An International Alzheimer’s Family
Reflections on the 2010 Alzheimer’s Disease International Conference

By Helga Rohra

Editor's note: Each year, Alzheimer’s Disease International (ADI) hosts a conference that brings together scientists, health care professionals, government and service providers, families, and other individuals interested in Alzheimer’s and related dementias. In the following essay, Helga Rohra, a German woman who lives with Lewy body dementia, speaks about her participation in ADI’s 25th annual conference held in Thessaloniki, Greece.

Our registration for the international meeting took place in a quite luxurious lobby of the Grand Hotel, Thessaloniki. From the very moment you are welcomed, you can feel the importance of the meeting. Everything is organized up to the smallest detail.

In the forthcoming days, well-known neurologists, carers, and all kind of experts in the field of Alzheimer’s and related forms of dementia will debate, present new figures, and inform the audience about the standings worldwide. There are many workshops, satellite symposiums, and exhibitions. You are amazed by all those people who represent Alzheimer’s associations worldwide. You get the feeling of being welcomed by a big family! All those present want to get more information, want to get answers to questions troubling them about the disease. Finally, they want to get involved and believe firmly in the strength and solidarity in facing dementia.

You realize how much is invested in research, you feel the endeavour of people’s work, and you learn about new approaches or ways of dealing with dementia in other countries.

You are grateful to the people who invited you. Of course, you speak up, you share with others your daily experience of living with dementia. You learn about the importance of nutrition, about physical and mental exercise, and not to forget social aspects and one’s own approach in dealing with the disease.

I am wearing a badge. My name is written on it, as well as that of the Alzheimer Association in Germany – Munich, which I belong to. It is a special feeling overwhelming me: I know I am part of the big Alzheimer family. There are many talks with all of the other people affected by (continued on page 2)
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dementia and I imagine they are all people like me, like you. Some have been living with a diagnosis for some years. There is a common fate. We are all united in our dementia. I never feel lost; together we are strong. This wonderful feeling accompanies me in all sessions, no matter whether it’s the workshops or the nice evenings. We, those touched by dementia, know it is important to speak up. We have to be respected, we are not only experiencing impairment, we can still do a lot. Just give us a chance, listen to us.

No decision about us without us! A message I stood up for in the workshops. You know I felt very strong all of those days. I strive for the “mission dementia.”

The ADI meeting had a very significant title: Dementia – Making a Difference. How true – yes, this difference we want to emphasise in our own countries. Believe it or not, it is a new consciousness of people affected by dementia.

I myself am very confident. We ourselves have to speak up. It isn’t sufficient to talk about statistics or interpret computer animations of our brain. Please don’t forget our own self. Don’t always ask about our deficiencies; see our existing abilities. Talk to us!

I especially remember one workshop: “Ways of embedding people with dementia in social decisions.” I know together we are able to change ways of dealing with people with dementia. We are all a big family! I learned about the power of solidarity in dementia – a feeling that is still with me today.

We go ahead and look forward to saying “Hello” and not “Goodbye” in Toronto in March 2011.

27th International Conference of Alzheimer’s Disease International
March 7-10, 2012
London, United Kingdom

Helga Rohra’s essay speaks to the excitement and sense of international community inherent in the annual meetings of Alzheimer’s Disease International (ADI). While many international meetings are primarily scientific in focus, ADI is truly a meeting for anyone involved in, or affected by, Alzheimer’s or a related dementia, including those diagnosed. Next year’s meeting theme is “Science, Fact, Fiction” and will include scientific updates, best practices in care for persons with dementia, and the use of creative practices, including literature and arts, to help describe the dementia experience. For more information on this conference, see the website:

Traveling Safely with Memory Loss

Travel and vacationing is a meaningful activity for many people with memory loss. “When I travel to a new place, it takes my mind off of all my worries,” says Al. “I see new things and have different kinds of experiences than I do at home.”

Alzheimer’s or a related disorder may have little impact on your enjoyment of travel, but you might need to modify travel plans somewhat. Memory loss, as well as being out of your normal routines, increases your risk of losing things or becoming fatigued or disoriented. Many people continue to travel on longer vacations or tour foreign countries, but if such trips become too challenging, short trips to a familiar destination can be satisfying. Consider taking a few small trips to see how you adjust before embarking on a longer trip to an unfamiliar place. The following travel tips may be helpful as you make plans:

• Simplify your travel itinerary. See fewer places in greater detail so you have more time to get accustomed to new surroundings. Some people enjoy small cruise ships because the boat provides a consistent place for sleeping and eating with the opportunity to dock at different ports for day trips.

• Schedule in “down time” when you are not on the go and can rest.

• Have identification with you at all times. Check with your local Alzheimer’s organization for programs to enroll in, such as Medic-Alert/Safe Return or Project Lifesaver so you can receive assistance if you get lost or become separated from your group.

• When you go out, carry a business card from your hotel in case you get separated from your loved one or need to inform someone of where you are staying. Make sure to replace the card with a current one each time you change hotels.

• Bring a nightlight for your hotel bathroom so you can find it in the dark.

• Ask your doctor about a mild sleep aid to use if needed. Disrupted sleep and jet lag can increase confusion. Don’t use over-the-counter sleep aids without a doctor’s approval.

• Write postcards to friends and family. Ask them to keep them for you so you can have them as mementos.

• Pack lightly so you are less likely to lose things.

• Keep a simple diary or take photographs to help you recall each day’s events and special details of your trip.

• Drink plenty of fluids. Travel during any season can be dehydrating, resulting in worsened memory and confusion.

• Consider telling other travelers or your tour guides that you have Alzheimer’s. This may put everyone more at ease and allow others to help you if needed.

Revised and reprinted with permission from “Living Your Best with Early Stage Alzheimer’s” by Lisa Snyder. Available at Sunrise River Press at 1-800-895-4585, in your local bookstore, or purchase online at http://www.amazon.com/Living-Your-Best-Early-Stage-Alzheimers/dp/1934716030.
Creating Caring Partnerships

We frequently hear and read about Alzheimer’s “caregivers.” This word implies that others give care to the person with Alzheimer’s who receives it. In fact, many people with Alzheimer’s or a related dementia are quite capable of being caring to those who are trying to care for them. More recently, the term “care partners” has received some attention as a more descriptive term for the relationships that can occur in the early-stages of a dementia.

We asked people living with Alzheimer’s or a related disorder:

What are the qualities of a good care partner?

Their following answers apply to all involved in the care partner experience whether you are the person with early-stage dementia or a loved one:

“Don’t gang up on or crowd a care partner. It can be overwhelming if too many people are trying to help at once with too many different ideas.”

“The ability to listen and not be talking all of the time is important in a respectful care partnership.”

“A happy person – someone who smiles and tells an occasional joke.”

“It’s good to have things that you enjoy doing together – shared interests and activities make a more positive care partnership.”

The ability to have open communication and say things that are important to you without the other person getting all worked up.”

“Compassion is an essential ingredient in a care partnership – trying to understand what the other person may be going through. Alzheimer’s can be hard not just on me but on those around me.”

“Don’t always do things for the other person; partner with the other person so you accomplish things together. My wife and I do the bills together now and although she does the cooking, I try to do the dishes.”

“Put on your ‘listening’ ears – it’s not enough to just hear someone. You have to pay attention and listen to their message without a lot of other distractions.”

“Adjust your expectations of each other. Sometimes my wife wants me to try to do something that I just don’t think I can do anymore. And sometimes I ask more of her and expect her to do too much or am not sensitive to everything she already does for me.”

“Try to reduce each other’s stress level. Sometimes small acts of love or kindness go a long way.”

“Look out for each other’s health. I need help with my medications because I forget what I have to take, but my husband needs to exercise so I make sure we walk every day.”

“Good care partners know when to step in and when to back away. Everyone needs a little space and some peace and quiet.”
QUESTION AND ANSWER

Q My husband has been diagnosed with early-stage Alzheimer’s and every time we go to the doctor, I feel like the doctor is sugar coating the situation and not being honest with us. It feeds our denial, but we need to cope with this. What can we do?

A It is not uncommon for doctors to “sugar coat” a diagnosis of Alzheimer’s or a related disorder because they fear that honest discussion will depress the person with memory loss. In fact, research from Brian Carpenter, PhD, at Washington University in St. Louis, Missouri reported quite different findings. Patients who were told their diagnosis and given the opportunity for a caring and candid discussion with their doctor did not report higher levels of depression or anxiety. Many expressed relief at being given an explanation for their troubling problems and for the opportunity to discuss them openly.

The following ideas may be helpful when consulting with your doctor:

• Provide a unified message to your doctor that you and your husband can tolerate an open and honest discussion about Alzheimer’s. Are you and your husband in agreement about the level of honesty that you want with the doctor? If not, your doctor may stray on the side of caution in his discussions with you.

• If you want to discuss concerns about your husband’s condition privately with the doctor at any time during your appointment, your doctor needs advance notice. Call and speak with the nurse or front office administrator to make sure the doctor receives this request.

• Give the doctor a clear description of a symptom or troubling behavior that you are trying to cope with including how often and when the problem occurs. This will help the doctor better advise you on coping methods or treatment options.

The Alzheimer’s Association has a helpful booklet called “Partnering with Your Doctor” that you may want to review and share with your doctor. It is available at: http://www.alz.org/we_can_help_partnering_with_your_doctor.asp. Also, call your local Alzheimer’s Association chapter to obtain a copy of the “Principles for a Dignified Diagnosis” that was written by persons with dementia for their doctors.

Q My sister who has Alzheimer’s takes the highest dose of Aricept (23 mg), but I recently read in the news that this might be dangerous. Is this true?

A Some patients may be offered a higher dose of Aricept by their physician if they tolerate the routine dose of 10 mg. and are hoping for greater improvement. The evidence of an increased benefit to higher dose Aricept for people with mild Alzheimer’s is not strong, however, and some people may have an increased risk of side effects. But given the few treatment options available to persons with Alzheimer’s, some patients want an opportunity to try anything that might improve their symptoms. As such, any medication decision is best reviewed with your physician who will need to determine the risks versus the possible benefits of any treatment. All responses to the medication should be monitored closely for either beneficial or dangerous side effects.
Managing Your Finances

Helpful Methods for People with Early-Stage Memory Loss

By James Lugannani

In this two-part series, we examine approaches to managing your finances. These steps will help you stay engaged, while allowing others to assist you as needed.

Most of us like to stay in control of our finances for as long as possible. However, managing money is difficult for many people. It requires memory, planning, judgment, and executing multiple steps. Alzheimer’s can interfere with these abilities and make financial management increasingly difficult.

Handling money is often discussed in all-or-nothing terms; many believe you either have the capacity to handle money or you don’t. In fact, you may be able to make some financial decisions, like paying for dinner, but not others, such as whether or not to sell your house. In the early stages of Alzheimer’s, this capacity can vary from day to day and changes over time. How can you arrange your financial affairs to retain control and independence, while preparing for the times when you will need help?

Simplifying Your Financial Management

It’s easy for our financial lives to get complicated with multiple credit cards, checking accounts, and investments. Simplifying your financial life can reduce burden on your memory and make it easier for others to help manage your finances, as needed. Ask your physician to evaluate your ability to handle your finances and ask family members, friends, or others you trust for assistance. Consider the following steps towards simplification:

Simplify Banking and Checking:

Make a list of all your checking and saving accounts. Do you need every account? Now is a great time to consolidate. With fewer accounts, there’s less to forget.

Auto-Pay Your Bills:

Stop writing checks! Many bills – newspaper, utilities, rent/mortgage, satellite TV – can be paid directly from your checking account. Auto-pay is often safer, more reliable, and easier to keep track of than writing checks. Make a list of your bills. Call each company and tell them you want to begin auto-pay. Ask someone you trust to help with this if needed. Once you are registered for auto-pay, review your account every month to make sure your bills are correct, and that there is enough money in your checking account.

Eliminate Waste:

Do you really need that magazine subscription that you don’t read anymore? When reviewing your bills, cancel things you don’t need! Your life will be simpler, and you’ll save money, too.

Simplify Investments:

If you have accumulated different investments, loans, credit cards, and insurance, consider consolidating accounts. Making changes to your finances could have monetary, tax or legal implications, so get professional advice first. Many banks and brokerages have dedicated professionals who build personal relationships with you. You don’t need to remember user IDs and

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passwords for them to help you.

*Stay Organized:*

Once you have simplified your financial life, it is important to stay organized. You need to know that you have received your income, paid your bills, and received your bank and brokerage statements. That way you won't miss anything, you'll detect problems early, and you'll be able to solve problems quickly.

You can use the list that you create of your bills and accounts as a means of keeping track of bill payments, income, and account statements. Reviewing your lists weekly or monthly can help to alert you or another trusted person as to when a bill is too big, a check is missing, or something else in your financial life needs attention.

*Make It a Habit:*

It is important to make it a habit of paying attention to your finances – just like your daily exercise or taking your medications. If you pay attention, your loved ones and professional advisors will also be attentive and you may be able to remember more and participate in your financial management longer.

To supplement this article series, we are happy to provide you with a step-by-step guide and sample worksheets free of charge. You can request them by email at james.lugannani@ubs.com, or you may call me at 415-954-5956.

James Lugannani is a Financial Advisor at UBS Financial Services in San Francisco. He is proud to work with families and individuals with cognitive and physical disabilities.

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New DVD Resource
From Scottish Dementia Working Group

Scottish Dementia Working Group is an advocacy and awareness-raising group whose members all have a diagnosis of some form of dementia. The group has produced a DVD entitled “Through Our Eyes” to help raise awareness and understanding of:

- The varied experiences of dementia
- How people adapt and use coping strategies for living with their dementia
- The potential and strengths of people with dementia
- How communities can be ‘dementia friendly’
- The difficulties people with dementia experience and what professionals can do to make challenges easier
- How involving and listening to people with dementia can enhance and develop the practice of staff in dementia services

The 44-minute DVD features seven members of the Scottish Dementia Working Group who speak about their experiences of living with dementia. It is aimed at dementia care professionals, as well as all health professionals and the general public. It can also be viewed by people with dementia to help them realize that they are not alone and there are ways to cope.

The DVD is available internationally and can be ordered from the Scottish Dementia Working Group Training website at http://www.sdwg.org.uk/. Training notes to accompany the video can also be downloaded from this valuable website.
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