We Can Make a Difference

By Dutton Teague

I have decided to share my story in the hopes that it might be helpful to others. In 1987, I was hired as the first paid Executive Director of what was then the Greater Phoenix Chapter of the Alzheimer's Association. I remained with the Chapter for more than ten years until my retirement in 1999. In March, 2008, I was diagnosed with early-stage Alzheimer's and in early 2009, I became a Board member of what is now the Desert Southwest Chapter of the Alzheimer's Association. I joined the Board as the Chapter was moving to develop a new core program for persons with early-stage dementia. I had decided I could make a contribution to others like me and to our care partners and families.

Because of my background with the Alzheimer's Association, I had a working knowledge of Alzheimer's and the disease process. It seems to me that each one of us who is diagnosed at an early stage has two choices. You can become preoccupied with what you have lost and are losing, and that will likely lead to despair or depression. Or, you can take stock of your remaining capabilities and decide how you can use them to build and enjoy the rest of your life. The latter is my choice.

My wife and I have reviewed our resources including family, friends, and the opportunities available to us, and we plan to use them to the fullest. One can still make a contribution to better our society in spite of the diagnosis.

Several actions have been taken since I joined the Board of Directors of the Desert Southwest Chapter of the Alzheimer's Association. The Board has now established early-stage programming as a new core area of services. The Chapter has held three successful forums for early-stage persons and their care partners in the greater Phoenix area and one forum in Tucson, Arizona. I thought that some of the participants were still in the process of "telling others," so following my presentation at the forum, I asked that affected persons put a star on their nametags so we could quickly identify one another during breaks. Most, if not all, did this and communication flowed very well. The Chapter has additional forums scheduled for other regions of Arizona and Nevada.

I also spoke to the professional staff at the Banner Alzheimer’s Institute in Phoenix about the need for doing more than just (continued on page 2)
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diagnosing persons and offering semi-annual sessions with a professional. I was distressed that I had met only four early-stage affected persons in about 20 months following my initial diagnosis. Banner has since initiated a six-session support group of 13 persons with early-stage Alzheimer’s that began in January and I was a member of the group. Our common concerns are: driving; telling others about the diagnosis; difficulty in understanding how to get where we are going; feeling isolated when family members and friends are reluctant to speak about the disease; and remembering names of people. Transportation is a major issue especially for persons without a spouse, significant other, or friends who drive.

One of my goals is to work toward getting assistance for affected persons shortly after early-stage diagnosis. It is lonely out there following diagnosis. Once a week, I call two persons I have met just to touch base and be supportive.

I am likely the most vocal Alzheimer’s Association Board member when discussing issues related to early-stage programming. I was influential in their changing the designation of “caregiver” to “care partner” when speaking about persons involved in early-stage dementia. I am very concerned that the Chapter and diagnostic facilities form working agreements to maximize referrals for support groups and other programming. I believe the major issue is connecting with doctors, physician groups, or medical facilities so that individuals and their families will have a resource following diagnosis. Members of my support group had virtually no information about the Chapter or its resources until I provided it.

We need to develop new support groups for early-stage persons and their care partners. We also need to do outreach and develop programming for younger early-stage persons and their care partners.

I believe the impact of a potential volunteer pool of affected persons and families facing early-stage Alzheimer’s can be significant for Alzheimer’s Association chapters. The volunteer pool needs to be developed and staffed properly. In my support group at Banner Alzheimer’s Institute, we have a retired physician, three nurses, two former teachers, a clinical psychologist, and myself with a social work background. I believe that involving affected persons in volunteer work will assist them in reducing depression and despair, help them focus on their talents, and introduce hope by their contribution to society despite the diagnosis.

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Editor’s note: Deborah Schaus, Executive Director of the Desert Southwest Chapter of the Alzheimer’s Association shares how she believes Dutton has helped to shape early-stage issues at the Chapter:

Dutton has been an essential part of our strategic planning work team around early-stage issues. He led us to recognize and/or implement the following:

1) We are in the process of holding town hall forums throughout Arizona and Southern Nevada to engage people with early-stage Alzheimer’s in helping us shape new services and activities that they want and need.

2) We provided training to our Chapter staff on early-stage Alzheimer’s issues.

3) We developed a new information kit resource and reading lists for people with early-stage Alzheimer’s who connect with us.

4) We are exploring ways to pair education with social support for couples facing early-stage Alzheimer’s together.

5) Because of Dutton’s advocacy, our Chapter expanded our five Core Programs to now include a sixth, focused entirely on early-stage needs.

6) At our Chapter’s Gala on February 13th, 2010, we introduced our new Early-Stage Core Program via Dutton’s inspiring thoughts in a video. Several attendees approached me immediately after seeing the video to share how positive Dutton’s message was about finding ways to live life to the fullest with early-stage Alzheimer’s. Donations we received immediately after showing the video raised an unprecedented amount of money that will help a great deal with developing our new early-stage services.

QUESTION AND ANSWER

Q I don’t have much of a sense of smell anymore. Is this a symptom of Alzheimer’s?

A Researchers are studying the functioning of smell in persons with Alzheimer’s because loss of the ability to smell or identify smells is an early sign of a number of neurological diseases including Alzheimer’s and Parkinson’s.

Your olfactory bulb is a region of the brain responsible for the sense of smell. It is located very close to the hippocampus, a region of the brain associated with memory functioning. Alzheimer’s disease usually begins in the area of the hippocampus, so it is thought that the olfactory bulb and sense of smell could easily be affected in the early stages of Alzheimer’s, too. Indeed, many people with Alzheimer’s will describe changes in their ability to smell. Other things can also compromise the ability to smell or to identify smells including history of smoking, chronic sinusitis, or a current head cold. Loss of smell can also contribute to loss of the ability to detect taste. Some people with Alzheimer’s begin to prefer salty or sweet foods because they are easier to taste.

If your sense of smell is diminished, it is important to make sure your home has smoke alarms in case you can’t smell smoke in an emergency. Be careful about eating food that has been in the refrigerator too long as it may be hard to detect the smell of spoiled food. Watch the amount of salt you may add to food to enhance flavor because excess salt can contribute to high blood pressure.
NEW RESOURCES

Living Your Best with Early-Stage Alzheimer’s - An Essential Guide
By Lisa Snyder, MSW, LCSW
Foreword by Douglas Galasko, MD

Many people living with early-stage Alzheimer’s or a related disorder want information about how to cope effectively with memory loss and other symptoms and move forward with life. Almost all books are written to caregivers, and people with Alzheimer’s have long needed a comprehensive resource that addresses their own experiences and concerns.

Living Your Best with Early-Stage Alzheimer’s - An Essential Guide is a new 280-page book that is organized into 30 short, easy-to-read chapters on topics including: talking about the diagnosis; managing memory loss and other symptoms; finding meaningful activity; social and family relationships; maintaining hope and humor; updates in nutrition, exercise, and research; the unique needs of young-onset people or those who live alone; and much more. Each chapter ends with practical suggestions and discussion questions to facilitate conversation with loved ones or peers in early-stage programs.

Written by Lisa Snyder, a social worker in the field of Alzheimer’s for over 20 years, Living Your Best with Early-Stage Alzheimer’s is also filled with important messages from people with Alzheimer’s around the world who share their thoughts and advice on how to live a meaningful and satisfying life in the face of a challenging diagnosis.

Living Your Best with Early-Stage Alzheimer’s – An Essential Guide is available in bookstores or online at http://www.amazon.com/Living-Your-Best-Early-Stage-Alzheimers/dp/1934716030 For discounted bulk orders, contact Karin Craig at Sunrise River Press at 800-895-4585.

I Still Enjoy A Good Laugh!
A Guide for the Journey Through Alzheimer’s Disease
By Sharon Gregoire, OTR/L

If you need to rely on others for assistance or care, it is important that they understand a bit about your likes, dislikes, values, and wishes.

I Still Enjoy A Good Laugh! - A Guide for the Journey Through Alzheimer’s Disease is a sensitive and unique 40-page workbook written by Sharon Gregoire, a very experienced occupational therapist. Use this workbook to write down important information that others can use to help you maintain your physical, emotional, and spiritual well-being including the activities you like, the personal objects you value, and life wisdoms you want to share. This provides others with a useful and personal tool to support your dignity and sense of self throughout the Alzheimer’s experience. Complete this workbook on your own or with the help of a loved one and it may open up very meaningful areas of discussion.

I Still Enjoy A Good Laugh! can be purchased through Therapy Solutions, Inc. at 612-619-7381 or order it online at http://www.therapysolutions-mn.com/index.html
**Brainstorming**

We asked people with early-stage Alzheimer’s:

*“Why is it important to get an accurate and thorough diagnosis of memory problems?”*

Here are some of the answers:

“A diagnosis answers questions about what is happening to you and why. If you don’t know what you have, then you can’t learn ways to work around the problem.”

“Peer support — if you get a diagnosis, then you can try to find others with the same problem to talk to.”

“My wife used to think I was ignoring her. Now she understands my problem is Alzheimer’s. She’s become more tolerant of my memory loss.”

“If you get a diagnosis then your care partners can also get support and learn how to get help for themselves and for us.”

“If you know what is happening with your memory and you have a medical reason for the problem, you get less impatient with yourself when you mess up.”

“I started participating in research once I got a diagnosis. You can’t enroll in clinical trials unless you have a good work up and diagnosis. I want to help and get help in whatever way I can.”

“My doctor said there are lots of reasons for memory loss so you need a good evaluation. I was depressed and that was making my memory worse. I’m on medication now and my memory is better although it hasn’t fixed it completely.”

“I didn’t like being diagnosed with Alzheimer’s, but I’ve made friends as a result of it and that was unexpected.”

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**Between Us**

By Ken Saulter

Losing my memory, losing it to disease, is getting to be a problem.

Like when I’m in a group and people talk to me and suddenly I fall silent, while my brain skips a beat.

They, and I, know it’s not a simple senior moment.

Eyes divert to shoe laces or thereabouts.

The moment becomes one of palpable regret.

So here I am, a fraction of a person, A clown without make-up or costume, waiting giant seconds to recover.

They say I will not remember these separation bricks in the wall that is, regrettably, being built between us.

I worry about forgetting habits, like my gym locker combination, after 20 years of use, and my many passwords, and then, someday maybe, where I live; or maybe not.

And, against our will, the wall gets higher and higher.

But, I keep on living, trying to lower the wall or slow it down, or build a gate, or do something.

RESEARCH UPDATES

Encouraging Preliminary Results from Intravenous Immune Globulin

At the recent April 2010 American Academy of Neurology meeting held in Toronto, Canada, researcher Norm Relkin, MD, from Cornell University reported encouraging findings from a Phase 2 trial of Intravenous Immune Globulin (called IVIg or sometimes, IgIV) in people with mild-to-moderate Alzheimer's.

IVIg has been approved and used successfully for over 20 years to treat other medical conditions. IVIg is being investigated as a treatment to slow the progression of Alzheimer's because it contains antibodies that may help to defend the brain against the damaging effects of beta amyloid protein (a protein involved in Alzheimer's). Dr. Relkin presented preliminary findings from a small study of 24 participants that showed encouraging benefits in improved thinking and functioning as well as reduced brain atrophy (shrinkage) in persons receiving 18 months of IVIg treatment. Although the study was small, the findings are significant and exciting enough to warrant further study.

IVIg is now going into a Phase 3 clinical trial with collaborative study sites across the United States. The study is recruiting persons with mild-to-moderate Alzheimer's ages 50-to-89. For more information or to contact a study site near you, see the Clinical Trials website at: http://clinicaltrials.gov/ct2/show/NCT00818662

My Name is Not Dementia – Findings from a Survey on Quality of Life

The Alzheimer’s Society recently reported on a research project carried out in collaboration with the Mental Health Foundation to explore the issue of quality of life in people with dementia. The research used literature review, interviews, focus groups, and a postal survey and included a total of 44 people with dementia. Although this is a relatively small number, the findings are consistent with other research into factors that affect quality of life. The report identified ten significant influences on quality of life including (in order of importance):

1) Relationships or someone to talk to
2) Environment (feeling safe and secure)
3) Physical health
4) Sense of humor
5) Independence (being able to do things for oneself)
6) Ability to communicate (being listened to and being understood)
7) Sense of personal identity
8) Ability or opportunity to engage in activities
9) Ability to practice faith or religion
10) Experience of stigma (the desire to be treated sensitively and fairly)

The report summarized that people in all stages of dementia are able to communicate about their needs and should be encouraged to do so. To read more about this research or to download the full report, see the Alzheimer’s Society website: http://alzheimers.org.uk/site/scripts/documents_info.php?categoryID=200149&documentID=1339&pageNumber=1
Being Lost and Getting Found
Disorientation and Alzheimer’s

Spring is here and with warmer weather, many people look forward to being more active and getting outdoors for walks or other outings. One of the more frightening experiences of Alzheimer’s is the risk of becoming disoriented or lost in a previously familiar place. Memory loss or changes in vision and perception can make familiar environments look unfamiliar. Many people with early-stage Alzheimer’s continue to value their independence and making use of a few helpful strategies can increase your autonomy and safety.

There are three helpful programs for people with memory loss that can assist you in getting home safely if you become lost, disoriented, or injured and can’t find your way. These programs involve wearing an identification bracelet, necklace, or tracking device that is linked to a national database that police or paramedics can access if you need assistance:

• **The Comfort Zone** at 877-259-4850 or [http://www.alz.org/comfortzone](http://www.alz.org/comfortzone)
• **Medic Alert/Safe Return** at 888-572-8566 or find the information online at [http://www.medicalert.org/safereturn](http://www.medicalert.org/safereturn)
• **Project Lifesaver** at 877-580-5433 or [http://www.projectlifesaver.org](http://www.projectlifesaver.org)

Although some people resist the idea of wearing a bracelet or a tracking device, many people with Alzheimer’s report an increased feeling of security and independence knowing that they can more easily be located if they are disoriented or have a spell of confusion. Other strategies to limit risk of becoming lost can be used to supplement these location systems. Some suggestions from people with Alzheimer’s include:

• My son and I walk together every morning. We take the same route for the same amount of time. If I go alone, the route is familiar and I’m more likely to find my way home. If I’m gone longer than usual, he knows to come looking for me.
• I like to take walks by myself but sometimes my husband comes walking with me. He doesn’t give any directions. He just goes along to make sure I still know where I’m going. I don’t always like it, but I know he’s right to be concerned.
• I carry an ID card with me when I go out that says who I am and where I live.
• I got to know the neighbors on my walking route and told them about my Alzheimer’s so I can ask for directions or help if I feel lost.
• My wife bought me a voice-activated cell phone that she has me carry and keep on. It’s easy to use because I don’t have to remember numbers to call someone. If I’m out and don’t come back on time, she can call me. We taped my home phone number to the back of the cell phone so someone can call my wife if I need help.
• I don’t go out of the house by myself in extreme weather. When I’m too warm or too cold, I don’t think clearly and I don’t want to get lost in bad weather.
• I carry a small pocket tape recorder to record reminders to myself about directions or where my car is parked.

Discuss this topic with your peers and loved ones and you may come up with your own strategies to add to the list!

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