

PERSPECTIVES

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HERE AND NOW

By Lou Bordisso

Following my dementia diagnosis several months ago, I came to realize that I have no idea how long my memory and cognitive functions will serve me. There is more of a sense of urgency so I am "seizing the moment" and enjoying life to the fullest, as I am able. In many ways, I am happier now than I ever have been in that I am focused on the "here and now," focusing on the present moment rather than being worried about the future, and having fewer regrets about the past. Prior to my health challenges, much of my life was taken up with striving for this or that and not really paying attention to the things I value most - primary and secondary relationships, spirituality, and health.

For me, to live in the moment and to really appreciate the things and people I value most, I have embraced the spiritual practice of mindfulness and stillness. The ability to live in the present moment deepens, develops, and matures when there is an *intention to pay attention*. I have found that I am unable to pay attention to the present moment when I am preoccu-

pied with the past or future. At this chapter in my life, in order for me to live life to the fullest, I need to take time out to find solitude, meditate, and contemplate on a regular basis. Real life is hidden from awareness and consciousness if I do not.

There are several ways I have discovered to be helpful in cultivating stillness and mindfulness. When I had a 40-hour work week, it was difficult to "fit in" the time for stillness. Now that I have been gifted with time and more appreciation of the things that I value most, I am more able to practice my spiritual disciplines by having a more balanced lifestyle.

I strive to take time each day for spiritual reading from the religious tradition I am most comfortable with and reflect on the wisdom of my spiritual tradition. Each day, time has been set aside for some sort of prayer, meditation, and con-

templation. I have discovered that morning is best for me in that my mind is fresh. Others might find that different times of the day for their spiritual practices can be more helpful. Daily walking (or some sort of physical exercise) can also nurture stillness and contemplation, as it is a deliberate exercise to strengthen body, mind, and spirit.

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Lou Bordisso with monks in Thailand

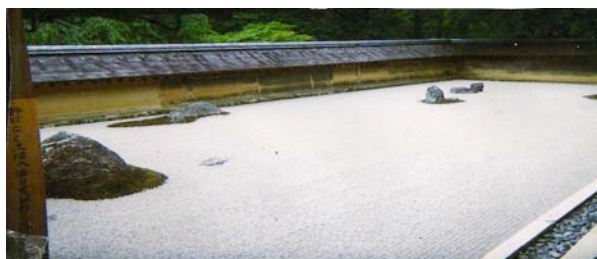
HERE AND NOW

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Finally, I have found that some form of a communal experience helps to kindle my spirits in that I am able to get support and encouragement with others who share similar values. Some people find that dementia support groups work, others find solitude in 12-step recovery meetings of some sort, while others have returned to their spiritual roots in a given religious tradition. Each of us is unique and is gifted with our own temperaments and spiritual styles.

Many years ago, I had an opportunity to visit spiritual traditions other than my own. When I was employed by the Navy as a civilian employee assistance program administrator and counseling psychologist, I frequently traveled to Asia to meet ships at various ports of call. I had many opportunities to learn about and appreciate different faiths. While en route, I stayed a few days in Thailand and took the Buddhist Temple tour. Later in life, I also had the great joy of visiting Kyoto, the Buddhist center of Japan. While there, I journeyed to a Buddhist monastery to

experience the famous meditation rock garden. I found the rock garden to be fascinating but I gained the most spiritual insight as I departed. There was a very small sign that said, “The Usual Path” (in order to direct tourists back to our destination). The sign did not say, “The Right Path” or “The Only Path”, it simply said “The *Usual* Path.”



Ryoanji Temple rock garden, Kyoto, Japan

There is no right way or one way to cultivate stillness or live in the present moment. Each of us living with dementia or related memory challenges is invited to discover our own path as we journey through this chapter in our lives. I have found that my diagnosis has turned out to be a gift in that I am more content now than I have ever been. Maybe it is because of my diagnosis and not in spite of my diagnosis that I have rediscovered and rekindled my spiritual roots and have come to appreciate what I have *here and now*.



Lou Bordisso has Masters degrees in Divinity and in Marriage and Family Counseling, and a Doctorate in Counseling and Educational Psychology. He is a former priest within the Old Catholic faith tradition and was a hospice spiritual care chaplain. He is currently a member of the ecumenical Order of St. John Vianney. Bordisso provides pastoral counseling and spiritual care for clergy and lay persons. He is currently program host for the public broadcast, Political Inquisitions, which addresses ethics, morality, spirituality, and politics. He also serves as an early-stage advisor for the National Alzheimer's Association and is active in his local Alzheimer's Association Chapter.

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RESEARCH UPDATES

Resveratrol Clinical Trial



Many people are interested in “natural” treatments for Alzheimer’s. Some will spend a great deal of money on supplements that claim to treat the disease, even when research does not support the claims.

Thus it is important to test any potential benefit of a natural supplement through well-designed clinical trials.

Resveratrol comes from plants and is found in the skin of red grapes and in red wine. Some research has suggested that limited consumption of red wine may lower the risk of developing Alzheimer’s, and researchers hope that beneficial compounds in resveratrol may also help to treat persons who have the disease.

This double-blind placebo-controlled study is coordinated by the federally funded Alzheimer’s Disease Cooperative Study (ADCS). The 12-month study will enroll 120 participants with mild-to-moderate Alzheimer’s from 26 sites across the United States. Participants must consent to blood draws, magnetic resonance imaging (MRI), and lumbar puncture (LP). Enrollment will likely open in April, 2012.

For more information on this clinical trial and a listing of participating sites see: <http://clinicaltrials.gov/ct2/show/NCT01504854>

Tau Protein in the News

Alzheimer’s disease is characterized by abnormal protein deposits in the brain. Beta-amyloid forms sticky “plaques” outside the brain’s nerve cells and tau protein forms “tangles” inside nerve cells. Both of these processes contribute to cell destruction and progressively damage

brain function. Much research has focused on reducing beta-amyloid plaque, but less research has been done with tau and its role in disease progression.

It has been known for many years that tau tangles begin in the region of the brain where memories are first made and then they eventually spread throughout the brain. But how this spread occurs has not been clear. Researchers at both Columbia and Harvard Universities now have data that suggests tau tangles spread by jumping from nerve cell to nerve cell across synapses, the connections between cells that allow their communication. Many researchers across the country have been quick to clarify that this spread of tau does *not* suggest that Alzheimer’s spreads like an infection or is contagious. The finding, does, however, open up exciting possibilities for research into new treatments that could ultimately block tau transmission and prevent disease progression.

The Buzz About Bexarotene

Researchers at Case Western Reserve recently reported on the ability of a cancer drug, bexarotene, to dramatically reduce beta-amyloid and improve functioning in Alzheimer mice. Since the drug is already approved to treat a rare form of cancer, some may be tempted to try to obtain it for treatment of Alzheimer’s. Much caution is warranted, however, because mouse models don’t fully replicate humans, and treatments that have work in mice have not always worked in humans. Bexarotene also has known side effects and has rarely been used in the elderly. Although someone could manage to obtain this expensive drug on his or her own, issues such as what dose to take, and how often to take it, and what side effects to look out for are not well understood. Results could be more harmful than beneficial. The findings from this study are novel and very interesting to researchers, however, and human clinical trials will likely begin soon. Stayed tuned!

Staying in Touch and on Track

Many people with Alzheimer's or a related disorder are at risk of becoming lost while out in their communities or while traveling. Yet most also discuss the importance of being able to maintain their independence. You may value being able to go out and about alone, but you or your family members may also worry about your risk of disorientation or an episode of confusion that could threaten your safety.

The National Alzheimer's Association estimates that up to 60% of people with dementia will become lost or disoriented as a result of memory loss, confusion, or disorientation. This may occur when walking or when driving. In October, 2008, the state of Florida established the "Silver Alert" program to help law enforcement find missing seniors with dementia, including persons lost while driving. Meredith Howe, PhD, RN and researchers at the College of Nursing at University of Florida reviewed data from 154 missing persons reported to the program. They found that more than 60% of drivers with dementia who were reported to the Silver Alert program went missing while on routine or familiar outings to local destinations. This is important to note because many persons with dementia think it is safe to drive as long as they stay close to home or in familiar places.

There is a growing interest in the use of global positioning systems (GPS) tracking systems to help people with memory loss maintain their independence while also maximizing their safety. Although the idea of being "tracked" may not appeal to

everyone, in fact, using current tracking technology with trusted family members or friends can help you to maintain some freedom and independence while also maximizing safety. In the event that you become lost or disoriented while out and about, there are a variety of devices that can help locate you so that you can readily receive help if needed. A few options are:

Tracking Shoes

Global Tex Exploration (GTX) Corp and Aetrex recently patented a GPS shoe for people with memory loss that comes in a variety of styles and allows the wearer to be located through GPS technology embedded in the shoe. An overview of the shoes is on the company website at:

<http://www.gpsshoe.com/>

Cell phone Technology

Some cell phones come with GPS technology that enables the phone to be found if it is missing. If you carry the cell phone and you become lost, you can then be located and found through tracking the

phone's location. See an explanation and review of these cell phone systems at:

<http://electronics.howstuffworks.com/gps-phone.htm>

Personal tracking devices

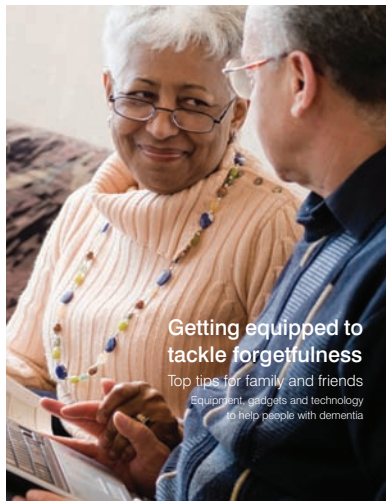
There are many devices on the market that can be used to keep track of your location. An internet search of "personal tracking devices" reveals many choices. The Alzheimer's Association provides a web-based location management service called "Comfort Zone" so families can track the whereabouts of a loved one. You wear or carry a locator device or have one mounted on your car, and family members can access information about your whereabouts by using the internet or calling a monitoring center.

<http://www.alz.org/comfortzone/index.asp>



HELPFUL RESOURCES

Getting Equipped to Tackle Forgetfulness

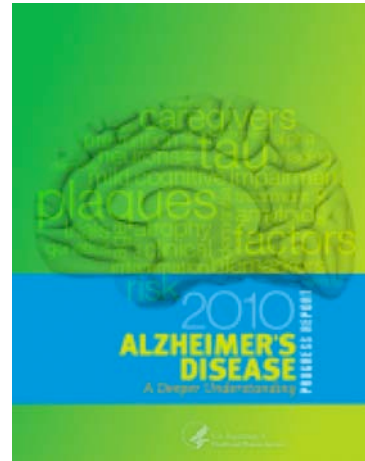


The Foundation for Assistive Technology; Innovations in Dementia; and Trent Dementia Services Development Centre are all innovative non-profit organizations in Great Britain that have collaborated on a free publication to introduce the role technology can play in helping people with early-stage dementia live more independently and enjoy better quality of life. The booklet aims to help readers understand how novel equipment and technology can support both the independence and safety of a person with dementia while also providing assistance or relief to care partners.

The guide discusses the role technology can play in daily activities such as finding things, maintaining safety, managing medication and staying connected to others. Content is based on experiences and testimonies of people with dementia and their care partners who were involved in development of the booklet.

Getting Equipped to Tackle Forgetfulness is available to download at the Foundation for Assistive Technology homepage at: <http://www.fastuk.org/home.php>

Latest Alzheimer's Research Progress Report Released



The latest annual Alzheimer's disease research report from the National Institutes of Health (NIH), is now available to read or download online. *2010 Alzheimer's Disease Progress Report: A Deeper Understanding* highlights important developments and directions in NIH-funded research. The comprehensive booklet is prepared by the National Institute on Aging, which leads the NIH effort conducting and supporting research on Alzheimer's and related disorders, including Mild Cognitive Impairment (MCI). Contents include:

- risk for developing Alzheimer's
- an overview of Alzheimer's
- genes that play a role in the disease
- neuroimaging and biomarkers that detect and track the disease
- research into new treatments
- lifestyle factors that may worsen or protect against the disease
- help for caregivers.

Special features include animation showing the progression of Alzheimer's in the brain and video interviews highlighting new insights into the disease. The publication is available in electronic format only. To read or download the PDF, visit the ADEAR website at:

<http://www.nia.nih.gov/alzheimers/publication>

INNOVATIVE PROGRAMS Using Photography and Film

SEPIA

Seniors Exploring Photography, Identity, and Appreciation

The SEPIA Initiative at the Museum of Photographic Arts in San Diego, California is a series of exciting and engaging opportunities offered for senior citizens including persons with Alzheimer's or a related dementia. The initiative encourages seniors to be engaged with both art (specifically photography) and their community by promoting art-based discussions and opportunities to create photographic images. Program Coordinator, Cara Goger states, "With the turning of every year the ways in which our eyes see the world changes. Experience and wisdom clarifies our perspective and allows for unique artistic expressions."

SEPIA aims to open creative avenues for seniors with and without dementia and can be modified for the varied needs and abilities of participants. The initiative offers a variety of ways to engage in photography and can be adapted to persons with varied levels of cognitive and functional ability. The program offers the following:

- Museum tours conducted by specially trained docents to engage visitors with dementia in discussion, art appreciation, and creative imagination about the photographic images on display.
- A simple and fun four-session digital photography course designed to intro-

duce participants to digital cameras and creative photo taking.

- Outreach to Alzheimer's residential care homes or adult day programs whereby SEPIA staff bring photographs from the museum collection to generate discussion and to inspire art appreciation and engagement.

Coger has coordinated one community-based exhibit of photographs taken from seniors without dementia in the SEPIA program. The images touch on themes of identity and self-expression reflecting meaningful experiences and places in the artists' lives, from capturing images of a



local community garden to visually conceptualizing the feelings of rebirth after major surgery. "It was a rewarding experience for me to watch these artists share their beautiful work with their family and friends. I am looking forward to showcasing more SEPIA work in the future," Goger states. She hopes to expand this coming year to profile the works of persons with dementia, as well. "People with Alzheimer's are often very

creative," she states. "They can be spontaneous and less self-conscious in our discussions and in their creativity and that makes them really rewarding participants to work with."

All programs, staffing, cameras, and other materials for the SEPIA Initiative are provided free of cost to the program participants. Funding for the initiative is generously provided by the Metlife Foundation and the James Irvine Foundation.

For more information about the SEPIA Initiative, please contact Cara Goger at: 619.238.7559 X 225 or goger@mopa.org.

TELLING OUR STORIES: Using Film to Hear the Voices of People with Dementia

Innovations in Dementia is a community interest company (not for profit) based in the United Kingdom. They work with organizations and communities to make sure that people with dementia can stay engaged in their communities and lead meaningful lives. They are also involved in a variety of collaborative and creative community-based partnerships and endeavors to help empower people with dementia and improve their quality of life.

Innovations in Dementia has undertaken two video-making projects to explore the varied messages of people with dementia. One project focuses on individual stories. The project directors note that the film contents are not solely about the experience of dementia. “They are about people living their lives positively, with vitality and creativity. They are about people who are still learning, and still growing. They show that dementia is life-changing, but not life-ending.”

Film provides a rich opportunity to share stories and reflections and also serves to challenge negative stereotypes or stigma associated with dementia. Despite memory loss and other symptoms that can affect communication, many people with dementia have a story to tell or something that they want to say. Additionally, some people with dementia who engage in public speaking have shared that they can often be unsure on a day-to-day basis how they will feel; they can become very worried about their ability to perform on any given day. “By using film,” states one of the program directors, “we can enable a wider range of people with dementia to have a say, in comfort, and in their own time, and in a form that allows their voice to be heard forever.”

Innovations in Dementia, Age Concern Woodley, and Be Inspired Films collaborated on a second project (funded by Big Lottery) that focused on the filming of a group of young-onset dementia participants at Age Concern Woodley, a club for people with dementia under age 65. The film called “My Life, My Dementia, My Club” can be seen at:

<http://www.myid.org.uk/films>

Based on their experiences of filming a two-day workshop at the club in October 2011, the project collaborators created an informative instructional booklet on involving people with dementia in film. The project and the booklet aim to encourage other organizations and groups to create their own films with people with dementia to ensure that their voices are heard. The booklet covers helpful information including:

- Ways you can use film with people with dementia
- How to get started
- How to involve people with dementia in the filmmaking process
- Obtaining consent to be filmed
- Choosing the participants to work with
- Equipment and technical advice

The booklet is available to download at: <http://www.myid.org.uk/films>

For more information about these projects contact Nada at Innovations in Dementia: nada@innovationsindementia.org.uk .



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