

younger-onset connections

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Living with Alzheimer's... Taking One Day At a Time

by Steve McGinnis

In April 2008, I was diagnosed with Alzheimer's disease. I was a High School Principal and was fifty four (54) years old at that time. I have been a teacher, Superintendent or Principal for thirty one (31) years. I have a Bachelors degree from the University of Tulsa and a Masters in Education Administration from Northeastern State University.

My wife started noticing odd behaviors...falling down/shuffling, slurring speech, blank spots in conversation, memory loss, anxiety attacks, trouble writing (even my signature,) tremors, personality changes (I became a complete jerk), was mean to people about things that had never bothered me before and became angry easily. All of these symptoms were pre-medication.

When I went to the doctor, I had MRIs and a spinal tap which revealed Probable Alzheimer's. At that time I was encouraged to continue working by the Local Board of Education and the superintendent. I began medication soon after the diagnosis. I am presently on Namenda and the Exelon Patch which has made an amazing difference in my life.

While I still have some symptoms, medication masks the others which allow me to function.

In June 2009, I was fired from my job for reasons that all relate to my disease. This is after thirty one (31) years of service, eight years as High School Principal in a small Oklahoma town.

I am living with Alzheimer's with the support of my loving wife and family.....taking one day at a time. I am thankful for the support of all my family and friends.

How to avoid caregiver burnout

Although your attention is focused on your loved one, be sure to mind your own physical and mental health. Make time for sleep, exercise, proper nutrition, socializing with friends, and moments when you can be alone. This may require asking for help, which is not always easy to do.

Remember that helping yourself will ultimately help your loved one. Monitor yourself for signs of caregiver burnout, which can include irritability, anger, anxiety, depression, sleeping problems, with-



Steve and Artha McGinnis

drawal from social activities, and denial about your loved one's diagnosis or your responsibilities as a caregiver. You might also experience extreme fatigue and health problems, such as ulcers, migraines, high blood pressure, or frequent colds and other illnesses.

Try joining a caregiver support group, which can provide education, emotional support, and connections to local services that can help you meet your caregiving responsibilities. Contact your nearest Alzheimer's Association for information about groups near you.

From Denyce's Desk:

A message from the new Younger-onset Coordinator



I consider it an honor and a privilege to follow in the steps of JoAnn Webster. She has been a great friend and mentor. I look forward to serving as the new Younger-onset coordinator. I am here to help both the person diagnosed with the disease and their care partners. Please email me: denyce.willis@alz.org or call me (918-494-5429) if you have a specific question or need. I would also like to ask each of you to send me your loved one's story, along with a picture. These articles will then be considered for future newsletters or other publications to inform the public about Younger-onset Alzheimer's disease.

Remember: When you learn that someone you care about has Alzheimer's, you may hesitate to tell the person that he or she has the disease. You may also have a hard time deciding whether to tell family and friends. Here are some suggestions for talking about the disease with your loved one and others.

Respect the person's right to know: You may want to protect the person by withholding information. But your loved one is an adult with the right to know the truth. It can be a relief to hear the diagnosis, especially if the person has suspected he or she had Alzheimer's disease. In many cases, people who are diagnosed early are able to participate in important decisions about their healthcare and legal and financial planning.

Help the person accept the diagnosis: The person may deny the diagnosis. Accept such reactions and avoid further explanations. If they respond well, try providing additional information. Reassure your loved one. Express your commitment to help and give support. Let the person know that you will do all you can to keep your lives fulfilling. Be open to the person's need to talk about the diagnosis and his or her emotions. Look for nonverbal signs of sadness, anger or anxiety. Respond with love and reassurance.

Telling family and friends: An Alzheimer diagnosis doesn't only affect the person receiving it. The lives of family members and friends may also drastically change. Be honest with family and friends about the person's diagnosis. Explain that Alzheimer's is a brain disease, not a psychological or emotional disorder. Share educational materials from the Alzheimer's Association. The more that people learn about the disease, the more comfortable they may feel around the person. Invite family to support groups sponsored by your local Alzheimer's Association. Realize that some people may drift out of your life, as they may feel uncomfortable around the person or may not want to help provide care. Alzheimer's disease can also impact children and teens. Just as with any family member, be honest about the person's diagnosis with the young people in your life. Encourage them to ask questions.

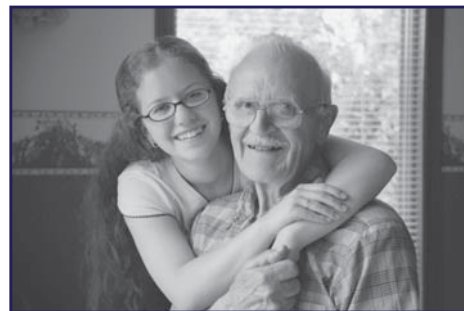
Board game helps families create memories

Making Memories Together® is an award-winning, non-competitive board game for people with major memory disorders such as Alzheimer's disease. The game does not help symptoms of Alzheimer's disease, but it does enhance the quality of life for the affected individual by making visits with family and friends more comfortable and enjoyable.

To play, families create individualized Memory Cards that help tap into pockets of preserved memories for the person with dementia. Materials for creating the Memory Cards are included with the game, along with extensive tips and techniques for

making the game engaging for all involved.

Making Memories Together® costs \$49.95 plus \$7.50 for shipping and taxes, and is available at Alzheimer's Association Shop for the Cause (www.alz.org/shop). Genco International, Inc., will contribute 20



percent of the gross sales price to the Alzheimer's Association through Dec. 31, 2010.

Notebook can help caregivers manage challenges

The Alzheimer's Association Caregiver Notebook, published by Meredith Corporation, can help a caregiver manage the challenges of caring for someone with Alzheimer's. The notebook's easy-to-follow format contains tips for care and planning for the future, as well as a list of resources to use when additional information is needed. Each of its eight chapters has a section to write notes or thoughts, making this book a personal record that can be referenced again and again.

Chapters include:

- Taking good care of yourself
- Understanding an Alzheimer diagnosis

- Basics of Alzheimer's disease
- Legal and financial planning
- Caring for a person with Alzheimer's

Convenient inside pockets and magnetic flap closure allow someone to store additional documents and keep information secure. Pilot testing of the notebook has shown that readers find it a valuable resource for their caregiving needs. Ninety-three percent said the notebook helped lessen their worries or concerns about being a caregiver, while 92 percent indicated they would continue to reference it.

The notebook will be available through Shop for the Cause (www.alz.org/shop) for \$17.95 plus shipping beginning Nov. 1, in time for National Alzheimer's Disease Awareness Month. To learn more about the Caregiver Notebook, visit www.alz.org/caregivernotebook.

2009 Tulsa Memory Walk a great success

A sincere thank you to all walkers, team captains, donors, sponsors, volunteers and everyone who contributed to the success of the 2009 Tulsa Memory Walk on October 3rd on the Oral Roberts University Campus.

From all those affected by this disease: Thank you to all who helped make our goal a reality! 6 teams were definitely connected to Younger-onset and among those 6 teams, \$17,260 was raised. The overall amount raised was \$233,315. The six team captains (and their team name) included Shirley and Bob Sillman (Forget Us Not), Chili Peppers (JoAnn Webster), Erin Peters (Team KK), Ben McGinnis (Team McGinnis), April Corser (Sharon's Cure Seekers), and Angie Carmichael (Angie's Team).



Pictured top clockwise: Steve McGinnis, 2009 Younger-onset Team, former Younger-onset Coordinator JoAnn Webster and Vice President of Marketing and Programs Tonda Ames.



Principles for a Dignified Diagnosis developed by people with Alzheimer's

Principles for a Dignified Diagnosis is the first statement of its kind written by people with dementia on the subject of the Alzheimer diagnosis experience.

In the 2008 report *Voices of Alzheimer's Disease: A Summary Report on the Nationwide Town Hall Meetings for People with Early Stage Dementia*, the Alzheimer's Association identified diagnostic challenges and dissatisfying interactions with the medical community as two major challenges articulated by people living with the disease. These principles are their insights on how to make that experience better.

o Talk to me directly, the person with dementia.

I am the person with the disease, and though my loved ones will also be affected, I am the person who needs to know first.

o Tell the truth.

Even if you don't have all the answers, be honest about what you do know and why you believe it to be so.

o Test early.

Helping me get an accurate diagnosis as soon as possible gives me more time to cope and live to my fullest potential and to get information about appropriate clinical trials.

o Take my concerns seriously, regardless of my age.

Age may be the biggest risk factor for Alzheimer's, but Alzheimer's is not a normal part of aging. Don't discount my concerns because I am old. At the same time, don't forget that Alzheimer's can also affect people in their 40s, 50s and 60s.

o Deliver the news in plain but sensitive language.

This may be one of the most important things I ever hear. Please use language that I can understand and is sensitive to how this may make me feel.

o Coordinate with other care providers.

I may be seeing more than one specialist — it is important that you talk to my other providers to ensure you all have the information so that changes can be identified early on and that I don't have to repeat any tests unnecessarily.

o Explain the purpose of different tests and what you hope to learn.

Testing can be very physically and emotionally challenging. It would help me to know what the purpose of the test is, how long it will take and what you expect to learn from the process. I would also appreciate the option of breaks during longer tests and an opportunity to ask questions.

o Give me tools for living with this disease.

Please don't give me my diagnosis and then leave me alone to confront it. I need to know what will happen to me, and I need to know not only about medical treatment options but also what support is available through the Alzheimer's Association and other resources in my community.

o Work with me on a plan for healthy living.

Medication may help modify some of my neurological symptoms, but I am also interested in other recommendations for keeping myself as healthy as possible through diet, exercise and social engagement.

o Recognize that I am an individual and the way I experience this disease is unique.

This disease affects each person in different ways and at a different pace. Please be sure to couch your explanation of how this disease may change my life with this in mind.

o Alzheimer's is a journey, not a destination.

Treatment doesn't end with the writing of a prescription. Please continue to be an advocate — not just for my medical care but for my quality of life as I continue to live with Alzheimer's.

The Alzheimer's Association is the leading voluntary health care organization in Alzheimer care, support and research. Our mission is to eliminate Alzheimer's disease through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health.

For reliable information and support, contact the Alzheimer's Association: 1.800.272.3900 or visit www.alz.org.

Caregiver Holiday Tips

Holidays are filled with opportunities for togetherness, sharing, laughter and memories. But holidays can also be filled with stress, disappointment and sadness. The person with the disease may feel a special sense of loss during the holidays. Caregivers may feel overwhelmed maintaining holiday traditions while caring for their loved one full time.

Here are some tips that will help you through the holiday season:

- ▶ Call for a conference call with family members to discuss holiday celebrations. No one can expect you as the caregiver to maintain every holiday tradition or event.
- ▶ Give yourself permission to do only what you can reasonably manage. Ask others to possibly consider hosting a holiday at their home. Or have several small gatherings at your home (in a familiar setting).
- ▶ Familiarize others with your situation by writing a letter that makes these points: “I’m writing to let you know how things are going at our house. You may notice that Dad has changed since you last saw him. Among the changes you may notice are _____. I’ve enclosed a picture so you know how Dad looks now. Because Dad sometimes has problems remembering and thinking clearly, his behavior is a little unpredictable. Please understand that Dad may not remember who you are and may confuse you with someone else. He appreciates your being with us and so do I. With your help and support, we can create a holiday memory that we’ll all treasure.”
- ▶ When hosting an event at your home, try having a quiet room, where your loved one can go as multiple conversations and background noise can be disturbing. Friends and family can go individually to this room to visit with your loved one.
- ▶ Assign friends and family to spend time (15–20 minutes each) engaged with the person with the disease. Engaging in conversation, looking at photo albums, or playing a game of checkers are a few ideas they could do together. Offer visitors communication techniques to use with the person with memory loss.
- ▶ If possible show pictures and discuss who is coming to visit. If your loved one has difficulty recalling names consider using name tags.
- ▶ Involve the person in safe, manageable activities. Ask your loved one to help you prepare food, wrap packages, help with decorations or set the table. (Note: Blinking lights may confuse the person with dementia). Maintain the person’s normal routine so that holiday preparations don’t become disruptive or confusing. Taking on too many tasks at one time can wear on you and your loved one.
- ▶ Build on past traditions and memories. Your family member may find comfort in singing old Christmas songs for example. They may also watch family favorite seasonal videos.
- ▶ Adapt gift giving: Encourage people to buy useful gifts for the person such as an identification bracelet (which the Alzheimer’s Association offers through MedicAlert + the Alzheimer’s Association Safe Return program); comfortable, easy-to-remove clothing, audio tapes of favorite music, videos, and photo albums with pictures of family members. Also get the person involved in giving gifts. For example, someone who once enjoyed cooking may enjoy baking cookies and packing them in tins or boxes. Or you may want them to help with wrapping presents. For the caregiver: A gift certificate for a massage, manicure or pedicure, or a household cleaning service. Others would appreciate respite care from an agency or a family member just to get away for a day or weekend. Maybe the caregiver needs some home repairs done or the garage cleaned out.



For a complete list of tips and other ideas visit our website at: www.alz.org/alzokar and click on the “News” link.

Volunteer Respite Buddy Program for people in early stage

The Tulsa office is expanding the current Respite Volunteer Program to include "Buddies" for people in the Early Stages of Alzheimer's and related dementias. Each "Volunteer Respite Buddy" would be matched with an Early Stage Alzheimer's family and spend 2-4 hours per week with the person with dementia doing activities they both enjoy. These could include going to museums and parks, to a coffee shop, out to lunch, golfing, fishing, shopping, a drive, or staying home and visiting or playing a game. Just a couple hours each week can make a big difference. If you are interested in volunteering or if you know a family who would like to be matched with a "Buddy" please call Cathy Sullins at 918-481-7892 or 800-272-3900.

Useful Resources

National Alzheimer's Association: www.alz.org
Find your local chapter, the younger-onset Message Board and Clinical Trials.

If you have moved and have a new mailing address, phone number and/or email address, please let Denyce Willis, younger-onset coordinator, know of this change. We want to stay connected with you and by providing us up-to-date information we can ensure you have the information you need. denyce.willis@alz.org, 918-494-5429.

CareFinder: www.alz.org/carefinder/index.asp
A website to assist in finding good care, coordinating care, planning and resources in your community.

Needy Meds: www.needy meds.com
A useful website for finding financial assistance for getting prescription medications.

