



# Crossings

A Newsletter of the Foundation for Alzheimer's and Cultural Memory

June 10, 2008

## Hello from Memory Bridge

I hope this edition of *Crossings* finds you in good spirits, deeply connected with friends and loved ones. Last year Memory Bridge launched our new Memory Bridge website ([www.memorybridge.org](http://www.memorybridge.org)), began to disseminate our Memory Bridge school program across the United States, and debuted our PBS documentary *There Is a Bridge*. We have received overwhelmingly supportive feedback about *There Is a Bridge* from around the world. Here is a sample of what folks are saying:

"I watched the clip with Mrs. Wilson and I saw Love in action. I cried. This was so beautiful, like something lifted out of time and space; proving that connectedness, regardless of outward differences or appearances, is the truth of us all. We are one."  
Trudy · Santa Cruz, California

"Last night, Monday the 8th of October, I saw your program and it absolutely renewed my faith in compassion for people. The only time I had seen this was in the 80s and 90s during the AIDS devastation. Unfortunately it rarely exists anymore. But you certainly hit my heart and mind last night. Thank you."  
Maurice Pacini · Los Angeles, California

"I watched the film last night. I thought it was fabulous! I teach nursing and am currently in a long term care facility with my students. I would love to make this a required viewing opportunity for them."  
Laura Herbert · Ohio

"Amazing!"  
A Young Person · Central California

If you have not seen *There Is a Bridge* and would like to know why the documentary is touching so many people in such a poignant way, you can see it when it airs on the PBS station in your area, or you can order a DVD of *There Is a Bridge* at [www.memorybridge.org](http://www.memorybridge.org).

We hope you will find our newsletter informative and inspiring.

Sincerely,

Athena Rebapis  
National Memory Bridge Outreach Coordinator



## A Message from Michael

### *The Mirror and the Bridge*



According to The Alliance for Aging Research (2001), Americans are more afraid of Alzheimer's disease than they are of dying. I find that statistic remarkable. How have a majority of Americans come to imagine that they would rather die than have Alzheimer's disease? The answer--through metaphors: We imagine Alzheimer's disease as a fate worse than death because the disease has been presented to us through metaphors that evoke the terrifying.

You will recognize these descriptions. Each is a picture in words:

The Long Goodbye

The First of Two Deaths

The Forgetting

And these are mere snapshots. We are also presented with moving pictures of Alzheimer's disease, attention-arresting images insinuated into narratives of utter loss. The following comments, for instance, appeared in the *New York Times Magazine* in 2007 and were offered by an internationally recognized authority in the area of aging and longevity:

*For me, one of the most disturbing experiences is putting a fully incapacitated Alzheimer's patient in front of a mirror and asking him who he is, and he doesn't know. It's just shocking to see that happen to human beings--they don't even recognize themselves. Elie Wiesel, the Nobel Prize winner who wrote "Night," said we are our memories. Which I think is a beautiful statement of the significance of memory, because when you're older, you also tend to review your life and to try to come to terms with it, and if you have Alzheimer's, you're denied that opportunity.*

Here, deftly and poignantly illustrated, is an existential nightmare: a picture of our self staring at our self and failing to recognize who we are. Biologically, we are alive, but intellectually, emotionally, spiritually--humanly--we are gone. The suggestion is clear: this is a disease that removes you from your body and leaves what used to be you

staring mindlessly in the mirror, at nothing.

This metaphor of self-extinction in Alzheimer's disease moves us to act. That is its purpose and value. But the marketing successes of fear-engendering metaphors come at a cost, and the people who pay the cost in this case are, ironically, those on whose behalf the metaphors are ostensibly circulated. The creation of that perception would be less objectionable if it fueled public action--if it inspired individuals and legislators to contribute resources to find a cure and/or support care--and that was the end of the story. But the picture we are painting about people with Alzheimer's disease is also instigating public inaction. Because we are imagining people with Alzheimer's as essentially gone, we often communicate with them accordingly, which is to say superficially, or not at all.

And thus our picture of people with Alzheimer's disease is coming true. They have and are disappearing. But not because of what is happening in *their* brains--rather because of what is happening in ours. Anyone who is imagined, and thus communicated with, as if she is already gone, will disappear, regardless of her cognitive condition.

I offer you another image of someone deeply advanced in dementia, a personal image. It is one that inclines me to think that our currently dominant metaphors regarding the experience of Alzheimer's disease eclipse vast domains of meaningful presence.

On the Sunday before my grandmother died from debilitations caused by Alzheimer's disease, my father wheeled her from her room in the nursing home to the cafeteria where a makeshift sermon and sing-along was in progress. Two dozen patients were lending feeble voices to old church hymns being played on a crudely strummed guitar. My dad placed my grandmother's wheelchair along a row of other wheelchairs and drew up a folding chair beside her.

My grandmother was not singing. She had not spoken in weeks, having long lost the ability to even swallow water. Again, this was the Sunday before she died. Several hymns into the sing-along, a familiar chord struck a living well in my grandmother's profoundly compromised memory. "The Old Rugged Cross" was the tune being played. My grandmother suddenly lifted a lifeless hand from her lap and extended it purposefully over the armrest of her wheelchair. Finding my father's leg, she twice squeezed it with an energy and affection that Alzheimer's disease was powerless to thwart.

It was my father who was now remembering--remembering the hundreds of times on a Sunday morning in the First Baptist Church of Sour Lake, Texas, that his mother, during one of the hymns, squeezed his thigh and said to him, "You are a good boy, John Michael." On this Sunday, some seventy years removed from those lived in Sour Lake, Texas, my grandmother did not speak. Even if she could have, she did not need to. There is speech after speaking, memories beyond mind. At the old rugged bridge between time and eternity, it is not our own face we long to see again on the other side. Memory serves us best when it serves our self least. There is no symbol less revealing of a life well lived than a mirror.

We need to find a cure for Alzheimer's disease. We must commit many more millions of dollars in meaningful ways to this vital goal than we currently are. Irreversible dementia is arguably the largest health and social challenge of the 21st century. And even greater than the public stakes related to Alzheimer's disease are the personal ones. Irreversible dementia is an experience that takes people, and those who care for them, into domains of despair and disrepair that few other pathways to death exact. There is nothing acceptable about the *disease* called Alzheimer's.

But people with Alzheimer's disease do *not* disappear before they die. They are *never* lacking the need for emotionally meaningful connections. Being able to draw a clock and recognize one's own face in a mirror are not the qualifying tests of our abiding humanity. No amount of marketing success justifies the creating of frames of perception that, however indirectly, leave people emotionally isolated.

A greater motivator than fear is love. Love moves us to each other, reveals that we are, beyond all categories of difference, profoundly related, and always in need of relating. Let us respond to this life-changing disease by inviting presence, not scaring it away.

## Stories from the Bridge

The Chicago Memory Bridge program is currently beginning its sixth successful semester of educating at-risk junior high and high school students about how to communicate in emotionally meaningful ways with people with Alzheimer's disease. The program teaches students listening, verbal, and non-verbal skills that help them form relationships with their "Buddies": individuals with Alzheimer's disease or other forms of dementia living in nearby long-term care facilities. The students and their Buddies visit four times in 12 weeks, which allows them to really get to know one another. Below is an example of how these "Buddy" experiences can grow to surpass even the confines of illness.

### *Singapore*

On the last visit of the Memory Bridge program, each participating student presents a gift to his or her Buddy, called the Buddy Project. This Buddy Project represents the relationship the student and resident have formed together, and is an enduring reminder to the Buddies that they are remembered and cherished. The Memory Bridge coordinators have the pleasure of seeing every one of these Buddy Projects during the final visits, and we are able to witness some extraordinary exchanges of friendship and meaningful human connection.

This January, Lawrence, a student from King College Prep High School, presented his Buddy Project to his friend Mr. Clarence, a resident of the Bronzeville Park Skilled Nursing and Living Center in Chicago. Mr. Clarence is a particularly quiet man--he has a difficult time with speech as a result of the progression of his illness. Lawrence is a polite and considerate young man, who would wear ties and button-down shirts to the facility, out of respect for Mr. Clarence. As the coordinator for this class, I previously had wondered how or what Lawrence would do about his Buddy Project, because occasionally students struggle with creating projects for their less talkative Buddies.

At the final visit, Lawrence presented Mr. Clarence with his Buddy Project creation--a "Travel Book." On the back of the book, Lawrence wrote a poem explaining how much he appreciated visiting with Mr. Clarence and the moments they shared. The second part of the poem was instructional--suggesting to Mr. Clarence that any time he wanted to visit a place, he could do so from the comfort of his home by turning to a

page in his Travel Book.

Each set of facing pages in the book had a different location: Tokyo, Beijing, Mexico, Jamaica, Hawaii, Singapore, Australia, etc. And on those pages were pictures of local sights--like a real scrapbook--with little tidbits of information about the locales and local expressions ("¡Hola!" on the Mexico page, "G'day mate!" on the Australia page, and "Aloha!" on the Hawaii page). I asked Mr. Clarence if he had traveled to those places, but Mr. Clarence didn't respond. Lawrence spoke up for him, letting me know that Mr. Clarence hadn't actually been to any of the places in the Travel Book.

Though Mr. Clarence had never before visited the sights in his new Travel Book, we discovered that he was certainly ready to embark on a new journey. When Lawrence was saying goodbye, Mr. Clarence, who was clutching his new Travel Book, slowly whispered, "Tonight I'm going to go to Singapore."

Kate Lindsay

## Profile: Margaret Price, Educational Coordinator



Margaret is originally from Northbrook, Illinois, and received a B.A. in Spanish Language, Literature and Culture from Syracuse University. Her interest in intergenerational work and the creation of communities stems directly from her work after college. In 2003-04 she taught English in a kindergarten, after-school program, and adult high-school equivalency program in an impoverished neighborhood outside Buenos Aires, Argentina. The agency she worked for placed an emphasis on serving the entire community, and in many families Margaret taught both parent and child. She learned a great deal about the many ways to foster a sense of solidarity from her host family, supervisor, students, neighbors, friends, and fellow volunteers.

After returning to the United States, Margaret began working at Legal Assistance Foundation of Metropolitan Chicago in the North Lawndale neighborhood. Her main duties were communicating with underprivileged clients and responding to their needs by providing them with legal advice and connecting them with resources in their community. She was regularly called upon to relate with empathy and clarity, while tailoring her message to an individual client's situation and sensibilities. For Margaret, assisting people in some of their most challenging life experiences was both trying and incredibly fulfilling.

After over two years at Legal Assistance Foundation, Margaret joined the Memory Bridge team in January 2008. She was particularly interested in returning to the field of education and introducing positive communication skills to children and adolescents. Part of Margaret's passion for the Memory Bridge program lies in its commitment to diversity and dignity. She is inspired by the students and residents with dementia who form meaningful connections with each other, oftentimes having little in common other than the human spirit.

Margaret's duties at the Chicago Memory Bridge Initiative encompass both class

coordination and administrative duties. She has translated much of our correspondence into Spanish, as a large percentage of Memory Bridge students come from Spanish-speaking homes. She regularly updates the website, [www.memorybridge.org](http://www.memorybridge.org), and responds to program inquiries from all over the world. In addition, she is coordinating the publication of an anthology of short stories dealing with Alzheimer's disease and adolescence. Margaret also recently took on the operational duties of the Memory Bridge program and did not realize until she was in charge of them just how much she loves details. Outside of work, her interests include reading, traveling, and sharing meals with friends.

## Innovative Programming

### ***Meeting of Minds:***

#### **South Central Wisconsin Chapter of the Alzheimer's Association**

Meeting of Minds is a program for people with early-stage memory loss offered by the South Central Wisconsin Chapter of the Alzheimer's Association. Twice a week, group members do tai chi-based exercises and collectively create poetry.

The tai chi exercises are adapted for the specific needs of group members and are accompanied by flowing music that mirrors the practitioners' movements. Group members comment on the paradox of feeling both relaxed and energized following a session. The consistent attention to breathing fully and rhythmically not only oxygenates the cells of the body but creates a sense of internal calm and spaciousness: the experience of being absolutely whole. One participant commented that the tai chi "just feels so good! I love it! I can't say what I want to, but... this feels beautiful. And it helps with my walking, too--my balance."

The poetry created by Meeting of Minds is inspired in part by Kenneth Koch's *I Never Told Anybody: Teaching Poetry Writing to Old People*, and John Fox's *Poetic Medicine: The Healing Art of Poem-Making and Finding What You Didn't Lose: Expressing Your Truth and Creativity Through Poem-Making*. At each session, the group facilitator initiates a discussion based on a theme. Questions are posed. Personal stories evoked by the discussion are crafted into a poem that the group together refines and edits. Regarding the poetry exercises, another group member stated, "It's kind of impressive, what we do here when we all join in. When it's read back, it sounds like something well put together. It sounds like we know something!"

The common language-related problems that often occur with a memory disorder, such as repetition, the use of metaphorical language, and word substitutions, are, in this context, not deficits to clear communication at all. The poems generated in this way make everyone feel capable of expressing their thoughts and feelings. The unanticipated connections that surface during these poetic rap sessions hint with inspiring frequency at the very purpose of our lives.

The following is excerpted from a poem, "Whole," which was collaboratively created by group participants during a Meeting of Minds session and is an example of an outcome of the creative group expression component of the Meeting of Minds program:

*Whole is a feeling.*

*Whole is feeling NOT-stressed.  
Whole is feeling satisfaction.  
Whole is peace.*

*Whole is feeling connected:  
Connected to others,  
Connected within myself.  
Whole is feeling I am all together....*

*Whole is what we are, together.  
There is nothing that is independent.  
We are interdependent.  
We are all connected.  
We are whole.*

For more information about the Meeting of Minds program, please contact:

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## Memory and the Media

Memory Bridge is deeply interested in how cultural assumptions about memory and identity affect people with Alzheimer's disease and related dementias. The way we imagine all sort of "realities," including other people, is always influenced by the social and cultural forces that shape and shift our world. For that reason, we are building our bridges with an attentive ear to and eye on the cultural assumptions and practices that impinge, however indirectly, on the lived experiences of people with dementia. Kim Bell, English teacher at Lake Forest Academy, has agreed to share with us her ongoing personal reflections about memory in literary and pop culture in America. We found the insights of her essay on *The Sopranos* profoundly stimulating and trust you will, too.

### *Memory Is a Mob Killer*



The final episode of the popular HBO series *The Sopranos* ends ambiguously. Tony and Carmela sit in a diner with their son AJ and await their daughter Meadow's arrival. The camera cuts between the inside of the restaurant where the other patrons leer ominously and the street outside where Meadow, grinding the gears, struggles to parallel park her car in the rain. Both scenes seem to be setting

the stage for Tony's takedown. Then, as bells on the door sound, Meadow enters the restaurant, Tony looks up, the music cuts out, and the screen goes dark. And that's the end of *The Sopranos*.

But the much-asked question remains: is it the end of Tony Soprano? The music (their last name is "Soprano") dying suddenly, the black screen--perhaps these are the filmic representations of the gunshot that the final scenes seem to anticipate. In a previous episode, Tony suggests that death will be just that: the lights go out, everything goes dark. Just poof, gone.

However, without a smoking gun or, as is more likely on any given episode of this show, a lot of blood, we can't know for sure. So the other possibility is that the series simply ends with a domestic scene fraught with the cosmic level of tension that accompanies any interaction of this family within *The Family*.

But the answer is perhaps more interesting than either of the above. This is because, toward the end of the series, before the final lights-out of the final episode, Tony's life as he knows it is *already* over. Strangely enough, this has very little to do with the mob war brewing between New Jersey and New York--the conflict most likely to result in Tony's murder in the diner--and everything to do with Alzheimer's disease and memory loss.

In many ways, this makes perfect sense: our greatest villains are usually inside of us. And Tony's greatest adversary has always been one of his own (biological) family members--his uncle, Junior Soprano, whom Tony usurps early in the series. Junior's rage at being passed over--and his potential revenge--are not what pose the biggest threat to Tony's power and well-being. Instead, Tony's power and the power of the Soprano Family depend on a kind of cultural memory remaining intact. Junior personifies the breakdown of this cultural memory when he is diagnosed with Alzheimer's disease. As the disease progresses, it causes not only the anticipated physiological and psychological threats to Junior himself, but also to Tony's existence as a character and as the symbol of a criminal institution. In one of the initial manifestations of his confusion, Junior shoots Tony in the gut. It is the only time, despite the violent world that Tony Soprano makes his living in, that he is ever shot by anyone. And it is a nearly fatal wound.

Tony survives the gunshot wound in a way that he cannot survive the dissolution of the memory of the "way things used to be." Junior embodies the "old ways" that the Family operated, and those ways are losing purchase, both on the street and in the person of Junior Soprano. The characters in the final season of *The Sopranos* are nostalgic and obsessed with their memories--rehearsing them in almost every episode as though they might, at any moment, disappear altogether. Then, when some of Junior's old cronies hatch a plan to liberate him from the low-security institution of incarceration which houses him, he affects confusion in order to remain where he is. Without his memory, there is nothing "out there" on the street to return to. When Tony pays his one and only visit to Junior, the real disease is revealed. Tony, frustrated with Junior's vague responses, says to him, "You don't know who I am, do you?" and "You used to run New York," to which Junior responds, "That's nice." Within the context of the plot of the show, the life of the Family depends upon generational memory that stretches all the way back to Italy. Without that, Tony Soprano, Mob Boss, doesn't exist, and viewers are simply tuning in to watch another banally dysfunctional family eat dinner together in a restaurant. And this is, after all, our final "shot."

Ultimately, the final season(s) of this show about The Mob offer a representation of Alzheimer's disease and what that disease has come to mean in the contemporary

media. In this show, an MRI reveals more than the FBI--and is more damning--because what keeps a man like Tony alive is not "mob mentality" but "mob memory." The loss of "mob memory" is a death sentence, or perhaps more aptly, an authorization for mass murder, because what's really at stake in the end is not a single life--Tony's--but a whole way of life. Once the link to a shared past disintegrates, so do the present and the future. In the last installment, the future is probably best represented by Meadow who, despite the hopeful fertility captured by her name, in the final moments, can't even park a car.

*The Sopranos* intelligently demonstrates the power of memory to be a bridge spanning the past, present, and future--and that the loss of it is in many ways devastating. More importantly, the ambiguous ending (is Tony shot or not? does he live or die?) also represents the ambiguous moment we are living in now regarding our relationship to dementia and Alzheimer's: when the lights go out, who's still there?

Kim Bell  
English Teacher  
Lake Forest Academy

*Thank you for your interest in Memory Bridge. If you have encountered a thought or feeling in Crossings that you believe will be meaningful to others, please forward this email along and encourage your contact to sign up for our newsletter below or at [www.memorybridge.org](http://www.memorybridge.org).*

*With warm regards,*

*Athena Rebapis*

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