Reflections on Being Resilient

So often when we hear about Alzheimer’s or a related disorder, the news is grim. We learn about the rising number of people with dementia, failed clinical trials, or the significant stress that families can experience. What is less recognized, however, is the inspiring resilience that individuals with dementia can demonstrate even in light of this challenging condition. But what does “resilience” mean and how can the experience of resiliency be achieved?

When discussing the topic of resilience during a recent support group for participants with early-stage Alzheimer’s, one man defined it for himself and said, “Somehow, you’re pushed so far, but you manage to come back – you compensate, withstand, and you bounce back.” A peer responded and said, “You try to analyze what happened and make plans to make changes and move on – it’s adjusting as necessary.”

Others talked about what helps to promote resilience. “You need to be assertive and let people know what you think,” states one man. Another participant adds, “Humor is essential. It would be hard to face the future knowing what you know if you didn’t have a sense of humor.”

In their recommendations of helpful steps towards building resilience, the American Psychological Association points to the importance of making connections with others and developing strategies for constructive and positive attitudes. Individuals with Alzheimer’s affirm these recommendations. One woman speaks to the value of attending her support group and the strength she gets from being with her peers: “If you don’t feel resilient in some way, you give up and you don’t want to do that. So that’s why we’re here.” And in their publication entitled “Don’t Make the Journey Alone”, Scottish authors diagnosed with a dementia write: “The best person to help you cope with your new life is yourself. It is your attitude that is going to be really important.”

Positive attitudes and coping strategies are acquired and developed throughout life. Some coping strategies may be familiar methods that you have used at other challenging times in life, while others may be new coping skills that you are developing to deal with memory loss and other symptoms. It’s never too late to learn helpful coping strategies. The following suggestions are reprinted here from the book Living Your Best with Early-Stage Alzheimer’s by Lisa Snyder

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(Sunrise River Press) and are summarized from feedback from many different people with Alzheimer’s who have advised on ways to be resilient and cope effectively.

**Get your mind off of Alzheimer’s.**
Staying busy can be a helpful way of coping with a variety of feelings. One woman says, “I don’t think about Alzheimer’s! I have lots of other wonderful things to think about - children, grandchildren, reading, walking, eating, and chocolate!” Another man agrees with this approach and says, “When my mind is on something else, I can’t think of myself, so I stay busy.”

**Learn to let go.** There may be times when you struggle to do something or make something go your way and it just isn’t going to happen. Try to stop the battle and take a break. Joe laughs when he says, “Look, half of having smarts is knowing what you’re dumb at. Don’t beat your head against the wall.”

**Focus on your remaining strengths.**
One man says, “Look, Alzheimer’s is only part of what I am not all of who I am.” You have many remaining abilities and positive qualities. Acknowledge them and make the most of them.

**Don’t give up on life.** Francoise states, “I am not giving up. There are other things besides having Alzheimer’s.”

**Think positive.** New Zealander Brian McNaughton writes, “If we passively shut up shop in the early stages of our disease and just concentrate on what a horrible card fate has dealt us, then we deserve to be miserable and should be ashamed of making the lives of those who love us so stressful. Instead, look for those opportunities to stray from the beaten path. Leave your dark rooms and open your hearts if you have trouble opening your minds. Hard at first I must admit, but easier the harder you try.”

**Give and receive support.** People with Alzheimer’s support one another through participating in groups, social programs, email chat rooms, or other activities. The opportunity to share with others who understand can ease many challenging feelings. Glen says, “You can always talk with your friends. We help each other out. We’d all be the first to help each other.”

**Learn to accept that you have Alzheimer’s.** Retired physician Dr. Donald Rhodes reflects on his process of coming to terms with his diagnosis stating: “There’s the intellectual acceptance part, and the emotional acceptance part, and you fuse them together for wanting to survive...With this, if you want to survive and continue, you have to accept. Then try and make realistic plans and accommodations for your life.”

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In a 2002 article that he wrote for Perspectives newsletter entitled “The Alzheimer’s Survivor”, Thaddeus Raushi embodies concepts of resiliency with his wise perspective: “I’d like to suggest that there are Alzheimer’s survivors. For me, surviving is both attitude and action. It means that even while knowing that I have this disease, I can still go on with life always doing the best I can with what I have at any given point. This is the attitude of seeing life worth living. This is also the action of moving ahead with doing whatever is quality living at that moment...As my wife and I move forward together, we want to be able to have a sense of humor about them...We want to remain believing that we are, at any time in our relationship and decision making, doing the best we can with what we have.”

As you think about the topic of resilience, consider discussing these questions with others: What does resilience mean to you? In what ways are you being resilient or adapting, as needed? What helps you to feel resilient?

Let us know your thoughts! Send any responses or comments to Lisa Snyder at lsnyder@ucsd.edu.

Article references:
Living Your Best with Early-Stage Alzheimer’s  
http://www.amazon.com/Living-Your-Best-Early-Stage-Alzheimers/dp/1934716030

The Road to Resilience  

Don’t Make the Journey Alone  
http://www.alzscot.org/. Click onto Information and Resources and find the section Living with Dementia. Scroll down to find title.

Question and Answer

Q I heard in the news about a new blood test that can predict if you will get Alzheimer’s. My kids worry about getting Alzheimer’s. Should they be tested?

A In recent years, researchers have been investigating ways to detect early changes in the brain through “biomarkers” such as blood, cerebral spinal fluid (obtained by a lumbar puncture), or brain imaging (using PET scans or MRI). These biomarkers may capture Alzheimer’s disease (AD) changes many years before any noticeable outward symptoms are evident. If these earliest changes can be detected, then ideally, persons at risk for developing AD could start a treatment or other intervention early on in an attempt to prevent or postpone disease onset. However, there is currently no treatment available to prevent AD.

Recently researchers at Georgetown University in Washington DC and University of Rochester in New York found low levels of certain lipid fats in the blood that were 90% accurate in predicting in a small group of seniors those who would go on to develop AD within two-to-three years. Researchers caution that this finding must be replicated in much larger numbers and in diverse populations in order for it to be valid. They also caution against anyone seeking a blood test at this time due to lack of treatment. Thinking that one is likely to develop AD may have negative consequences. The bottom line: Worried offspring should not pursue this blood test and much more research is needed.
Mindful and Spiritual Living with Alzheimer’s

By Lou A. Bordisso, Ed.D

Many years ago, I journeyed from Sacramento, California to Milwaukee, Wisconsin to begin a year as a Novice with a Roman Catholic order. In the middle of my cross-country journey, I stopped in Nebraska at a monastery for a mini retreat and rest from the long drive. During my short retreat, I was assigned a senior monk as my “mentor” who helped me to get through the complicated morning and evening prayers, songs, and flipping back and forth through the pages of monastic rituals. I was honored to have him give me a guided tour of the monastic grounds as well.

The monk, as I recall, was quite elderly and disfigured with his shoulders slumped forward as he walked with his cane. He looked like he was in a considerable amount of pain as he attempted to move about. Even with his body failing him, I could not help but to notice a glow on his face and a sense of gentle compassion in his voice and gestures. I recall being in awe of him. Even when we were not engaged in conversation he appeared to have a manifestation of something sacred or a divine presence. At the same time, there was no explicit talk about God or a Higher Power, or anything spiritual. St. Francis once said, “Preach often, but use few words.” Even though this monk was a Benedictine and not a Franciscan, he embodied the spiritual wisdom of St. Francis in his very being. I came to know and respect his patience, prayerfulness, and sage-like wisdom.

Living with Alzheimer’s or a related dementia can be daunting on a daily basis. As many of us know, there are good days and not-so-good days. I often liken my “not-so-good” days as a desert experience of dryness and thirst for my life to be more than it is in the moment. However, I then reflect on my experience with my elderly monk-mentor with his physical pain and brokenness. In the midst of his pain and brokenness, he was able to become a manifestation of peace, joy, and hope. He modeled for me a way for me not to get rid of my pain and suffering, but a way to live through it. Through years of introspection, contemplation, and meditation, he came to encounter a sense of the sacred or divine within himself, which sustained him during moments of daily strife.

I may never come to embody what my monk-mentor has discovered on his journey. However, when Alzheimer’s becomes overly “dispiriting”, what I can do is reflect back to his example and look deep within, be honest with myself, and identify what may be “disfigured” and seek to “transfigure” my attitudes, actions, and physical/emotional sufferings by finding a “quiet place” within – even if it is just for a moment or two – in order to quench my thirst in the midst of my desert experience.

Editor’s note: Lou Bordisso resides in northern California. In December 2013, he received a “Threads of Hope” award from his community for his courageous and inspiring perspectives on living with Alzheimer’s. He has recently started writing a blog that can be viewed at: http://alzreflection.blog.com/.
Living Well with Alzheimer’s – Our Perspective
By Ken and Mary Margaret Lehmann

Recently, we watched a PBS documentary about a program for persons with dementia in California. The conclusion suggested that for many people in the program, there was a much slower rate in the progression of the disease than expected. We looked at each other and immediately agreed that our experience in the Living Well Program in Minnesota has had the same results for many of its participants.

Living Well: A Holistic Program for People with Early Memory Loss is sponsored by the Minnesota/North Dakota chapter of the Alzheimer’s Association, the Amherst H. Wilder Foundation, and the St. Paul Jewish Community Center (JCC). It is a twelve-week program, which offers participants learning opportunities to live well each day with good nutrition, exercise, cognitive challenges, socialization, and creative arts.

The outstanding staff, led by Susan Ryan, an occupational therapist from the Wilder Foundation, is welcoming, caring, and inclusive with all their smiles, hugs, and laughter. There is no judgment and ACCEPTANCE is the by-word. The program and staff have sustained and supported us and as a result, we are thriving in the face of Alzheimer’s.

We have learned that a diagnosis of Alzheimer’s does not represent the end to all that is good in life. Staff members focus on the positive strengths of each person, celebrating their successes and achievements. The results are amazing to observe. Who does not thrive with the rewards of recognition and validation?

The program, depending on the focus of the day, includes a myriad of activities such as: painting, clay, movement/dance, writing, poetry, learning about other cultures, learning local transportation options, discussions on a variety of topics, field trips to museums, restaurants, and also, question/answer information sessions with Dr. Michael Rosenbloom, MD, Neurologist, and Dr. Terry Barclay, PhD, Neuropsychologist. Each session begins with 30 minutes of Ageless Grace™ exercises. The smiles turn to laughter as the creaks and cracks in our bodies transition to smooth, uninterrupted movements so important for the brain and heart.

As a person with Alzheimer’s, I, Ken, always return home energized, enthusiastic about life, and smiling. What I like best about Living Well is the socialization. I have “best friends” and this is very new for me. For years before my diagnosis, I withdrew from social situations and friends. I became more and more isolated. Socialization is essential for persons with Alzheimer’s.

And I, Mary Margaret, the care partner, could not be more grateful. Living Well also embraces a Caregiver Café just down the hall. Here, education of the disease, as well as discussions in the areas of health and wellness, relationships, sense of self, and managing stress, are offered. It is led by Jen Finstad, an incredibly knowledgeable, supportive, Wilder social worker. I began Living Well’s Caregiver Café “at high risk of distress.” I tested at “mild to no risk” twelve weeks later and have maintained that status for the last year.

For more information about the Living Well program, please contact Susan Ryan at: susan.ryan@wilder.org.
Helpful Resources

Counseling People with Early-Stage Alzheimer’s Disease – *A Powerful Process of Transformation*

Robyn Yale, LCSW has long been a pioneer in helping people with early-stage memory loss to have a voice. Her first book *Developing Support Groups for Individuals with Early-Stage Alzheimer’s Disease* raised awareness to lay the groundwork for those working to develop discussion forums and support programs for people with early memory loss. Many people with Alzheimer’s around the world now speak to the value of being able to participate in a support group and the healing that comes from feeling that you are not alone.

In her new book, recently published by Health Professions Press, Yale creates a model for counseling persons with early-stage dementia that also provides a hopeful framework for living with dementia. The counseling approach was implemented in collaboration with the Atlanta, Georgia Chapter of the Alzheimer’s Association and evaluated by the Georgia Health Policy Center. With so many people being diagnosed earlier in the course of Alzheimer’s, working with a skilled counselor can be life-changing. As one person who participated in the counseling program stated: "You get your diagnosis and a prescription, and the doctor says to come back in six months. So you’re left thinking, ‘Now what?’ It’s a very scary feeling. The counseling has been tremendously helpful, informative, and reassuring to me, and I hope it will become available to more people in my situation."

But the process may not only be remarkable for the person with memory loss. Counselors who participated in implementing the model also speak to the “powerful transformation” that Yale discusses. As one counselor said, "Counseling one of our participants was one of the most profoundly moving experiences of my professional life; I felt privileged to witness her capacity for accepting her Alzheimer’s and continuing to live her life with joy. To just be with her while she panicked, surrendered, and then found her way back..."

For more information about *Counseling People with Early-Stage Alzheimer’s Disease* or to order a copy, see:


**Alzheimer’s Association "I Have Alzheimer's" Website**

The Alzheimer’s Association recently created *I Have Alzheimer’s* — a new section on their website to provide useful information and advice to people with early-stage Alzheimer’s or a related disorder. *I Have Alzheimer’s* was created with input from individuals living with Alzheimer’s. The website content helps answers many questions including:

- How do others respond to the diagnosis?
- How does Alzheimer’s progress?
- How should I plan for my future?
- How do I live day-to-day?

The website offers information and advice directed to people with Alzheimer’s but can be helpful to families, friends, and professionals, as well. You can explore content on the *I Have Alzheimer’s* website at: [https://www.alz.org/i-have-alz/i-have-alzheimers-dementia.asp](https://www.alz.org/i-have-alz/i-have-alzheimers-dementia.asp)
New Series of 2014 Clinical Trials

In the past decade, there have been a series of disappointing clinical trials in which hopeful treatments have not proven beneficial. Researchers remain determined, however, to make headway in more effectively treating mild cognitive impairment (MCI) and Alzheimer’s disease (AD). The following are two hopeful clinical trials that will be enrolling participants throughout the US in 2014:

**NOURISH AD – Providing Energy to the Brain**

There are many supplements on the market that aim to boost brain power, but rarely are these supplements evaluated through rigorous or unbiased clinical trials where they are compared to a placebo. This study will test a powdered drink (AC-1204) that has been scientifically formulated to increase ketone bodies in the blood. Ketones are a naturally occurring energy source for the brain. Researchers hope the treatment can improve thinking, functioning, and quality of life in study participants with mild-to-moderate Alzheimer’s. Contact Janet Vogel at 303-999-3703 or jvogel@accerapharma.com. Read more about the clinical trial and it’s 65 enrollment locations across the US at: [http://www.clinicaltrials.gov/](http://www.clinicaltrials.gov/). Put AC-1204 in the website’s Search for Studies box.

**SNIFF – The Study of Nasal Insulin to Fight Forgetfulness**

Growing evidence has shown that insulin, a naturally occurring hormone, has many purposes in the brain. Abnormal insulin levels, or fluctuations in levels, may contribute to the development of Alzheimer’s disease. This study will examine the benefits of nasally administered (sniffed) insulin on thinking abilities in people with mild cognitive impairment (MCI) or mild Alzheimer’s. Individuals with diabetes or those with a history of insulin use are excluded from this trial. This trial is enrolling at 29 sites across the US. For more information, contact Jeffree Itrich at jitrich@ucsd.edu or 858-246-1317. Read more about the clinical trial at: [http://www.clinicaltrials.gov/](http://www.clinicaltrials.gov/). Put SNIFF, Alzheimer’s in the website’s Search for Studies box.

**New 2012-2013 Alzheimer’s Disease Progress Report:**

The latest edition of the annual Alzheimer’s Disease Progress Report from the National Institute on Aging (NIA) at the National Institutes of Health (NIH) is now available online. Each year, this excellent report highlights recent progress in NIH-supported Alzheimer’s disease (AD) research. Contents include: discussion of the National Plan to Address Alzheimer’s Disease; biology and biomarkers of AD; genetics; risk factors; advances in detecting AD; potential new therapies to treat, delay, or prevent AD; caregiving; and gender and racial differences in the impact of Alzheimer’s.

Other features include a video introduction by NIA Director Dr. Richard Hodes, a primer on Alzheimer’s disease and the brain, tables listing NIA-funded clinical trials, and videos that further explain critical areas of study.

Read this comprehensive report online at: [http://www.nia.nih.gov/alzheimers](http://www.nia.nih.gov/alzheimers). Click onto Publications for many NIA resources.
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