Reflections from a Physician Living with Alzheimer’s

By Arthur Riven, MD

I am a retired physician and an emeritus professor of medicine. I also have Alzheimer's disease. Before my diagnosis, I was certainly familiar with the disease, having seen patients with Alzheimer's over the years in my internal medicine practice. But I was slow to suspect my own affliction.

Now that I've been diagnosed, I can trace my problems back some 10 years, to when I was 76. I had been chairing a monthly program in medical ethics, and I knew most of the speakers and found it easy and enjoyable to introduce them. Then, suddenly, I found I had to rely on prepared material to make the introductions. I started to forget names, though never faces. These kinds of lapses are common in aging brains, so it was easy for me to write them off to "senior moments."

In the following years, I had coronary surgery and then two TIAs (transient ischemic attacks), or small strokes. My neurologist attributed my problems to them, but my mind continued to deteriorate even though I had no more strokes. The final blow was the occasion one year ago when I was receiving a citation for service in my hospital. I stood up to thank the presenters and found that I could not say a word.

It was my wife who insisted I go to the doctor for a diagnosis. As much as I was in denial and tried to dismiss my lapses as normal aging (doctors are often not willing patients), she knew something was wrong. My internist put me through a few memory tests in the office and then ordered a PET scan of the brain, which predicts Alzheimer's with 95% accuracy.

After the diagnosis, I was started on a medicine called Aricept, which has been used for many years and which has many side effects. I had two of them — bad diarrhea and appetite loss. I'd had a few Alzheimer's patients in my practice who had taken this medicine with no benefit, so I wasn't expecting much. I wanted to abandon it because of the side effects, but my doctor urged me to continue. The side effects disappeared and another drug, Namenda, was added. These drugs are by no means miracle cures, and in many patients they have little effect. I was one of the rare lucky ones.

In two months I was much better, and I am now close to normal. At my worst, I had difficulty speaking, did not know the
Reflections from a Physician
(continued from page 1)

names of my grandchildren or my doctor, could not add or subtract or find my way home. Now I can do all these things.

We've come a long way in our understanding of the disease since Dr. Alois Alzheimer, a German physician, first established a link in the early 20th century between dementia and the presence of plaques and tangles of an unknown material. That material is now known to be the accumulation of a peptide called Beta-amyloid. The leading hypothesis for the mechanism of Alzheimer's disease is that Beta-amyloid accumulates in brain cells, leading to neurodegeneration.

Some pharmaceutical approaches are now targeted at clearing this protein from cells. However, amyloid plaques can be detected only in autopsy, so they have been associated only with people who had full-blown Alzheimer's symptoms. It is unknown whether these are the earliest biomarkers of the disease. Despite years of study, there is still so much we don't know.

(Editor’s note: Since Dr. Riven wrote this essay, there have been exciting advances in the ability to detect amyloid plaques in the brain during life through brain imaging).

But there are also things we are learning, some of them from personal journeys like my own. Since my improvement, I have developed a list of insights I’d like to share with others facing memory problems. Carry a small book and write notes whenever there’s something you want to recall later. When you cannot remember a name, make a joke and ask the person to repeat it, then write it down. Read books. Take walks. If you cannot walk, exercise in bed. Draw and paint. Garden, if you can. Do puzzles and games. Try new things. Organize your day. Learn to prepare food, eat, dress, wash, and go to bed in an efficient way. Eat a healthful diet that includes fish twice a week, fruits and vegetables, and omega-3 fatty acids. A reliable and good-humored book on a serious subject is "The Memory Bible" by Dr. Gary Small.

Don’t withdraw from your friends and your family. This is advice I had to learn the hard way. Afraid of being pitied, I tried to keep my condition a secret, and that meant pulling away from people I cared about. But now that I’ve decided to be open, I’ve been gratified to see how accepting people are and how willing to assist.

(continued on page 3)
Reflections from a Physician
(continued from page 2)

For help with your own or a loved one's severe memory failure, the best source is the Alzheimer's Association, with offices in most cities and a central office in Chicago. It has information about caregivers, treatments and research, and it exists to help. Its latest information is sobering.

There are currently 5.3 million Americans with the disease. It affects one in eight people over 65, and almost half of those over 85. The number of people in the U.S. with Alzheimer's is expected to double by 2030.

This rapidly growing problem has prompted pharmaceutical companies to join together in 2004 with the National Institutes of Health to form a partnership called the Alzheimer's Disease Neuroimaging Initiative. It is developing clinical trials and freely exchanging information about its results. Its findings will be reported to the public in July.

I know that I, like every other human, will eventually die. So I made myself aware of the documents that I needed to examine and sign while I was still able and alert, things like advance directives, living wills and POLSTs (physician's orders for life-sustaining treatment). I’ve tried to make sure that those who love me know my wishes. When I do not know who I am, or recognize anyone, and I am incapacitated with no chance of improvement, I want comfort and palliative care only.

Editor’s note: Dr. Rivin practiced internal medicine in Los Angeles and is a professor emeritus at UCLA. His essay was printed in the Los Angeles Times, June 27, 2010, and is printed in this issue of Perspectives with the author’s permission.

Poetry Corner

Editor’s note: The following poem is inspired by the author’s experience in his early-stage Alzheimer’s support group.

Alzheimers

By
Charles A. Berger

We meet, this gang of oldtimers,
To learn about this alzheimers
Which draws us all together
in this room.

And while the most of us don’t know
Just where our future road will go,
We want to steer it clear
of any gloom.

So gather round, and get a dose,
Then maybe you can diagnose
The way to make your future
flowers bloom.

And you will hear these others say
How they have found a happy way
To still enjoy the scent
of life’s perfume.
QUESTION AND ANSWER

I don’t have a very good feeling for time. I can’t tell whether ten minutes or two hours have passed. Is this a common problem for people with Alzheimer’s?

It is very common for people with Alzheimer’s to have difficulty with issues related to time. This can be due to multiple different changes happening in the brain including changes in memory abilities and the ability to form concepts or ideas.

Awareness of time is frequently related to memory, and Alzheimer’s significantly impacts short-term memory. We often judge the passing of time by remembering what happened in the prior moments. For example, if we just finished watching the evening news, we may recall that the news is a 30-minute program, so that is how much time has passed. But if Alzheimer’s affects your ability to remember what you did a few minutes ago, it may be hard to tell how much time has gone by. You may wonder, “What did I just watch and how long have I been sitting here in front of the television?” Or, if your wife goes out and says she’ll be back in an hour, you may not only forget that she told you that, but you may also forget what time it was when she left and where she said she was going. This can be troubling or worrisome and minutes can feel like hours.

Our sense of time is also influenced by our ability to read a clock and make sense of it. Alzheimer’s can interfere with the ability to understand how the hands or numbers on a clock represent actual time. Even though you can read the clock, it may not make much sense or accurately reflect how you experience time. Also in order to calculate how much time has passed, you may need to remember what time it was when you last looked at the clock so you can compare it with the current time. So, all of this can become quite confusing!

Finally, Alzheimer’s and related disorders can affect your circadian rhythm which is your 24-hour internal time clock that regulates your sleep cycles and helps you distinguish between day and night. Some people find that they wake up at night and think that it is day or are not certain about the appropriate time to get up in the morning.

Making sense of time is indeed a complex issue, but a few general tips include:

Maintain a daily routine. When possible, try to do some daily activities at the same time each day and for a consistent amount of time. This can add helpful structure to the day and assist with awareness of time.

If your loved one leaves the house, ask him or her to leave you with a written note next to the clock that says the estimated time of return to lessen any anxiety you may have about the passing of time.

If reading a watch face is becoming difficult, consider getting a watch that speaks the time with the press of a button.

Increased fatigue and stress levels can contribute to confusion about time and should be monitored as much as possible. Make sure to consult a doctor if you have persistently disrupted sleep cycles.
RESEARCH UPDATES

Informative Website

The news media often report on updates and findings in Alzheimer’s research and clinical trials. It can be hard for many people to make sense of these stories or to tell whether these are reputable findings and reports. The Alzheimer’s Association has recently launched a comprehensive new website that provides research updates and general information about Alzheimer’s and related disorders at: http://www.alz.org/research/. Although some of the information provided is directed to the scientific community, there is also much helpful information and interesting updates for the general public.

Achieving Goals Through Cognitive Rehabilitation

Linda Clare, PhD of Bangor University in the United Kingdom and colleagues recently reported in the American Journal of Geriatric Psychiatry on the benefits of eight weekly 1-hour individual sessions of cognitive rehabilitation for persons with early dementia that was catered to each participant’s personal goals. Examples of goals included: learning to use a cell phone; remembering names of people in a fitness class; or being able to do a particular household task. Participants who received training on their goal showed significant improvement in their chosen activity suggesting that with routine training and practice, people with mild dementia may be able to learn new tasks or improve performance on tasks that have become more challenging with memory loss. For information contact Linda Clare at l.clare@bangor.ac.uk.

Alzheimer’s Breakthrough Ride

Alzheimer’s researchers from around the country are riding their bicycles from California to DC to raise research funds and awareness for Alzheimer’s. On September 21st, World Alzheimer’s Day, the riders will gather at the Capitol in DC to deliver over 50,000 signatures supporting the Alzheimer’s Breakthrough Act. This Act aims to increase Alzheimer’s research funding at the National Institutes of Health (NIH) to 2 billion dollars annually. You can also track the progress of the Breakthrough Ride at: http://www.alz.org/research/breakthroughride/overview.asp. It is possible to sign the Alzheimer’s Breakthrough Act petition or sponsor a rider and raise funds for research at this website.

Benefits of Early-Stage Support Groups

Rebecca Logsdon, PhD and colleagues at the University of Washington, Seattle, recently reported their findings from research into the effectiveness of a 9-week educational support group for persons with dementia and their care partners. The support group experience was particularly beneficial for the participants with dementia. Participants reported better quality of life and family communication, as well as reduced symptoms of depression on measures administered before and after the nine-week series and as compared with a control group. For more information, see the article reference below or email Rebecca Logsdon at logsdon@u.washington.edu.

Three Innovative Programs Explore the Theatre Arts

The Northwestern Cognitive Neurology and Alzheimer's Disease Center in Chicago and the Lookingglass Theatre together developed The Memory Ensemble to provide a theatrical experience for persons with early stage Alzheimer's disease and related disorders (ADRD). The program aims to offer a unique, enriching, and healing experience to individuals with ADRD. Additional benefits for participants include: social engagement; creative expression; engaging the mind/brain in new ways; and enhanced confidence, mood, and self-esteem.

The improvisational acting course offers instruction and exploration of improvisational theater specifically designed for people with early stage ADRD. Because the essence of improvisation is to “be in the moment”, this style of ensemble allows persons with memory loss to feel empowered, successful, and free from the concerns and stress of making mistakes or questioning decisions. While the first few weeks of class allow members to learn basic skills and to establish trust and comfort with each other and with the staff, the remaining weeks focus on sophisticated improvisational theater work.

A 7-week pilot of the Memory Ensemble was launched in the summer of 2010. Meeting weekly for 90-minute sessions, classes were led by experienced teaching artists and managed/facilitated by social work staff. Feedback from the ensemble members has been exceptionally positive. One member states, “It expands my whole thinking. It gives me a sense of wellbeing which in turn helps to enlarge my sense of wellbeing.” Another adds, “I'm not sure that my memory has objectively improved but I'm sure that my ability to cope with memory loss has improved.” Members also discussed how they enjoyed the cognitive challenge and stimulation of the improv exercises.

The pilot project generated great interest for a second Memory Ensemble session, and we are seeking additional funding to help support and sustain the program.

In the Limelight

Artsdepot is a thriving arts centre in North London, England, with a vibrant program of theatre, dance, music, exhibitions, talks, and classes. In 2009, we were awarded funding from The Learning Revolution Transformation Fund and Arts Council England's Older People's Fund to deliver a pilot theatre project for older people with dementia.

The workshops began in January, 2010 and were facilitated by Suzy Harvey and Harry Blake. The Alzheimer's Society and artsdepot provided hands on support during these sessions. “This is a chance for the participants to unleash their creativity, to play, to sing, to laugh, and to explore together,” says Suzy Harvey. “What I love about theatre is that there is
no right or wrong answer and it gives space for people to come alive. It can be so empowering and this is particularly important for people with dementia.”

The group explored reminiscence through drama using storytelling, music, and classic stories. During the 12-week project, they created and performed songs, sketches, and poems based on personal experiences. Participants recollected their wedding day, reminiscences from the war and tales of their childhood, and worked towards a final performance in artsdepot's Studio Theatre.

The final performance was a powerful and touching experience for the 100-strong audience. Carers supported the participants to perform songs, and recite prose, and other prepared pieces on material from the workshop sessions. When the audience gave a standing ovation, the cast were visibly pleased with their achievements. "I'm taken aback by everything you've put into it," said Pat. "You've made me feel very special.”

All of the participants want the project to continue and we are currently exploring funding avenues to make this happen.

TO WHOM I MAY CONCERN

By Maureen Matthews
info@towhomimayconcern.org

To Whom I May Concern® is a theater project that allows people with early Alzheimer's or a related disorder to share their experience in their own words with an audience of people who are concerned about them. To Whom I May Concern® goes beyond the signs and symptoms of illness and places the spotlight on the person whose life's drama is now changed by dementia.

The process is simple: As the facilitator, I ask an Early Stage Support Group the question, “What is it like to live with Alzheimer's?” and the answers come in stories that capture feelings of frustration, hope, embarrassment, humor, and courage. These stories form the basis for the script written as a series of letters. I review the script with the group, and the writing and rewriting continues until the group feels ownership of the script. Four or five people from the group agree to be the readers. Rehearsals follow until the curtain goes up to an audience of care partners, peers, family, friends, and professional care providers. Following the performance there is a talkback session that has been known to last longer than the actual performance.

The process may be simple but the outcome is transformative! For the participants, it is an opportunity to speak without being interrupted, and perhaps more importantly, to be heard, as is evident in the response of the audience. For a few of the participants it has led to a new career in advocacy for Alzheimer's.

The audience never fails to be touched by the performance. The wife of one of the performers said: “I thought I knew a lot about Alzheimer’s, but today I learned so much more.” A doctor responded: “Doctors need to see this.” And a woman in the audience who was aware of her own Alzheimer's diagnosis recognized her experience reflected in the words of the play when she said, “That was me!”

Every performance is unique and reflects the people and community in which it is created. Please contact me for information on our upcoming video and website.
SUBSCRIBE TO *Perspectives*

The annual cost of four issues of *Perspectives* by surface mail is a suggested $20.00 donation or **FREE by email**. For surface mail subscriptions, please complete and mail the information below to begin your subscription. For email subscriptions, simply email your request to lsnyder@ucsd.edu.

**Name** ________________________________________________

**Address** ________________________________________________  
  ________________________________________________________

**Phone/Email** ____________________________________________

For surface mail, please send donation by check or money order only (**payable to UCSD ADRC**). International orders must be received payable in U.S. dollars on a U.S. affiliated bank. Please add $2.00 for postage for international subscribers. Mail to:

Lisa Snyder, LCSW  
UCSD Shiley-Marcos Alzheimer’s Research Center  
9500 Gilman Drive – 0948  
La Jolla, CA  92093  
Phone: 858-622-5800    Fax: 858-622-1012  
email: lsnyder@ucsd.edu  
http://adrc.ucsd.edu

Lisa Snyder, LCSW  
UCSD Shiley-Marcos Alzheimer’s Research Center  
9500 Gilman Drive – 0948  
La Jolla, CA  92093