caution on stairs; installing grab rails in the bathroom; using a walking stick when outdoors; and discontinuing driving.

Because movement may be slowed down considerably, it is important to allow for more time with daily activities to reduce stress. Some people with LBD benefit from physical or occupational therapy to help maintain strength, coordination, and functional abilities.

For more information, contact the Lewy Body Dementia Association, Inc. on their (continued on page 5)
Dementia is like life: it never goes down a straight path for an individual or a family. I am currently following twists which were not planned for my future. It has been an interesting and challenging change.

-- Graham

Frontotemporal Dementias

Frontotemporal dementia (FTD), also known as frontotemporal lobar degeneration (FTLD), usually develops in individuals under the age of 65, is the most common cause for young-onset dementia, and likely accounts for 10-20% of all dementia cases. Unlike Alzheimer’s that begins in areas of the brain responsible for memory, FTD damages the frontal and/or temporal regions of the brain that are associated with language, behavior, emotions, judgment, movement, and the abilities needed to complete complex tasks that require multiple steps.

There are many subtypes of Frontotemporal dementia that can affect behavior (behavioral variant FTD) and language (primary progressive aphasia, progressive non-fluent aphasia, or semantic dementia). Other more rare forms of frontotemporal disorders primarily affect movement (progressive supranuclear palsy, for example). People with all forms of FTD may also have some slowness or rigidity in their movements or a tremor similar to Parkinson’s disease.

Individuals with behavioral variant FTD can have very disruptive changes in social behavior and personality and may have little insight into these problems. These symptoms can be very challenging and they can struggle to function in social situations. Younger caregivers often have difficulty managing these challenges at home especially with job commitments.

People who have FTD in the form of aphasia are unable to find the right words to communicate effectively and eventually are unable to speak, while people with semantic dementia tend to lose ability to understand the meaning of words and may not comprehend simple words. It may also be difficult for these individuals to recognize familiar people or objects.

Many people with FTD who have these language difficulties retain other thinking abilities and may try to develop ways to manage their communication challenges. Researchers at the University of California, San Francisco, have found that some individuals with semantic dementia can have considerable non-verbal creative abilities, including painting. In an article published in Alzheimer’s New Zealand’s, Alzheimer’s News, Graham, diagnosed with semantic dementia at age 59, states, “Dementia is like life: it never goes down a straight path for an individual or a family. I am currently following twists which were not planned for my future. It has been an interesting and challenging change.”

Since FTD can include a complex set of symptoms that vary considerably from person-to-person, strategies for managing the condition may vary and it is important to seek help from professionals and peers who are familiar with this dementia.

For more information on FTD, contact the Association for Frontotemporal Dementias on their toll-free help line at 866-507-7222 or visit them online at their website: http://www.ftd-picks.org/
HELPFUL RESOURCES

An Introduction to Lewy-Body Dementia

From the Lewy Body Dementia Association

This 12-page brochure is directed to newly diagnosed individuals and their families and provides a very general but helpful overview of the symptoms of Lewy Body Dementia (LBD) and some discussion of symptom management. Particular attention is given to the potentially dangerous side-effects of common dementia medications on individuals with LBD and the importance of a thorough diagnostic evaluation.

To read or download this brochure, see http://www.lbda.org/feature/1942/an-introduction-to-lewy-body-dementia.htm

Other informative publications on LBD can be found on the LBDA website at http://www.lbda.org/category/4115/publications.htm or you can call LBDA at 404-935-6444.

Frontotemporal Disorders Information for Patients, Families, and Caregivers

From The National Institute on Aging (NIA) and Alzheimer's Disease Education and Referral (ADEAR)

This 30-page booklet describes the three types of frontotemporal disorders including: behavioral variant frontotemporal dementia; primary progressive aphasia; and related progressive movement disorders. Informative tables are provided that help to distinguish the symptoms of each disorder and more detailed text provides helpful descriptions of these complex forms of dementia.

Although there is currently no cure for these disorders, the booklet provides a practical discussion of symptom management including problems with behavior, language, and movement. Information and advice for caregivers and a list of resources are also included.

Order print copies of this informative booklet through ADEAR at 1-800-438-4380 or download a PDF of the booklet at: http://www.nia.nih.gov/Alzheimers/Publications/FTLD/
BOOK REVIEW
The Japanese Therapists: Another Alzheimer’s Autobiography by Mike Livni

Reviewed by Robyn Yale, LCSW

Mike Livni has worked in dementia care for 22 years, serving on the boards of Alzheimer’s and Related Disorders Association in South Africa as well as Alzheimer’s Disease International (ADI). In the early 1990’s he became aware of my own work with early-stage support groups and was instrumental in bringing it to the ADI forum. While helping to advocate and raise awareness, he also began to facilitate early-stage groups for people with dementia and their families in South Africa. Now he has arrived at the pinnacle of a 10-year effort to accurately diagnose his own symptoms of dementia, and would like others to hear of his first-hand experiences.

The Japanese Therapists is a masterful weaving of Mike’s personal and professional backgrounds, the writing process with the impact of the disease, and the quest for a diagnosis with the journey to accept it. Because he wants us to understand what Alzheimer’s is like for him, he chose not to perfect the text in terms of editing and flow – so we witness in raw and authentic form how his thinking is affected by slowly progressing cognitive impairment. What may at first seem scattered and disorganized quickly becomes quite engaging. One must admire the skill and courage it took to persevere in recording his story while simultaneously facing and integrating his decline. We are with him “in real time” as he painstakingly writes the book while poignantly searching for answers that were unknowable (as symptoms were mild) for quite some time.

The story unfolds around such themes as working through denial; maintaining independence vs. needing assistance; retaining one’s personhood; the ongoing impact on his relationship with his wife, colleagues, and others; and the search for and reaction to his diagnosis. Mike’s ongoing reflections are posed to the only “therapists” he worked with during this process - Mr. Sanyo and Mr. Sony - who, being tape recorders, listened without judgment or criticism.

This is a unique and fascinating read that I highly recommend. Although experienced in the field of early-stage dementia, I was educated and enriched by Mike’s interesting (and at times wildly funny!) anecdotes, clever musings, and honest expression of feelings. After championing early-stage work in his own country and internationally, Mike Livni now contributes to our understanding of the early dementia experience and reminds us of the power one can find to cope with it.

The Japanese Therapists can be ordered for $25 (US) which includes shipping & handling. For ordering information, contact livni@corpdial.co.za

Robyn Yale is a clinical social worker and the author of Developing Support Groups for Individuals with Early-Stage Alzheimer’s Disease: Planning, Implementation, and Evaluation.
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