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The Foundation for Alzheimer's and Cultural Memory

Crossings

October 2008



Dear Michael,

Welcome to Memory Bridge's autumn edition of *Crossings*. Along with the change of season have come many wonderful new expressions of Memory Bridge's mission. You can read about our new projects in upcoming editions of *Crossings*. This month we will introduce you to our new Memory Bridge Director and share articles that highlight ways people are listening to learn and learning to listen to people living with Alzheimer's disease. We hope you find our newsletter informative and inspiring!

Athena Rebapis
National Outreach Coordinator

Message from Michael

The Power of Attention

The people who change our life are never famous. Presidents, kings, billionaires, movie stars, legends of sport and entertainment, the great minds in art, science, and technology—these are the people who change the news, occasionally the world, but never our lives. While we pay attention to these people, the people who change our life are paying attention to us.



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S.T.R.I.D.E.: A Life Mission

Harika Rayala

In a small room in Roxbury, Connecticut, a man sits at his desk, hunched over. He has graying hair; he's about the age of seventy. Many may actually recognize him as Arthur Miller, the renowned Pulitzer Prize-winning author. Bewildered and confused, he stares at his picture that appears on the back of a book. This book is none other than *The Crucible*, a play that he himself had written, 40 years ago. Yet he does not seem to recognize this play, nor does he remember that he is a writer. Why?

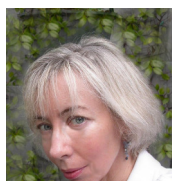


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The Science of Caregiving

Mona Johnson

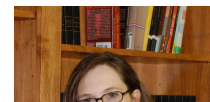
This summer, I went to ICAD (the International Conference on Alzheimer's Disease). Almost all the presentations at the conference were about molecular biology. They dealt



Memory Bridge Director

Dr. Susan Bussey

Susan grew up in Beaumont, Texas, and attended the liberal arts college Austin



with proteins and genes, and the inner workings of brain cells. Sitting in dark conference rooms watching these presentations, it was easy to lose sight of the real-life problems of people with dementia and their caregivers.

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Sin Aviso

Margaret Price

Without Warning™, a program of the Rush Alzheimer's Disease Center in Chicago, provides support and fellowship for people with early-onset Alzheimer's disease and their caregivers. The group began in 2004 and has grown to about thirty-five families since its inception. Without Warning began when a patient at the Rush Alzheimer's Disease Center advocated for its founding after he was diagnosed with early-onset Alzheimer's disease in his early 50s. He felt out of place in traditional Alzheimer's support groups because he faced different challenges than people 20 and 30 years older than he. The name Without Warning came from a woman living with early onset. She said the illness came to her "without warning." Early-onset Alzheimer's disease is characterized by a diagnosis before the age of 65.



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College in Sherman, Texas, as an undergraduate. She studied English and International Studies, traveled to Australia, Quebec, and Central America, and served as the editor of the college newspaper for a year and a half.

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Memory and the Media

The Bridge at the End of *The Road*

"Only Connect."
(E.M. Forster , *Howards End*)

Kim Bell

Cormac McCarthy's post-apocalyptic novel *The Road* is not, like most literature and movies of its kind, set in a sci-fi future. No fancy flying machines slice across the sky, no pneumatic doors whoosh open allowing entry to clones or robots. In fact, the remnants of civilization as we know it are contemporary, even ordinary ones: shopping carts and backpacks and a few cans of food. It is this world, our world, which has become a devastated wasteland.



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The people who change our life are never famous. Presidents, kings, billionaires, movie stars, legends of sport and entertainment, the great minds in art, science, and technology--these are the people who change the news, occasionally the world, but never our lives. While we pay attention to these people, the people who change our life are paying attention to us.

The single most powerful force in the universe is attention. Only that which is attended to lives. The flower unattended by the sun withers; the whale unattended by the sea washes lifeless to the shore; the baby unattended by its mother will not live to become a child. All of life depends upon the attention given to it by some other part of life. We live in, by, and for communion.

Remarkably, only we humans ever forget that, forget that we personally have a contribution to make to the cycle of attendance by which life keeps itself alive. A monkey will look in a mirror and delight in his reflection, sometimes for hours, but a monkey, even a conceited one, never mistakes the monkey in the mirror for the meaning of the universe, never says about his reflected other half: "Why, you're all the monkey I will ever need." People crave attention, but we alone forget that we, alone, atrophy and die.

By attention I do not mean applause, or praise, or public celebration. We like it, of course, when people clap for us, or when they recognize who we are and what we have accomplished in some demonstrably noticeable way. But the attention that changes our life is far less public, and far more meaningful than all that. When another person really attends to us, he is not trying to make us feel better; he is trying, rather, to feel what we feel, so that whatever we are feeling--good, bad, or worse than terrible--he is feeling with us, and thus whatever we were feeling alone we are now feeling *together*. The attention that connects us to the heart of another person is the kind we truly crave. More than being cared for, in the sense of someone doing something for us, and more than being applauded, we most deeply desire to be connected to others, heart to heart.

When we wonder what the future holds for our species, we would be wise to consider the state of our art of attending; for if we lose that art--the art of feeling in our heart how another feels in hers--then we shall surely die. There is no technology, and never will be any technology, that can substitute for our need to give and receive love. We must learn how to listen, and learn how to talk, from a place beyond judgment. We must forget our egos and remember each other.

To whom are you attending? Who is attending to you?

Michael Verde
President

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This summer, I went to ICAD (the International Conference on Alzheimer's Disease). Almost all the presentations at the conference were about molecular biology. They dealt with proteins and genes, and the inner workings of brain cells. Sitting in dark conference rooms watching these presentations, it was easy to lose sight of the real-life problems of people with dementia and their caregivers.

But I went to two sessions about research on how to improve the lives of people with dementia and their caregivers. It turns out that caregiving is as much a science as it is an art! Here's what I learned:

- A set of programs known as the Seattle Protocols focuses on how to reduce the depression, agitation, sleep disturbances, and physical problems sometimes associated with dementia. The methods and techniques that make up the Seattle Protocols, including exercise programs and "behavioral management" techniques, have been tested in clinical trials, and are now taught to facilities-based and home-based caregivers.
- Preliminary research shows a combination of measures such as changes in diet, reducing light in bedrooms at night, scheduling enjoyable activities during the day, and limiting daytime napping appear to reduce sleep disturbances in people with dementia.
- There's no substitute for the human touch. But technology, if adapted to the needs of people with mild dementia, can make everyday living easier. Even for people with

more severe memory loss, "Intelligent Home" technology can guide them through everyday activities such as hand washing after using the toilet or remembering to take medicines, and can recognize an emergency and call for help. Research on the design and use of this type of technology is in the early stages.

- Scientists are also studying whether Web-based communication can extend the positive results of short-term training for caregivers.
- Clinical trials show that people with mild dementia can still learn, and can maintain improvements in functionality gained from participating in scientifically designed cognitive rehabilitation programs.
- Antipsychotic medicines are used to manage dementia-related agitation and anxiety, but they aren't always effective, and any benefits are often outweighed by their serious side effects. Research shows that nondrug treatments such as aromatherapy, bright light therapy, and caregiver education may be effective alternatives.

This kind of research doesn't usually make the headlines. But for millions of people with memory loss and their caregivers, the science of caregiving is as important as the search for a cure.

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Without Warning™, a program of the Rush Alzheimer's Disease Center in Chicago, provides support and fellowship for people with early-onset Alzheimer's disease and their caregivers. The group began in 2004 and has grown to about thirty-five families since its inception. Without Warning began when a patient at the Rush Alzheimer's Disease Center advocated for its founding after he was diagnosed with early-onset Alzheimer's disease in his early 50s. He felt out of place in traditional Alzheimer's support groups because he faced different challenges than people 20 and 30 years older than he. The name Without Warning came from a woman living with early onset. She said the illness came to her "without warning." Early-onset Alzheimer's disease is characterized by a diagnosis before the age of 65.

The group aims to address the sense of isolation often felt by people with early-onset Alzheimer's disease. Many feel their identity has been lost or significantly altered by memory loss and its accompanying life changes. In addition to providing group support and creating a community, Without Warning connects participants to other programs and society at large. Among other activities, the group has sponsored a picnic for families, joined the Alzheimer's Association's Chicago Memory Walk, and held annual fundraising galas. Each semester, Memory Bridge invites people from Without Warning to speak to our students about living with memory loss.

Without Warning's sister group, Sin Aviso™, offers a similar support system for Spanish speakers. Sin Aviso, which means "without warning" in Spanish, began meeting this summer. While smaller in size than Without Warning, Sin Aviso provides a growing community and support to Spanish speakers in their native, conversational language.

Each group meets once a month and is facilitated by staff from the Rush Alzheimer's Disease Center. After a time for coffee and conversation, caregivers and those living with Alzheimer's disease break into small groups. In each group, attendees share about their journey, struggles, and joys. Caregivers often discuss resources and research advances as well.

Both groups are open to people with early-onset Alzheimer's disease and their caregivers regardless of hospital or doctor affiliation; however, pre-screening is required. For more information about Without Warning, please contact Susan Frick, MSW, at Susan_Frick@rush.edu. For more information about Sin Aviso, please contact Nieves Lopez-Barrera at Nieves_Barrera@rush.edu.

Margaret Price
Memory Bridge Coordinator

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In a small room in Roxbury, Connecticut, a man sits at his desk, hunched over. He has graying hair; he's about the age of seventy. Many may actually recognize him as Arthur Miller, the renowned Pulitzer Prize-winning author. Bewildered and confused, he stares at his picture that appears on the back of a book. This book is none other than *The Crucible*, a play that he himself had written, 40 years ago. Yet he does not seem to recognize this play, nor does he remember that he is a writer. Why?

The cause is this: Alzheimer's disease. It is also the cause when, five years later, he passes away unaware that he had written one of the greatest American masterpieces studied in high schools and colleges nationwide.

However, Alzheimer's is not restricted to Arthur Miller. It lingers in every region of America, depriving our senior citizens of their cherished memories. In fact, scientists predict that by the year 2050 the number of Alzheimer's cases will quadruple to 50 million.

My goal is to prove them wrong.

I have been volunteering in nursing homes ever since fifth grade. I saw that too often our grandparents are either neglected or placed in a nursing home with little social contact. Consequently, there is no one to help them understand the importance of mental and physical stimulation.

So I started a local nonprofit organization called S.T.R.I.D.E. (Students to Rid Dementia in Elderly) to fill that role and help the elders in our society fight dementia. We do so in three ways: mental, physical, emotional. We hold monthly

workshops and publish a monthly newsletter, which includes brain puzzles and trivia and is distributed to residents in Central Ohio nursing homes. Also, we regularly bring in tai-chi and yoga instructors to the nursing homes.

We are also trying to establish the Memory Bridge Initiative, where we pair high school students with dementia patients, in Ohio. Because of the program, the students gain a newfound understanding of dementia, and the elderly also benefit from conversations they have with their new friends. The Memory Bridge Initiative was originally started in Chicago and has gained a lot of success there.

Furthermore, by working with senior citizens, I learned a lot myself. I realized that it makes a difference when we spend those two extra hours every Saturday reading Helen her favorite novel, *Jane Eyre*. It makes a difference when we hold a seminar on dementia and discover that people are actually interested in learning more. It makes a difference when a person realizes that she does not have to spend her entire day in bed, but now is her time to finally take those dancing lessons she has always wanted to take. It makes a huge difference.

In retrospect, I have been able to turn my idea into reality. However, my job is not over. For me, STRIDE is a life mission that I wish to expand further as I enter college and beyond.

Harika Rayala
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Susan grew up in Beaumont, Texas, and attended the liberal arts college Austin College in Sherman, Texas, as an undergraduate. She studied English and International Studies, traveled to Australia, Quebec, and Central America, and served as the editor of the college newspaper for a year and a half.

At graduation, Susan went to work for the academic publishing company Wadsworth, which eventually became International Thomson. The job took her around the country, and she lived in St. Louis, northern California, and Oklahoma while working on college textbooks. Eventually, however, the increasingly competitive environment in the publishing industry began to wear on her. Although interacting with academics and developing educational materials had drawn her into publishing, she no longer felt those aspects of her job defined it. "It dawned on me that I would always really be working for profit," Susan explains, "and it wasn't even my own."

In 1996, Susan left publishing to work with academics directly--by becoming one. She earned an M.A. and Ph.D. at Washington University in St. Louis, graduating with a specialty in nineteenth-century American literature. Her dissertation, which she considers a "work still in progress," deals with social status anxiety in 1890s novels that feature a racial discovery plot, where an adult character discovers they have "black blood." Her work has been published in *African-American Review*, *Crosstimbers: An Interdisciplinary Journal*, and the Greenwood Encyclopedias, and she received a grant to study a Mark Twain manuscript at the J.P. Morgan Library.

After finishing her degree in 2003, Susan took a position as a Visiting Assistant Professor at Wake Forest University in North Carolina, where she was commended by three different student bodies for her teaching and advising work. She also received funding from the university's Kaufman Foundation office to help develop a service-learning program specifically for English majors. It was that work that brought Susan back in touch with Michael Verde, a childhood friend and longtime correspondent: "I looked Michael up after my mother forwarded me a piece about him from our hometown paper--last I knew he was teaching, and I couldn't believe the directions his work seemed to be taking." Michael was in the midst of filming *There Is a Bridge*, and his own service-learning curriculum was under development. When they discovered their overlapping interests, Susan brought her old friend out to North Carolina to speak directly to her students, and the two of them also planned a conference panel together on reading and community.

In 2006, she accepted a tenure-track position in the English Department at the University of Science and Arts of Oklahoma, a public liberal arts college much like the one she had attended herself as an undergrad. She continued trying to develop service programs and innovative literature courses for college students, but found much of her time was caught up in administrative duties. Her family--husband Forrest and three sons, Lafayette, Wells, and Ambrose--were having their own difficulties adjusting to life in rural Oklahoma. "My husband grew up in a small town," Susan says, "and we thought we would enjoy the slower pace of life. But I guess we were a little too used to the conveniences of a city after all. It drove us crazy that we had to drive 45 minutes just to find ethnic food!"

When Michael called in June of this year, suggesting Susan visit Chicago to consider taking her place with Memory Bridge, she was hesitant at first: "I had spent a long time getting to that particular place in my academic career. Despite my enthusiasm for Michael's work and this initiative, I had to do some soul-searching to envision life as anything other than a professor." The trip to Memory Bridge offices, where she met the Worldview Education team and sat in on a teacher roundtable discussion, helped ease the transition. When her husband admitted he was secretly dying to move to a large (very large) city, the decision became an easy one.

"August was probably the most hectic month of my life," Susan admits, "and I had defended my dissertation and had a baby in one month in 2003." But the family is settling in to a home in Oriole Park while they wait for their home in Oklahoma to sell, and Susan has found a place in the Worldview offices for most, if not all, of her books. She has jumped into the job headfirst, and will be coordinating two Chicago Memory Bridge classes this fall at the same time she is working to develop a college version of the curriculum. "Every once in a while I feel like I jumped off a cliff," Susan says, "but the people working here, and the program itself, are so very heartening. I couldn't imagine a better parachute."

Dr. Susan Bussey
Director of Memory Bridge

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Cormac McCarthy's post-apocalyptic novel *The Road* is not, like most literature and movies of its kind, set in a sci-fi future. No fancy flying machines slice across the sky, no pneumatic doors whoosh open allowing entry to clones or robots. In fact, the remnants of civilization as we know it are contemporary, even ordinary ones: shopping carts and backpacks and a few cans of food. It is this world, our world, which has become a devastated wasteland. And the novel never reveals what happened. The nameless father, the protagonist of the story, knows more about the series of events that caused our world to collapse than we ever do. Thus, the reader finds something in common with his son, born the day everything shifted toward ruin, and too young to have any memory of the world being anything but ash-covered and desolate. From the beginning, the reader occupies a de-historied position. The world has changed in its entirety, and now, to read on, is to inhabit an absurd, "cauterized" landscape--only sparsely dotted with instances of familiarity--and to have very little idea how all of this came to be. Perhaps the only readers who might recognize something about the bleak road the man and his boy are traveling down are the readers who have gazed into the eyes of someone with advanced Alzheimer's disease. *The Road* and the road ahead are bleak and unfamiliar. But by the end of the book, every reader has "glassed the horizon" and gotten a glimpse--not just of the emptiness and terror, but of the bridge.

Ironically enough, it is the child in the story (a boy of about ten) who has no memory of the past. And it is his father who is at a loss to resurrect it for him: "He could not construct for the child's pleasure the world he'd lost without constructing the loss as well." The disparity between their experiences of the world is perhaps most poignant (and darkly comic) when the man finds a can of Coca-Cola in an otherwise ransacked overturned vending machine. As the man offers it to the boy, the boy asks twice, "What is it?" The man urges him to accept the treat and drink it all, from which the boy deduces, "It's because I won't ever get to drink another one, isn't it?" For the man, memory is not only fading, but becoming irrelevant because he cannot share it with the boy. The Coca-Cola is a sweet, but ultimately a fleeting and singular artifact from the old world, never to be revisited again.

Man and boy are, in a sense, unmoored from Time. The man has long ago forgotten to count the boy's birthdays. There are no seasons by which to catalogue life and growth. When the boy asks his father about what happens "later," the father gently corrects him and says: "This is later." There is no future and no past, yet they struggle to stay alive and make their journey south. Deprived of the metaphor of time, they are also deprived of the metaphor of the journey. In this story, a journey even of this magnitude will not result in transformation or change. And with the absence of these metaphors, along with "most of what has made them human--memory and color and the names of things"--two questions that pertain equally to the narrative and to our experience with AD arise: 1) why keep talking? and 2) why keep going? (from Ron Charles' review in the *Washington Post*). The novel offers compelling answers to both questions.

Why would you continue to communicate with someone who seemingly has no understanding of the richness and variety that life once held? For the man and his boy, their dialogue is the only salve to the psychological wounds that are inflicted daily as they fight to survive. Even when their discourse is frustrating or frustrated, it is the human contact which provides comfort. In fact, at one point in the novel when the boy stops talking to the man, the man says, "You have to talk to me." The exactness of the dialogue conveys the urgency in the appeal. We understand very early on in the novel that, without the boy's companionship, the man will die: "The boy was all that stood between him and death." McCarthy's observation carries in it,

however, a dangerous ambiguity. Is it a good thing that the boy keeps the man alive? As Ron Charles in the *Washington Post* put it, "The fear of dying, so prevalent in McCarthy's previous novels, is balanced here by the fear of surviving." Living on without our memories as companions or without human companions who have shared those memories with us represents the greatest fears we have of Alzheimer's disease. Man and boy, facing these fears, keep going partly because they keep talking--even when a very limited understanding is possible.

Even with no shared culture between them (because the collapsed world does not support civilization and, therefore, any kind of culture), and with the death of familiar metaphors, the man and boy do not give up; instead, they are called upon to invent new metaphors. The father tells the son that they are "carrying the fire," that they are "the good guys." At the end of the novel, the father, who has been sick all along, dies. The boy speaks to him one final time to tell him, "I'll talk to you every day.... And I won't forget. No matter what." The connection between father and son has perhaps always been a connection between alien worlds; it is no surprise the communication will continue between this world and the next.

The final paragraph of the novel offers this vision of the world before:

"Once there were brook trout in the streams in the mountains. You could see them standing in the amber current where the white edges of their fins wimpled softly in the flow.... On their backs were vermiculate patterns that were maps of the world in its becoming. Maps and mazes. Of a thing which could not be put back. Not be made right again. In the deep glens where they lived all things were older than man and they hummed of mystery."

Even though his father is now dead, this knowledge and memory of the world prevails, as though, despite its seemingly utter impossibility, the father has managed to transmit an image of life and fertility to his son amidst the dust and death. Here is the power of communication and perseverance. Even in an ashen landscape devoid of memory and metaphor and organic mystery, our voices are bridges stretching across the insurmountable. At the end of *The Road*, there is redemption: after his father's death, the boy encounters a man and a woman who are also "carrying the fire" and who vow to protect him. At the end of any road, there is a bridge.

Kim Bell
English Teacher
Lake Forest Academy

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