

Alzheimer's and Employment

By Carole Larkin

I am encouraged by seeing more and more excellent articles on various aspects of living with Alzheimer's or related dementias. One of these articles that caught my eye is in the December/January issue of *Neurology Now, the American Academy of Neurology's Magazine for Patients and Caregivers*. The magazine is **FREE** to individuals with a neurologic disorder and their caregivers. Order yours by calling 1-800-422-2681 or just go to: www.NeurologyNow.com and sign up. The article was called "Dementia in the Workplace" and was written by Gina Shaw. It had a number of issues and possible answers in it about being on the job with Alzheimer's (or Mild Cognitive Impairment, MCI). I'd like to bring some of them up for discussion.

1. The impact of Early Onset and Early Diagnosis:

This question is relevant because of the number of "boomers" at the age of Early Onset. Additionally, many see the need to work longer, due to the loss of assets set aside for retirement during the last several years. Many are planning to work into the years defined as "Late Onset". If they are diagnosed early in the disease (say during MCI, often a precursor to Alzheimer's disease), before symptoms mandate they leave their jobs, then they and their families will have the ability to determine when they will leave the workforce. They may be able to negotiate with their employer a change of positions, to one that they could more easily handle using aids such as day planners and checklists or by handing over more responsibility to co-workers and subordinates. This seems to be a far superior option, rather than being "let go" or "fired" due to job performance problems or having to deal with a crisis caused by an action or non-action due to the advancing cognitive disease. Pat Summitt, (the coach of the famous Lady Tennessee Volunteers basketball team, and a person diagnosed with early onset Alzheimer's disease), has used strategies such as handing over responsibilities and tasks to assistant coaches and keeping to a strict daily schedule using day planners and check lists to remain in her position as head coach.

2. Deciding to relinquish the job:

What factors should be considered when making the decision to give up the job? The author says safety is the first consideration! If other people's lives literally depend upon that person being cognitively at "full speed", that should be the first priority of the person with the cognitive issue and his family. Some of the examples she gives are: "a surgeon, a nurse, an airline pilot, or a school bus driver". Secondly, consider if the job holds great responsibility or involves large sums of money (either the company's or individual's), whether financial ruin could occur due to action or non-action due to the advancing cognitive disease. Third, consider the **stress on the individual** and the burden on his coworkers to pick up his "load" of work. If a job is a repetitive job, such as stocking shelves or being on a manufacturing line, the person may be able to stay on the job longer than a person who has to learn and process new information all the time, such as an Information Technology worker or a stockbroker.

3. After leaving the job:

Social Security recently ruled that Early Onset Alzheimer's disease qualifies for its "Compassionate Allowance" list of diseases. Diseases on that list get fast-tracked through the approval process for Social Security Disability benefits. Money isn't everything in life after being employed. Each and every one of us needs a reason to get out of bed every morning, meaning a sense of purpose and meaning to our day. People who have Alzheimer's are no different. It is **VERY IMPORTANT** to plan in advance, if you can, to have something that is either meaningful to your loved one, or helpful to others for them to do, after leaving employment. Things like yard work or gardening if that gives your loved one pleasure (a planter box inside if it's winter!), knitting clubs, or painting classes, if that's their interest.

Volunteering is excellent, perhaps at church assisting church personnel or at a hospital delivering flowers to patients, or assisting a little league team with their equipment. The possibilities are endless, and all non-profits need volunteers all the time. Without meaningful engagement, isolation and

depression can appear quickly. Your job as caregiver of a person with Alzheimer's is tough enough as it is, without depression adding to the challenges.

Friends of mine, Lee and Pat Sneller, are great examples of doing it right. Lee was diagnosed in 2009 while participating in a clinical trial for Alzheimer's (as a "normal" subject). Lee was an engineer, teacher and a businessman. After his diagnosis and the end of his employment, Lee is busy doing things he feels passionate about and also helps others. Pat and Lee give speeches about the fact that there is life after Alzheimer's, have been very active in the local and national Alzheimer's Association, working on committees, and generally being one of the "faces" of Alzheimer's in a uplifting and positive way.

Lee also volunteers for SCORE (Service Corps of Retired Executives), an agency of the Small Business Administration. As a business person, Lee always mentored people. He continues that today by coaching people who have their own small business or those who want to start a business. As a SCORE volunteer, he works as a counselor to provide guidance and advice. Lee (and his SCORE partner) meet with clients every week in the Flower Mound Chamber of Commerce offices. He also helps to organize monthly meetings, sends out emails, collects RSVPs, and helps the chapter stay on top of things. He does have some problems with this occasionally, sometimes forgetting to add something to a communication. He has decided to ask someone to review the emails before he sends them out so that he can continue to fill this role. He finds this responsibility very satisfying, since it speaks to his strengths in organization. I admire this couple for their attitude and their ability to create "Life after Alzheimer's."