

Part One: One Caregiver's Journey  
"Lessons Learned In a Decade of Alzheimer's Caregiving"  
by Jake Mascotte

In January 2000, my wife Sarah and I met with Dr. Richard Mayeux, co-director of The Taub institute for diseases of the brain at Columbia/Presbyterian in New York. Sarah had been experiencing tiny lapses in comprehension and often seemed a bit confused in the short conversations which comprise daily life. On that cold, grey winter morning, Dr. Mayeux asked Sarah to tell him 1) what day of the week it was, 2) what month we were in and 3) the name of the city in which his office was located. In baseball parlance, Sarah "went one for three"; a terrific batting average in the major leagues but a terribly poor one for a woman who once worked for The Federal Reserve and Citicorp, then managed a home, raised 4 active children and greatly contributed to the success of her husband's peripatetic business career. Rigorous testing followed, but Dr. Mayeux's initial diagnosis, made at the end of that first visit, proved correct; my warm-hearted, outgoing bride of 34 years had contracted Alzheimer's, just four months shy of her 62<sup>nd</sup> birthday.

In the years since then, I've retired from a career in the insurance industry and the two of us have witnessed our only daughter's wedding, rejoiced in the births of 5 grandchildren and celebrated the return to good health of a seriously ill son, all while laboring with Sarah's growing inability to complete her favorite recipes, travel by herself, use a telephone, read the daily papers, engage in simple conversations or pronounce words of more than one syllable. Yet her essence remains undiminished; her eyes still sparkle with recognition in the presence of family and old friends and her ability to skewer my daily absurdities continues unabated. She laughs at examples of her increasing incapacity with the utter lack of pretension that's been the hallmark of her personality since we first met 45 years ago.

Needlepoint has replaced reading and long walks now substitute for her doubles play on the tennis court, but the Sarah of today is as vital as ever; candid about and accepting of her condition and determined to continue living the life she's fashioned with me and our family over 4+ decades. In doing so, she's taught me some important lessons about life, myself and most importantly, what it means to be a care-giver. What follows is a random collection of observations about how this pernicious disease has affected our lives and how those who suffer from (and with) it are forced to adapt to its inevitable toll.

The most important thing I've learned is this: the matter in which both the patient and caregiver respond to the irreversible impact of Alzheimer's makes an enormous difference in the process.

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**IADL'S & ADL's** - Sarah and I live in a small mountain community, located in Pitkin County Colorado, which funds and staffs The Senior Services Center, a facility that meets the needs of elderly citizens who can't live independently. Each participant served by The Center must complete a questionnaire which allows the staff to ascertain appropriate levels of need. The county then divides its clients into two broad categories: Those capable of performing what the center refers to as the Instrumental Activities of Daily Living (IADL's) and those able to handle

a simpler list of functions called simply Activities of Daily Living (ADL's) as follows:

IADL's

- I can manage money without help
- I can take care of shopping without help
- I can take my medication without help
- I can prepare meals without help
- I can do ordinary housework without help
- I can use the telephone without help
- I can use transportation without help

ADL's

- I can eat without help
- I can get dressed without help
- I can bathe without help
- I can use the toilet without help
- I can get in/out of bed/chairs without help
- I can get around inside my home without help

When she was first diagnosed in January of 2000, Sarah could perform the activities in all 13 categories; as she approaches her 71<sup>st</sup> birthday, (May, 2009) she can handle all 6 functions in the second category...but none of those in the first. For the two of us, this means that with my support, Sarah still enjoys a quality of life which continues to provide her with opportunities for self-expression, the enjoyment of family and friends and most importantly, a sense of her own individuality.

For me, the ADL/IADL lists provide a rough but useful guideline as an Alzheimer's caregiver. They outline the functional levels of incapacity caused by the disease, thus identifying the challenges which confront both of us in the normal course of daily living. Since I'm no longer working, Sarah's ability to handle everything in the ADL category means we can still lead our lives without needing extra help. While we don't yet utilize the taxpayer-funded services provided by our Senior Services Center, Sarah and I do deliver lunches for them to shut-ins. That gives both of us an activity we can perform together, allowing Sarah a chance to do something useful for others while providing me with a preview of what lies ahead as her condition continues to deteriorate.

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**Early Detection** - Looking back to the time of Sarah's initial diagnosis, I see the wisdom in the old admonition, "When in doubt, see a doc". There may be no cure for Alzheimer's, but there are medications that can slow its progression. Sarah's utilization of them (Aracept initially combined with Namenda later on), in the very early stages of her treatment has allowed her to continue functioning and Doctor Mayeux believes they've proven more effective in slowing her decline than would have been the case had they been initiated later on.

But Alzheimer's obviously affects individuals differently; those who suffer from it can mask the symptoms of the disease when it first emerges by employing techniques that disguise the problem. The self-diagnoses which emanate from an Alzheimer's patient's increased confusion are many; complaining of poor eyesight for example or insisting that those around them aren't speaking loudly or clearly enough. Sarah has employed both those rationalizations and more recently has developed an irritated reaction to loud noises and sudden interruptions; my once easy-going spouse now believes that she's merely responding to the increased rudeness she perceives in those around her. She's also begun to display an uncharacteristic annoyance at the hustle and bustle in our house when our young grandchildren are with us and she's especially bothered by their crying.

Simply recognizing these potholes in Sarah's capacities has become important; the two of us had dinner recently with old friends from out of town and Sarah delighted everyone at the table when she invented a game of hide and seek with an appetizer she was sharing with her dinner partner. Later that evening, I asked her to sign our tax return and she was unable to spell our last name properly. There appear to be variations in Sarah's mental capacities from day to day and it can make dealing with her like walking through a swamp – on firm ground one minute and sinking the next – yet what appears so inexplicable to me simply doesn't register with the same impact on her.

Determining what these signals mean (and how they can be at least temporarily ameliorated when they first emerge) takes patience and creativity – and most importantly, a commitment to sharing the Alzheimer's diagnosis with the person actually afflicted. Sarah has known from that first meeting with Dr. Mayeux that she suffers from Alzheimer's; while we don't broadcast that information widely, we have shared it with all those with whom we interact on a regular basis, from the members of our extended family to Sarah's hairdresser. We think being open about her condition is important for all concerned; we don't have to waste precious time and energy trying to disguise anything and candor helps quickly distinguish those who are accepting of Sarah's circumstances from those who, for whatever reason, find it difficult or uncomfortable to be around her. I've noticed that Sarah can actually shrink the number in that latter category by signaling that she remains comfortable in her own skin, which seems to allow others the opportunity to relax and be less self-conscious in her presence.

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**LITTLE THINGS MEAN A LOT**

Remember that old song? I've found it's especially important in dealing with Sarah's struggle to remain connected to her daily routines. Extra pairs of reading glasses along with large print books and periodicals have gone a long way in eliminating some of her frustration. Since past experiences are often more accessible than more recent ones, renting old movies and listening to familiar music from years ago on satellite radio stations provides reassuring connections to the past and a welcome respite from dealing with the confusion of the present. We go through old family photo albums together to trigger her memory and stimulate the tangled pathways in her

brain. I supplement that with “post it” notes to jot down the name of someone whose face is no longer familiar. Her old address book is a treasure-trove; she’ll frequently read it in bed for a few minutes before turning off the lights. I’m convinced it provides a great way for Sarah to remember and reconnect with old friends.

In Sarah’s case, simple “to do” lists have proven vital, so long as she writes them in her own words; they make more sense to her that way while providing me with fresh clues as to those areas with which she’s having the greatest difficulty.

Staying connected to others is terribly important too, so I’ve asked friends and family to buy a supply of post cards and drop them in the mail to her on a frequent basis ... just a few words delivered by the post office can brighten Sarah’s day and avoid the difficulties she faces when trying to talk on the telephone.

### **SELF CONFIDENCE: THE BEST RX**

Sarah does best when she’s aware that the tasks of daily life aren’t completely beyond her, so I’ve come to believe that it’s my job to encourage her to do what she can do for herself while avoiding any signal that I expect her to do those things she’s no longer capable of. She can help me fix a simple meal if I’ll supervise her role in preparing it. She still dresses herself, but has some difficulty remembering what she’s worn recently, so I lay her clothes out on the bed in the morning and she takes it from there. I choose her jewelry; she puts it on. I remind her that some lipstick and perfume would be nice; she applies them.

### **CATEGORIZING OTHERS**

As our friends react to Sarah’s condition, they can be divided into two groups; one large, the other small. Most offer sympathy, which I take to be completely genuine ... but only a tiny number display the capacity to fully accept her just as she is, Alzheimer’s and all. Can she still recognize the difference between courteous treatment offered by the former and the real companionship so generously given by the latter? Absolutely; she glows in the presence of that small circle of special people who send the signal that they care for her as they always have. As a caregiver, it’s not my job to grow angry with the first group for failing to do more; I spend my time endlessly thanking that inner circle who responds so warmly and un-selfconsciously. Their grace-filled compassion has proven almost as important to me as it is to Sarah.

### **COMMUNICATION**

In the early years following Sarah’s diagnosis, I thought her hearing had deteriorated, but it finally struck me that she frequently can’t attach meaning to the sound of my words, or comprehend what they convey in two aspects of our conversations:

- Context: Sarah was headed into the kitchen one day to get herself a glass of water and I asked her to put a candy wrapper “in the garbage.” She disappeared into the kitchen in utter silence and then returned to the living room with the trash in her hand and a look of complete confusion on her face. With gestures and a muffled word, she finally made me understand that she didn’t know whether to put the item I’d given her in the wastebasket, down the disposal in the kitchen sink, or in the trash can out in the garage.
- Specificity: When there are multiple options involved, Sarah seeks further instructions even when the choice is obvious... when I ask her to please turn on a light, she’ll respond

with a gesture at a specific switch and mouth the words, “this one?” Clothes laid out on our bed for her to put on have to be confirmed as the items she’s to wear; medications placed on the bathroom sink each morning for her daily consumption are never ingested until she points to them and asks, “these pills?” followed by “take them now?”

The 13<sup>th</sup> century philosopher, Thomas Aquinas, articulated an axiom that appears at first to be a complete contradiction, i.e., “what is last in the order of intention is first in the order of execution.” For example, if you’re watching a football game on television and you’re suddenly thirsty for a cold beer, you must initially get out of your chair and head for the refrigerator (or get someone to perform that task for you) before you can take that first sip. This insight has been an especially useful tool for me because it helps me avoid the twin challenges of complexity and “add on’s”; asking Sarah to do some simple task and then adding another request before the first one had been completed ... when I fail to remember Aquinas’ maxim, Sarah usually winds up frustrated... and, unfortunately, so do I.

One afternoon not long ago, I took some Havarti cheese out of the refrigerator to bring to room temperature. An hour or so later, I asked Sarah to put some slices of cheese on Triscuts and Saltines from the cupboard. Confusion reigned; first I got only crackers, then a different cheese she’d taken out of the fridge, then other crackers with the wrong cheese, followed by my anger and frustration as I finally got up and fixed this simple snack myself. I failed to remember that my request involved 1) Getting crackers out of the cupboard; 2) Locating the cheese I’d put out; 3) Slicing same and putting it on two different kinds of crackers. Without meaning to, I’d created a case of information overload with the end result that Sarah was forced to confront once again the frustrating limits of her inability to do what she used to do with ease... so we now do things like this together, allowing me to assign her a single element among those in a sequence, thus avoiding the likelihood of creating situations in which she feels diminished.

Any request I now make of Sarah requires that I remember two necessary elements: her need to break down even the simplest task into its smallest components, coupled with my willingness to provide detailed step-by-step assistance to provide her with the ability to complete the task and draw satisfaction from doing so.

### **AVOIDING COMMUNICATION “BURN OUT”**

Since nearly endless repetition is one of the hallmarks in the progression of Alzheimer’s, finding a way to respond to it that doesn’t wind up frustrating me is a skill that goes a long way in reducing my stress. Outsmarting repetitious questions or the reiteration of comments often requires Herculean patience, but with a little bit of self-diagnosis, the instances that produce annoyance can be significantly reduced. I’ve tried to build an informal catalogue of the situations that seem to trigger repetition; for example, Sarah and I live in a skiing community and during the winter season, she discovers each day that people are actually on the slopes, pointing it out every time she looks up the trails. Knowing in advance that I’m going to get that reaction (now delivered in charade-like fashion) allows me to slough the repetition off, because I’m programmed to expect it; if she sticks on that observation, I’ll ask if she finds it surprising that skiers would be where they are.

I actually encourage repetitions when they serve to underscore positive experiences; I do some volunteer work for our local community foundation and Sarah accompanies me when we go to

their offices, where the staff is always extraordinarily kind to her. Each time we leave, she remarks over and over again how nice they've been to her; I agree with each repeated declaration because it's obviously important to Sarah that there are people whose treatment of her reinforces her value as a person worthy of their courtesies.

When all else fails, I've come to employ "tender teasing"; with the right inflection and careful attention to my accompanying smile or hug, I try to indicate that although I've heard it all before, I enjoy hearing it repeated all over again, converting her repeated comments into a running joke. I don't know whether this technique has any value for Sarah... but it's an awfully important release for my emotional pressure cooker.

As Sarah's condition has worsened, I find that my biggest challenge lies in converting the innumerable 2-way conversations that form the bedrock of a long marriage into fruitful soliloquies. Sarah appears to understand most of what I say, but her highly restricted ability to form the words necessary for replies has created a conundrum; how do I go about sharing my thoughts with her in a manner that's helpful and reassuring to her without sounding like Tom Hanks' chats with his soccer ball in the movie *Cast Away*? Are the smiles which Sarah provides to my ramblings a signal of gratitude for my continued efforts to communicate or are they merely her signal of polite resignation to the circumstances in which she now finds herself? I have no real way of knowing.

But I have begun to learn one new, important skill – how to relax in comfortable silence with my now nearly wordless wife. We've become like a pair of monks in a cloistered monastery which seems at times to operate under a vow of silence. Yet, her warm and uncomplaining presence has become strangely comforting to me; it has provided a sense of peace I would never have dreamed possible.

PART THREE: ONE CAREGIVER'S JOURNEY  
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WORDLESS AFFECTION

Our culture worships youth and beauty, but above all, we prize mental capacity and see it as not only the key to our individuality but also the essential ingredient of our personal worth. Alzheimer's is the Cheshire Cat of human diseases, the slow disappearance of self. If it's a demanding situation for me to deal with in my wonderful wife, how much more difficult must it be for her to endure it? Sarah's quietly slipping out the back door of our marriage, but she still welcomes my hugs and kisses – and when she takes my arm or simply holds my hand, we share a non-verbal connection that's easy for her and reassuring for me. We've also discovered the power of little rituals; Sarah likes to turn down the collar of my pajamas over my bathrobe for example while I like to fuss over fixing her morning coffee with just the right amount of cream. Anything which combines (1) repetition (2) physical touch and (3) the opportunity to reinforce in Sarah's mind that I need to receive care as well as give it seems to reconfirm her ability to reciprocate. When that occurs, she positively glows with satisfaction.

Sarah's blessed with the ability to sleep like a drunken sailor; unfortunately, she snores like one too. On the other hand, I toss and turn constantly at night, hog the bed and am awakened by the slightest of sounds or movements. In order to maintain marital bliss, each of us has our own bedroom. (This presents a special challenge when we travel; we're restricted to those hotels which provide connecting rooms.) Now that our children are grown and we're alone in the house, I've developed the habit of getting Sarah up in the early hours of the morning and bringing her to bed with me so we can cuddle up to one another. She falls asleep again very quickly and while I rarely do, I find the physical sense of touching her in complete silence wonderfully satisfying. In those half-awake moments before she doses off, her inability to carry on a conversation is irrelevant; for a few precious minutes, the Sarah I married so many years ago returns – the one whose body carried our 4 children and gave me countless moments of pleasurable lovemaking. To me, Sarah's whole again in these brief intervals before I roll out of bed and allow her another hours or so of slumber. Then I dress as quietly as possible and enjoy some private time, setting about my morning's chores and staying in touch with family and friends by phone and e-mail.

This daily ritual has made me realize that physical intimacy isn't just balm for the fractured mind of someone with Alzheimer's – it can rejuvenate the spirits of a married caregiver too, creating a silent bond of affection that makes our continued commitment to each other, even if wordlessly expressed, wonderfully comforting.

#### CHILDLIKE WARMTH

As Sarah's condition progresses, she grows ever more spontaneous. Doctor's appointments, some boardroom work and visits with two of our sons who live in New York City bring us there with some regularity and we've become familiar with the staff at the hotel where we stay. Sarah has developed the habit of enthusiastically hugging the doorman and bellhops each time we enter or leave the hotel. After initially being startled by this behavior, they've come to enjoy her displays of simple affection as much as I enjoy the expressions on their faces when she greets them like long-lost friends. Is this spontaneous and repetitive reaction a reflection of her joy at suddenly remembering familiar faces, the substitution of physical touch for the cheerful verbal exchanges she used to employ, or a childlike response of thanks for simple courtesies like holding the door or handling her packages? Perhaps it's all three (or something entirely different which I can't fathom); whatever the motivation, this newly-acquired habit brings her such joy that it infects those who receive it like a ray of unexpected sunshine on a grey, overcast day.

When we travel, I've begun to ask airline gate agents to let us board flights early, especially when Sarah and I aren't seated together. We recently boarded a flight as a burly mechanic tried to pass us on the way off the airplane. Sarah was confused by his sudden appearance, so he looked at her with a mischievous grin and said, "Don't forget to kiss the mechanic." Much to his surprise, Sarah promptly did so, leaving him flabbergasted and nearby stewardess helpless with laughter. Sarah enjoyed their respective reactions and proceeded to her seat, unaware of how much she'd brightened the day of two strangers – providing further proof that while here ability to speak has greatly diminished, her ability to understand what's going on around her hasn't.

#### PHYSICAL PROXIMITY

Proximity has become Sarah's lifeline. Her lovely mother, a Southern belle from the pine forests

of southern Georgia, contracted Alzheimer's in her 70s and died some years ago after a long and excruciating battle with the disease. She spent the last years of her life nearly glued to my father-in-law and now, like her mother before her, Sarah's decline causes her to seek very close physical proximity to me whenever we're performing even the simplest task. For me, the old '60s cliché about "needing my space" is simply not an option – Sarah's so eager to be at my side that she'll literally bump into me as I try to make a simple dinner, fix an appliance (for which I'm constitutionally ill-suited) or even button my own shirt. (Even using the bathroom has become a team sport.) This eagerness to be constantly connected, especially while engaged in some useful task is apparently central to her self-image; even when it drives me a little crazy (or thwarts my natural desire to do something as quickly and efficiently as possible) I've had to learn how to slow down and let her help me. She may be the one who's becoming more child-like, but it requires me to move and act at her pace and function at her level; in the winter of my life, I've got a new vocation – special needs teacher to a physically-adult, appealingly-childlike student.

### PLAYDAYS

When I put her to bed each night, Sarah asks a question we heard from our kids when they were growing up ... "Is tomorrow a playday?" She's really asking if tomorrow will be one in which we'll be continuously together. Unless we're traveling or I'm especially busy and Sarah's being looked after by one of our children or an old friend, I've learned to categorize every day as a playday, because Sarah seems to take comfort in the knowledge that I'll be with her on a steady, consistent basis.

### MYSTERIOUS DISAPPEARANCES

I want to fix a meal, but I must first spend half an hour searching for a necessary utensil that's been misplaced. We're getting ready to go out for the evening, but Sarah's favorite earrings have suddenly disappeared into one of the many hiding places she's created in our rather compact house ... a favorite pair of socks, the remote control for our television set, her reading glasses; it makes no difference, I'm now committed to spending a great deal more time than I have in the past simply locating the tools of daily life. I suspect these unexpected and irritating searches are simple mistakes, born out of Sarah's desire to be helpful, but it's also quite possible there's some mild paranoia at work, a fear Sarah may have that one of her especially treasured objects will be lost because it isn't adequately protected in a secret place. Whatever the underlying motive, I try to limit these household search parties by creating rituals around the return of everyday objects to containers with visually different characteristics; necklaces in one box, earrings in another, etc. It's also helpful to make a little ceremony out of removing and returning these objects in Sarah's presence – silverware places in kitchen drawer trays together, glasses on the same part of a shelf, and so forth. It takes a little more time, but the development of rituals devoted to these aspects of daily life seem to reassure Sarah while giving me a little downtime as a caregiver.

### KEEPING TRACK

How do you keep track of someone who appears perfectly capable of taking care of themselves one minute but who's equally capable of veering off into complete confusion the next? Cautioning won't help; Sarah has no memory of anything I say seconds after the words have left my mouth and restricting her movements (and mine) to guard against a possible reoccurrence (of

getting lost) would be, in most circumstances, needlessly constraining for both of us.

I realized that I either had to be with Sarah constantly or find a friend to accompany her when I went out with others.

**PART FOUR: ONE CAREGIVER'S JOURNEY**  
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**CARING FOR THE CAREGIVER**

**THE CAREGIVER'S CURSE**

Despite my attempts to respond to Sarah's condition with tact and understanding, I inevitably found myself hurting her from time to time with an irritating tone of voice that unconsciously expresses my annoyance with her or ridicules something she's said or done. This type of behavior leaves me ashamed, since it arises from my failure, not hers.

I've come to believe that self-pity's the caregiver's curse; in my case, the worst form it takes is a condescending attitude. That attacks Sarah's sense of self-worth; as such, it's conduct two or three steps below that of a school-yard bully. There's no doubt that life with Sarah has grown more claustrophobic; the loss of my personal freedom, the need to circumscribe or simply give up activities I previously enjoyed, and the constant need to attend not only to my daily needs but hers as well can produce the sense that life's become akin to living in quicksand. When I find myself brooding on the state of things, I remember the bracing message contained in five lines by the British author and essayist G.K. Chesterton:

*Think how much larger your world would be  
If yourself could be smaller in it;  
Break out of the tired and tawdry theater  
where your plot is always played  
And find yourself under a freer sky.*

**SAVORING SURPRISES**

Every so often, Sarah delivers a short, incisive reply to some comment I've made which demonstrates that whatever decline she's already endured, my quick-witted bride still retains the ability to appropriately tease me, despite being nearly speechless. I know she can't recapture her earlier verbal skills; nevertheless, I've come to treasure such moments – they remind me all over again how wonderful she is and most importantly, they help me treasure the capacities she still retains while spurring me on to assure that she wrings all the joy and satisfaction she possibly can from our time together before her condition deteriorates further.

**BANISH EFFICIENCY**

I'm cursed with large amounts of nervous energy and during my business career, I bought enthusiastically into the American passion for maintaining a hyper-kinetic, multi-tasking lifestyle. Now that's over; I've had to learn how to take a deep breath and relax ... my days of

sophisticated time management are at an end. Nothing makes my life more miserable as a caregiver, (nor more upsetting to Sarah) than falling back into my old habit of insisting on a level of daily productivity that's simply no longer possible. It's not a question of altering priorities, but of allowing them to be disrupted by Sarah's immediate needs. Learning to "let go" is the best advice I can give any caregiver interested in assuring their own peace of mind.

### **MASKING CONCERNS**

I struggle with the need to avoid transferring my fears to Sarah. As her caregiver, I try to not get ahead of where we are right now – those days will come in their own good time and if I worry about them, the result will be either or both of the following: 1) I'll detract from the available joy of the present moment or 2) send Sarah the signal that something's wrong, which I'm convinced would only heighten the sense of insecurity she already feels.

### **FIND ANOTHER OUTLET**

The growing inability to share my thoughts with Sarah in conversation has driven me to my computer keyboard; after completing the morning chores, I spend the first couple of hours of each day writing – a journal, reviews of movies that we've seen and perhaps of greatest therapeutic value for me, an electronic correspondence with our four children as well as friends and the fellow caregivers with whom I've become acquainted. Talking with Sarah has become like dropping rocks into a bottomless well, so I obtain the feedback needed in my life by broadening and deepening my correspondence with others. It's not nearly as instantaneous and emotionally-satisfying as the conversations I used to have with Sarah ... but it most certainly is better than no interaction at all.

### **THE THRILL OF REDISCOVERY**

Sarah's repetitions suggest that Alzheimer's allows the joy of discovery over and over again; oddly enough, this realization has enhanced my own experience of the commonplace. I'm more focused on the beauty around me now than ever before and the slower pace of our lives permits me an increased sense of satisfaction in almost everything we do.

### **NO COACH POTATOES**

Medical research suggests that regular exercise does two things simultaneously for those with Alzheimer's: it stimulates overall brain function while avoiding the added stress that inevitably comes from the physical deterioration associated with aging. If it's challenging enough to care for someone with this disease who is otherwise in good physical condition, I can't imagine how much more difficult it would be if Sarah's body as well as her mind was failing. But just as importantly, I've also learned there's an added and indispensable benefit for me when I exercise with her. After all, my ability to provide her care is equally dependent on my physical health. Taking care of me has become just as important as taking care of her.

### **FINDING HAPPINESS**

I strive to find accommodations in our daily routines that I hope will provide Sarah the happiness she deserves. In doing so, I often find myself far from where I'd imagined my own future would take me. When that occurs, I ponder the definition of happiness provided by the 16<sup>th</sup> century humanist Erasmus: *Happiness is the wish to be what you are.* Sarah's afflicted with a disease that's free of physical pain, but suffused with mental/emotional/psychological challenges I can

only dimly comprehend. She faces her condition each day with lighthearted candor and a courageous refusal to feel sorry for herself. It's an honor and ongoing joy to be her caregiver. Paraphrasing Erasmus, I now wish to be exactly what I have become.

### **CARPE DIEM**

I've become addicted to Horace's admonition – "trust not to the morrow." That's my mantra; Alzheimer's is progressive, so my life with Sarah will inevitably get more difficult for both of us as time passes. Since there is no way to recapture her lost functioning, today's missed opportunity to experience something joyful will be forever lost. That knowledge drives me to make my remaining time with her like the last days of a perfect summer vacation: a wistful mixture of disappointment that things can't remain as they are, combined with the delight that comes from squeezing the last drops of satisfaction out of what remains.

### **WHAT LIES AHEAD**

Despite my repeated inquiries to Dr. Mayeux, I have no idea when to expect further decline, nor what trajectory Sarah's disease is likely to take. On the rough calculus which divides the disease into three phases (mild, moderate, and severe) the psychological exams Sarah takes each year, (I think of them as SAT tests for those with Alzheimer's) indicate only that she's entered that final phase with her cognitive ability still largely intact. Apart from that, Dr. Mayeux and his colleagues can only offer candor; Sarah's current condition may continue to moderately decline over time ... or she might face a precipitous plunge in the near future. That leaves her with an uncertain outlook, and me with the need to continue trying to fathom whether the latest incident of incoherence/confusion is an episodic blip or an early indication of the next stage of the disease.

When I worry about the future, I tend to focus on the day when Sarah will wake up and look at me without a trace of recognition. Perhaps that will never occur; we're both nearing the average life expectancy of those in our age cohort and perhaps some other medical condition will claim Sarah before Alzheimer's can savage the rest of her mental capacity and the joyous personality it sustains. I certainly hope that's the case; my prayer for the future is simple – I want to remain healthy enough to outlive Sarah, caring for her until the end of her life. If I'm lucky, she'll still know the man with whom she's so generously shared her life all the way to its completion.

Whatever the future holds, I'm certain of this; it will pale in comparison to the joy that's preceded it.

-- Jake Mascotte, May '09