



Perspectives

A Newsletter for Individuals with Alzheimer's or a Related Disorder

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Living with Alzheimer's

By Kris Bakowski

I think there comes a point in everyone's life when we pause to reflect on the past, realize the present and look to the future. That happened for me at the age of 46. I'd been married for over 20 years, our son was in his freshman year of college, I was happy in my job and my husband was looking forward to retirement. We were all healthy, tried to exercise, eat right, and live an active life.

However, in the fall of that year I started to become forgetful – which was not like me at all. I had an almost photographic memory and relied on that all my life. I had a very stressful job and worked long hours, so I blamed that for my forgetfulness. I couldn't remember things like my home phone number, my associates' names or on bad days, how to get home. I remember that many times I would stop at a gas station, and after filling my tank, not know whether I was going to work or coming home from work. I tried desperately to hide it and became pretty good at it! But one day in December, my husband and I were out shopping, and he went to a different department in the store. The next thing I knew is that I couldn't remember where I was or how I had gotten there. It was time to fess up.



Kris Bakowski

I sought medical attention and after eight long months of testing, including all of the alphabet soup tests (EEG, EKG, MRI, etc.), blood work, spinal taps, B12 shots and neuropsychological testing, I was diagnosed with Alzheimer's. It was a relief to me because there was a name to it. Although it is an incurable disease, at least I knew what I was dealing with. My family, however, took a dimmer view. My husband likened it to the Titanic – that the ship was sinking, and he and my son were going to survive and I wasn't. My son re-

lected that it was like his mother was on death row, but innocent of the crime. Alzheimer's does not run in my family, or at least that I know of. My parents both died in their early 60s of other causes. My father was adopted when he was young, so we had no knowledge of his biological family's medical history.

After the diagnosis, my first call was to the Alzheimer's Association in Georgia where I live. My questions ranged from "What's next?" to "What can I do to help in finding a cure?" The staff at the Association were my saviors during the first days and months of my diagnosis. They guided me and were there to hold my hand through the whole "adjustment" phase.

All of that was five years ago, and thanks to the available medicine, I am able to live

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a somewhat “normal” life; although the definition of “normal” changes every day. I’m definitely not the same person I once was. I’m not as outgoing, not as self-sufficient, not as engaging, and definitely not the life of the party! We’ve mourned the things I can no longer do, and we celebrate the things I can still do. I have good days and bad days. I can no longer work because of this dreaded disease, but I still have feelings. I’m still a wife, a mother, a sister, an aunt and a friend.

But this is a silent disease. No one wants to talk about it. They don’t want to admit that they know someone with Alzheimer’s. Many treat you like you have the plague and if they acknowledge it, they will somehow get the disease. That is so hard for many Alzheimer patients. We want people to understand this disease because it is only through educating people that we are going to get the funds we need to help fight Alzheimer’s.

I don’t see a cure in my lifetime, but I’m hoping that by the time my son gets to middle age that there will be more available to him if he should inherit this from me. To me, the worst part of this disease is not what it does to me, but what it does to my family. It is not fair for them to have to take this unwanted journey with me. My son once wrote me this note: *“I know that you worry about your disease and how it affects our relationship, but I want you to know that I do not feel as if you have changed as a mother. I cherish the closeness of our relationship, and I understand the many forces acting on it. But you have remained unflinchingly loving and understanding, and I am indebted to you for it. I owe you my life. What makes me sad is that although I will always love you – in time you won’t*

be able to remember that I do. So, I’ll say it as often as I can now – I love you.” For that, if for no other reason, I hope a cure can be found.

The Alzheimer’s Association has been a partner with me. I have been able to feel helpful being involved in advocacy work, media interviews, speaking engagements, and Memory Walks. If you are reading this story, and are just learning a loved one has the disease or perhaps yourself, I would encourage you to seek help from the Association. If not from them, from other sources so you know that you are not alone. My involvement is my “therapy” because I’m hoping that in some small way I can help fight Alzheimer’s.

Family, friends, and others with Alzheimer’s help get me through the days. Love and support can come in all forms. Reach out to those who love you. You are not alone. I chronicle my experiences at <http://www.creatingmemories.blogspot.com/>. There are also forums on the Alzheimer’s Association Web site for you to participate in. It’s going to take all of us to help fight Alzheimer’s.

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Question and Answer

Q *I'm 70 years old and live alone. I was diagnosed with Alzheimer's a few months ago and my kids think I should move to a retirement home. Is that really necessary? I'm fine on my own.*

A Many people with mild symptoms of Alzheimer's live alone and function well. At some point, however, advancing symptoms can lead to safety problems and other risks to your quality of life. It will become necessary for you to either have help in your home or move to a new residence that provides assistance. Consider the following if you live alone or are alone during the day due to a working care partner:

Food preparation can become challenging. Burnt pots on the stove, spoiled food in the refrigerator, or weight loss from forgetting to eat nutritious meals can all create safety and health risks. Consider a home-delivered meals program. Limit stovetop cooking and use a microwave.

Many persons with mild memory loss have trouble **managing a checkbook** and keeping track of bills. Consider having mortgage or utility bills automatically paid through your bank account. Give a trusted family member or accountant power of attorney so he or she can work with you to manage your finances.

Consider signing up with an Emergency Alert program. If you fall and injure yourself or have a **medical emergency** while alone, you can get immediate assistance

by pressing a button on a special wristband or necklace. Contact your local hospital for the programs in your area.

Memory loss often makes it challenging for people to **manage medications**. This is a considerable safety risk for people who live alone or have to take medication during the day when their care partner is out. Purchase a pill organizer at your local pharmacy. Have someone work with you to fill the container for the week so you can keep track of your medications.

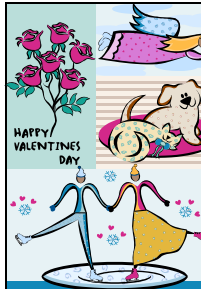
At some point memory loss or other symptoms will interfere with your ability to **drive a car**. Many seniors or others

with various medical disabilities face this challenge. Consider how you will get around if you can no longer drive. You may sell your car, eliminate your insurance costs, and put the money into a transportation fund to hire a driver. You can also explore any senior transportation services in your neighborhood or through local churches or senior centers.

Living alone with memory loss puts you at risk for **social isolation**. This may also be the case if you are at home alone all day. It may be harder to keep track of appointments on your calendar or to do activities you previously enjoyed with others.

Among the benefits of a retirement community is the built-in activities, meals, transportation, and community. If you stay in your home, it is important to stay connected with others and have some safety networks in place. Contact your local chapter of the Alzheimer's Association or senior center to see what programs, activities, and services may be available in your community so you can maintain independence while being realistic about safety and symptom management.





Brainstorming

Staying Young at Heart

In a recent support group meeting for persons with memory loss in San Diego, participants talked about how they stay “young at heart” despite their symptoms of Alzheimer’s. As you read their comments, you might want to ask yourself how you stay “young at heart.”

“I walk by the ocean and dig my feet in the wet sand.”

“I sit on the back porch with my dog and we watch the cats and birds in the yard.”

“I stay in bed in the morning as long as I want!”

“I was a high school swimmer so doing laps now at the YMCA makes me feel young at heart except I get out of breath easier!”

“Anything having to do with chocolate keeps me feeling young at heart.”

“Being with children. I’m drawn to them.”

“A good cup of coffee, tea or Schnaps gives me a boost.”

“I search out old items on the computer and re-read about history. It takes me back.”

“Music makes my heart sing. I love classical music especially.”

“I played football in college. Sometimes it’s like being there again when I watch a game on TV.”

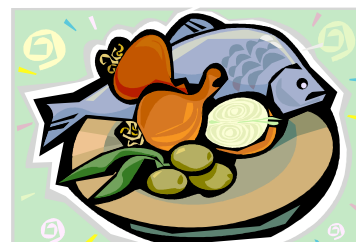
“Sometimes I feel like a big kid. Every day is a new day with new discoveries because I can’t remember anything! I laugh about it and that keeps me young at heart.”

Research Updates

Fish oil continues to be under investigation for prevention or treatment of Alzheimer’s. Fish oil contains DHA, an omega-3 fatty acid that is essential in human nutrition and healthy brain cell function. Greg Cole, professor of medicine and neurology at the University of California in Los Angeles (UCLA) and associate director of UCLA’s Alzheimer Disease Research Center, and his colleagues recently determined that the presence of DHA near neurons (brain cells) increases production of a protein called LR11. This protein is found at low levels in people with Alzheimer’s, and may be helpful in reducing the amyloid plaques associated with the disease.

The National Institutes of Health is currently conducting a large clinical trial with DHA in persons with Alzheimer’s. It is not yet clear whether DHA can have an impact once symptoms of Alzheimer’s are well underway, but the current trial hopes to shed light on this question. Dr. Cole is also hopeful that a large-scale prevention trial can be done in the future using fish oil at the earliest stages of Alzheimer’s where it may have the most benefit.

In the meantime, while we await the findings from the current clinical trial, research supports eating a few helpings of cold-water fish (especially salmon) each week to help maintain healthy brain function. Vegetarian sources of DHA are available through nutritional supplements found in health food stores.



BREAKFAST CLUB

By Donna Velarde, MSW

The Breakfast Club is a socially-based program for people with early-to-moderate stage memory loss and their care partners offered through the Orange County Chapter of the Alzheimer's Association in Southern California. The Breakfast Club provides a relaxed atmosphere where everyone has an opportunity to enjoy discussions and engaging activities together. While there is benefit to participation in separate activities designed for persons with AD or their care partners, the Breakfast Club provides a unique opportunity for couples to enjoy socializing and learning together. As one participant states, *"It is much more fun to be able to stay together with my spouse rather than in a separate group."* The group meets weekly for two hours and brunch-type snacks are available throughout the meetings. The Breakfast Club also takes field trips to destinations chosen by the group.

New friendships and lots of laughter are two major components that have made this group so successful. The group began less than a year ago with 4 participants, and now has 18 consistent participants. Group members cite the friendly, relaxed atmosphere and the socialization as reasons to attend every Tuesday morning. One participant speaks for many when she says, *"We are able to share problems and feel lighter when we leave."*

Upon arrival at the meeting, group members help themselves to snacks while engaging in lively conversation. When everyone is seated, and after check-in, the group engages in brain-stimulating edu-

cational games and activities, such as discussions regarding various subjects that have been researched by designated participants, or newspaper/magazine articles brought in by group members. Other activities include sharing of new and past experiences, family traditions and customs; bringing in and sharing crafts, photographs, skills, or hobbies; singing familiar songs from the past; and celebrations of birthdays and special occasions. Seasonally, the group discusses the significance of certain holidays, exchanges small gifts, and shares memories. And, there is always so much laughter!

Twenty minutes of light exercise follows and usually involves chair exercise, lifting "weights" (water bottles), or practicing balance movements. Guest speakers to the Breakfast Club have included an instructor of Laughter Yoga, and entertainment has been provided by the Dancing

Grand Daughters of one of the facilitators. Discussions are ongoing about future guests. The group also decides which activities and outings are of interest. Most recently, they visited the traveling Terra Cotta Warriors exhibit from China. Other excursions have included two botanical gardens, and the local zoo with more outings to other destinations being planned.

Group participants have expressed repeatedly that The Breakfast Club meetings are very important to them. One participant sums up the experiences of both persons with Alzheimer's and their care partners: *"We always go away from the group with something positive."*

For information about Breakfast Club, contact Donna Velarde at 949-757-3759 or email to Donna.Velarde@alz.org.



Voices of Alzheimer's: A Report from Alzheimer's Association Early-Stage Town Hall Meetings

By

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As many as half of the estimated 5.2 million people with Alzheimer's disease (AD) in the US are in the early stage, or beginning, of the disease. They have a unique opportunity to play an active role in their own decision-making and to participate in planning their future. Based on their testimony, they seek to be defined not by their memory loss or functional decline, but by their remaining abilities.

Between July 2007 and May 2008, the Alzheimer's Association hosted four regional meetings, launched an online "Virtual Town Hall," and Association chapters coordinated local town hall discussions in communities around the country. Each of these meetings used a common agenda to elicit feedback from participants with early-stage AD on specific topics and included open discussion. Based on emerging evidence in the field, guidance from the Association's national advisory group of people with early stage dementia, and discussions by the team convened for this project, three general

topics were identified for discussion: Interactions with the medical community; Changes in daily life; and Engaging community resources.

More than 300 people with early-stage AD participated, sharing their thoughts and perspectives on the experience of living with the disease. The results shed light on several important directions for empowering persons with AD. The following summary of themes is a brief review of the perspectives that were shared.

The Stigma of Alzheimer's and its Impact on Relationships

The main theme influencing much of the discussion is that people with early-stage AD are misunderstood because of myths and misconceptions about the disease and stigma associated with having AD. People with early-stage AD repeatedly point out that they are living with Alzheimer's, not dying from it.

Negative associations with AD have a direct impact on the relationships between people with AD and many people with whom they come into contact. People described changes in interactions with their family and friends, colleagues and co-workers, and with the medical community. People with early stage AD seek to work together with their communities to improve communication, positive involvement in life, and an acknowledgment of their ideas and contributions. Many want to be active in advocacy and awareness-raising in order to diminish stigma and enable the continuation of their personhood. One participant states: *"I'm not ashamed of having Alzheimer's. All of my neighbors are aware I have a problem and there is no ridicule, no stigma, and so I wish we would get it out of our minds that we've done something – that we need to go under the table and hide."*

Dissatisfying Interactions with the Medical Community

People with early-stage AD (especially younger-onset AD) report significant challenges in obtaining a diagnosis and follow-up treatment. They feel burdened by diagnostic testing procedures. Once AD is identified, they seek more complete information about what to expect and the steps that can be taken to enhance their quality of life through available medications and community resources. One participant echoed the concerns of many and said, *“Healthcare professionals need to take us more seriously and most of all, listen to our questions and concerns.”*

Uncertainty about Availability of Support Services

Many people with AD have limited knowledge about accessible and appropriate community support services. Still, they acknowledge the benefit of the services that are available and in which they have participated. Specifically, they highlight the importance of finding support, and seek support groups to connect with others that have shared experiences. They also describe the need for more services to educate them about AD, what to expect, and new developments in available research and emerging treatments.

Sources of Major Concern in Daily Life

People with early-stage AD recognize the changes in their independence and functional abilities. They fear the continued decline in independence and the prospect of becoming increasingly reliant on loved ones and other care providers. They hope that recognition of these fears will lead to their inclusion in decision-making and planning for the future. In the words of one participant: *“I’m not incapacitated and I don’t want to be treated as though I can’t be trusted to do things. It’s a bal-*

ancing act that for me, is constantly being navigated.”

Desire to Stay Involved and Make a Difference

Perhaps above all else, people with early-stage AD want to be heard and fight to remain engaged as contributing members of their community. They want to be included in everyday activities and remain social. They hope to have the opportunity to take advantage of their retained abilities by raising public awareness and advocating for change. One participant states, *“We need to educate and we need to let the National Institutes of Health (NIH) know to keep being funded and we need the money and we need the research and the medications. We need to fight, so please keep your voices going and keep pushing and keep moving.”* Whether in their community or with federal policy makers, they hope to tell their story and in doing so, put a “real face” on AD. When people with AD can continue participating in meaningful activities, then there is less focus on being defined by their symptoms.

The views expressed in the Town Hall Meetings provide a much-needed perspective on the experiences of those with mild AD. These individuals retain many capabilities, want to remain as independent as possible, and seek ways to contribute to the world around them. They hope to partner with others to express themselves and to remain the people they have always been, despite their symptoms.

Going forward, there is a shared responsibility -- for people with or without AD-- to preserve their humanity and work toward a world that welcomes the contributions of people living with AD and facilitates their participation in a variety of ways.

To access the full Town Hall Report, visit <http://www.alz.org/townhall>.

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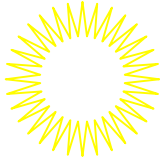
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