

MEMORY AND IMAGINATION

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Editor's note:

The following essay was delivered as a Major Forum address on 20 January 2005.

About twenty years ago, I was walking around the block in Salt Lake where I grew up and met a neighbor whom I had not seen in many years but whom I had known most of my life. She was now a woman in her late seventies, and I called her by name as we met on the sidewalk. I could tell that she didn't recognize me, but she began a lively chatter that I soon realized was mostly incoherent. I stood politely and listened, nodding and laughing when she laughed. It was the least I could do for an old woman, whom I remembered in her better days as elegant and refined. She used to wear a blue-gray coat with a silvery fur collar that matched her graying hair perfectly. Now she looked a bit ragged in scratchy polyester pants covered with a faded wool coat. The artist in me wants to say it was that same blue-gray coat that she once wore to evening sacrament meetings years before, but it's unlikely.

Later, I told my mother, who was then in her late fifties, about this strange one-sided conversation. "Puh," she said. "If I ever get like that, hit me over the head with a bat."

She spoke too soon. Or she spoke it aloud and let her words float out into the universe where they became a prophecy.

When was the first time I realized my mother might have Alzheimer's?

One weekend, about three years ago, my parents came to dinner, and my mother handed me a pink sheet of paper. It was her Relief Society newsletter. Her name appeared under "Sister Spotlight" in bold type. "Have I given you a copy of this?" Mother asked, her face eager. She pointed at her name under the Sister Spotlight and read aloud, "She was born in Breukelen, Utrecht, the Netherlands."

I shook my head. "No, you haven't," I said. I read through the short biography. It told about her athletic youth when she played soccer as well as any boy. How she had immigrated to America with my father and five small children when she was twenty-six years old. How she had raised eight children. It told about the two missions and the work in the Salt Lake temple.

"This is great!" I said, tacking it onto the bulletin board in my kitchen. She looked pleased.

This was the third time she had given me this same newsletter. My mother was then seventy-five years old. Was that the first time I knew?

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Or was it the extended family weekend at Bear Lake? On my night to cook, I made sloppy joes. Actually, I didn't "make" anything. I fried hamburger and opened a half dozen cans of Hunt's Sloppy Joe Sauce and poured them onto the cooked hamburger. Then I spooned the mixture onto hamburger buns. Not a very big culinary deal.

Mother thought the sloppy joes were delicious.

"Really?" I asked her.

"I love these," she said, taking another bite.

"Well," I said. "I was a little embarrassed to make them, because your recipe is the best I've ever tasted."

"My recipe?" Her eyes seemed to search the past.

"Best sloppy joes in the world," I said. "You would simmer it all afternoon and then we'd put the whole pot in the car and go to George Washington Park and have a picnic."

Her nod was hesitant. "I didn't know I made sloppy joes." She shrugged and laughed.

It worried me at the time that she couldn't remember her own sloppy joe recipe, but her laugh, free and relaxed, assured me that it was just one of those memory glitches.

Perhaps it was the time she forgot the appelflappen that I realized she was really sick.

All my growing up years, my mother spent New Year's Eve Day making appelflappen. They are cored apple slices dipped in pancake batter and deep-fried like doughnuts to a golden brown. That's the extent of the recipe. We kids fought over who got to sift the powdered sugar over them. To make and eat appelflappen during New Year's is as Dutch as wooden shoes.

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Some Christmases ago my mother volunteered to bring appelflappen to a holiday party with Dutch friends. On the afternoon of the party, my father asked, "Aren't you supposed to bring appelflappen tonight?"

"Oh, I forgot," Mother said, and went about making up the pancake batter. My father had an unfinished project out in the garage, which he went to complete. When he returned, Mother had made, not appelflappen, but a huge stack of pancakes.

When my father told this story, he told not only of her confusion but of her mortification at making such a foolish mistake. She had memory enough to be embarrassed.

Our large family was capable of playing the denial game for a long time, but my brother Ted and my sister Janie had a very telling experience with her. All three of them sat at the kitchen table. Both Janie and Ted had done some Christmas shopping for Mother, and she was paying them back with a check. She wrote a check to Janie and gave it to her, but then it became clear that she didn't want to write Ted a check. She

held the closed checkbook tight to her body. Ted tried to kid her out of it, but she wouldn't relent. Finally, Janie said, "It's okay, Mother, if you write him a check."

Mother set the checkbook down on the table and poised her pen to write: "Pay to the order of." She looked up at Ted with a face that we now know is the Alzheimer's face, a face that indicates absence. "Now who are you?" she asked him.

His experience hurt all of us. Sooner or later our mother would not know us, her children.

Dad grew irritated with Mother's memory lapses as if this was something she had chosen: "I have to repeat things a dozen times," he said. "She asks me what show is on television, and I tell her, and five minutes later she asks me again."

My father's complaining didn't seem like sufficient evidence of any kind of dementia. She probably wasn't really listening. I do it myself all the time.

"Why don't you take her to Al?" I suggested to my father. "He can tell if it's serious." Al is a neurologist friend of ours.

My father took Mother for a check-up. Al said that Mother, at worst, had marginal memory loss but suggested that she be tested by a psychologist. He named someone who, as it happened, wasn't covered on my parents' insurance. "It costs \$250," my father told me over the phone.

"You can afford that," I said.

"I guess," was all he said, but he never made an appointment.

I know why he didn't. It wasn't the money. It was simply not wanting to put a name, a diagnosis to her lapses. We didn't want her condition verbalized. Our whole family was in denial.

Alzheimer's is hard to diagnose in a living person. With a patient showing signs of dementia, the physician's main task is to rule out other possible causes, such as strokes, tumors, or vitamin deficiencies. If all of these are absent, the patient is given a simple cognitive test called the Mini Mental State Exam that has a 30-point perfect score. Average scores range from 29 to 25 diminishing with age. My mother took this test years ago and did pretty well; but each time she retakes it, she misses more questions.

She is especially good at subtracting from 100 in units of seven as the test requires. My mother could add and subtract as fast as any cash register or computer. She remembered phone numbers after seeing them once. My sister can do the same.

I, on the other hand, find that particular question the most bothersome. You receive one point for each correct answer, and you stop after five subtractions. Five points for subtracting sevens!

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I don't think I've ever been able to subtract sevens from any number. I am not a number person. If you were to ask me to subtract fives or twos, maybe I could get by, but seven is an evil number—one has to think of combinations of threes and fours, or fives and twos, or sixes and ones. These are troubling numbers for me. I would be better off being asked how many syllables in the word *velutinous*. [ve lu ti nous] Four! And it means velvety.

Ask me how many lines in a sonnet? Fourteen.

Ask the difference between an English sonnet and an Italian sonnet?

English has three quatrains and a couplet (abab, cdcd, efef, gg)

The Italian sonnet is divided into an octave and a sestet. (abba)

Dante and Petrarch, both Italians, wrote Italian sonnets, but so did Milton, Hopkins, and Wordsworth, who were English—and even Anne Sexton, who was an American.

Shakespeare wrote English sonnets.

Subtract a sonnet by seven lines and you have seven lines left. Seven lines of concise expression of contemplative thought and emotion.

Some four million Americans—one in five of those 75 to 84 and nearly half of those 85 and older—are now afflicted with Alzheimer's. It is projected that by the end of this decade six million Americans will have the disease; and by mid-century it could hit 14 million people. Autopsy studies show Alzheimer victims' brains littered with wads of sticky debris, or plaque, and their neurons contain twisted protein filaments known as tangles that exterminate brain cells. It has only been in the last twelve or so years that scientists have learned what the plaque and tangles are made of and the chemical triggers that set the disease in motion.

Early onset Alzheimer's is hereditary in families where the cells overproduce A-beta proteins which then turns into the toxic plaque. These mutations run in families, and virtually everyone who inherits one develops Alzheimer's by the age of 60. But familial early-onset Alzheimer's is rare, accounting for only three to five percent of all cases—and does not include my mother.

But studies suggest that the common form of the illness also has a large genetic component. Alzheimer's incidence is three times higher among people with one affected parent than in people whose parents were both spared. And folks with two affected parents experience a five-fold increase in risk.

Environmental triggers, on the other hand, are still something of a mystery. Researchers have identified several nongenetic factors that may affect people's odds: head injury is probably the best documented. Dr. Richard Mayeux of Columbia University found that those who'd been knocked unconscious as adults developed Alzheimer's at three times the

rate of those who hadn't. But because head trauma is so rare, Mayeux doubts it accounts for more than 1 percent of cases.

A lack of stimulation can leave the brain vulnerable.

Those from rural backgrounds and less than seven years of schooling suffered 6.5 times more Alzheimer's than educated city dwellers. This fits my mother.

There is a possibility that people who grow up with more than five siblings are at higher risk than people from smaller families. This fits my mother and me and my siblings as well. The bottom line is that well-nurtured brains are more resilient. "They have more capacity," says Dr. Bruce Yankner of Harvard Medical School, "so they can withstand more damage before showing signs of disease."

Will I get Alzheimer's? I don't want to put the idea into the universe, but frankly, it's too late. The first symptom of the disease is that you misplace things and common nouns evade you as stubbornly as the names of acquaintances. I have been misplacing things, stammering nouns, and forgetting names all my life. I have been a dreamer, absent-minded, mostly disinterested in life and its realities outside my head. *Now* this has become a *symptom* of disease. I have cared much more for the *created* memory than for the real thing itself. Now I wonder if this is simply a kind of looniness. If in fact, I could not remember something accurately if I tried.

Forty some odd years ago, when I was a teenager, I made extra pocket money by babysitting. One young couple, with a new baby, hired me on an almost weekly basis. They were not Mormons. I knew this because my mother was an ad hoc membership clerk of our ward, and they were not on her list. Even more telling was a pack of Salem filtered menthol cigarettes in front of the toaster in the kitchen. They had no television but they did have a wall full of bookcases filled with the latest novels. This was better than TV. If I got tired of reading, I pulled out a Strathmore Premium Sketch pad I had brought along and drew long, leggy women in beautiful clothes. And if I tired of that, well, then there was always the bathroom mirror. Theirs covered the whole upper half of a wall. It was nothing like that little medicine cabinet mirror we had in our bathroom at home which had to be shared with nine other people. This mirror was a stage for great performances. I made all my faces in it: the haughty face, the laughing face, the sexy face *à la* Bridget Bardot, the distraught face. I strutted, primped, pranced, minced, and tap-danced in front of that mirror. I sang "St. Louis woman with your diamond rings" in a sultry alto voice. I was a star.

One night, I decided to have a smoke in front of the mirror. I pulled one of the Salems out of its pack, my fingers fluttering nervously. I had never smoked before. I was not planning to be a smoker, but on this one

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night I wanted to be Bette Davis for five minutes. I lit up in front of the mirror raised my eyebrows, looked down my nose and inhaled.

It was then that I remembered a talk I had heard in sacrament meeting. It was about a woman who was traveling in Asia and had been in a devastating automobile accident. Her injuries were massive and she needed thoracic surgery. The surgeon asked her if she smoked.

“No,” she said.

“I need to know if you have ever smoked even one cigarette, because if you have, I cannot perform the surgery.”

The woman had never smoked even one single cigarette, and because she hadn’t her life was spared.

I blew smoke through my mouth. Too late. If I was ever in a car accident in Asia, it would be the end of me.

I was a grand Bette Davis, saying, “But Dahling, you’re being absurd,” while holding the cigarette at what I thought was an elegant angle.

The next morning, I confessed to my mother. “I tried smoking last night,” I said. I sat in my nightgown at the kitchen table while she cleaned up the breakfast dishes. I told her how I had watched myself in the mirror.

Mother never overreacted. “Well?” she asked, “Did you like it?”

“I liked holding the cigarette,” I said. “I don’t know if I actually liked smoking it all that much.”

“I tried smoking once,” Mother said.

I perked up. “You *did*?” Suddenly it wasn’t all about me. Mother had taken center stage.

She nodded. “I worked as a maid for the mayor of Nieuwersluis. They had lady cigarettes in silver dishes. They were long and thin and colored—light pink and green. I took a couple home with me and smoked them as I rode my bike back to Breukelan.”

I had seen pictures of my mother in her maid uniform: a crisp full apron over a dark dress and I pictured her on her bike with two pastel cigarettes in her mouth at the same time. I laughed. “You smoked!” We were co-conspirators now. “Did *you* like it?”

She shrugged. “I just wanted to try it once.”

It was a gift, her sharing her own smoking story. I thought she was thoroughly generous. I thought she was an amazing mother, not like other mothers at all. Not like mothers who might have said, “Louise, *how could you?*” or “You’re never babysitting for them again!” or “We’ll have to talk with your father about this.”

No, it was a bonding moment between mother and daughter. It has always been one of my favorite stories of her.

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In fact I reminded Mother of this about five years ago. She and my dad were at our house for Sunday dinner and I was retelling the whole story, my point being how generous she had been.

I can still see my mother, her hair now white, sitting on my sofa. “I never smoked!” she said. Her indignance almost knocked me down.

At the same time, my father said, “Your mother has never smoked in her life.”

“You did! Don’t you remember the pastel cigarettes? You smoked them on the bicycle on the way home?”

Mother was genuinely shocked. “I never did.”

“Your mother never smoked. You made it up,” my father said. This is what anyone in my family uses as a stock answer to anything I say that they don’t want to believe: You made it up. That’s what you do. You make up things.

“How could I make up pastel ladies’ cigarettes? Even I couldn’t make *that* up!”

“I never smoked,” my mother said. “Never.”

“She would never smoke,” my father said.

Tom, my husband, yelled from the kitchen. “Give it up, Louise.”

Memory is wily. It hides in the dark and rises to the surface with a smell, a taste of madeleine cookies dipped in tea, a turn of phrase, a melodic line of a Gershwin tune. Where did it come from and who can distinguish it from imagination, which also surfaces mixed with old photos and faded, pressed flowers. In my heart I know that my mother told me that story and that she never told my father. I could not make up pastel cigarettes.

On the other hand, shouldn’t I be thrilled if I *did* make up pastel cigarettes? If I invented them deep out of my core where imagination dwells: Ladies’ pastel cigarettes. Wouldn’t that be a significant sign of my genius?

It might be best, as Anthony Hope writes, to aim at being intelligible. Now that my mother is loony with Alzheimer’s I feel loony too—almost unintelligible. John Bayley, who writes about his wife’s Alzheimer’s (the novelist, Iris Murdoch) says that “the loss of her memory becomes in a sense, his own. In a muzzy way.”

So, the story of Mother’s smoking could or could not be true. It’s my word against hers. But on this next story, I have witnesses.

One Sunday evening a few months ago, my father called to say that Mother was sitting on the kitchen floor and couldn’t get up. He suffers a degenerative disease and is not strong enough to help her. “She’s acting funny,” he said.

We were babysitting our grandchildren, so Tom drove over to help. He called to tell me that Mother seemed unusually disoriented and

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physically weak. “She can hardly walk,” he said. “I’m taking her to the hospital. I’m afraid she’s had a stroke. She also has a bad cough—maybe it’s pneumonia.”

Later he called again. “They’ve done a head scan and a chest x-ray and taken blood, but they can’t find anything. She can hardly sit up and she’s quite disoriented.” He stopped for breath. “This strange thing happened,” he continued. “I was sitting next to the gurney where she was lying and she looked at me and said ‘No one deserves to be abused!’”

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“Mother said that?” I was surprised not only by the content but by the fact she could even conceive of such a sentence.

“Yes,” Tom said “And I said to her, ‘No, no one deserves to be abused, especially someone as nice as you.’ She just lay there for ten more minutes. Then she turned to me and said it again, ‘No one deserves to be abused.’”

“Oh my gosh, do you think someone abused her?” My mind filled with ugly visions of abuse that might suddenly become part of our family’s history. Please, don’t let it be true, I prayed silently.

Tom broke into my thoughts: “Well, I asked her if anyone had abused her.”

“What did she say?”

“She shook her head,” Tom said. “And then I said, ‘Well, why are you saying no one deserves to be abused?’”

“And?” I interrupted.

He chuckled. “She pointed at the wall behind my head,” he said. “And there was a sign that read, ‘No one deserves to be abused.’”

Hours later, Tom came home shaking his head. “They couldn’t find anything, but there’s something definitely different.” He had taken my mother to the hospital in our Miata, a two-seater, low-slung sports car, because our children had borrowed the Cherokee.

He described getting Mother in and out of the car, evidently a highly skilled feat. “When we got home,” he said, I told her to swing her legs out to the street and then I would help her stand up. By the time I got around the car, she was sitting on the curb. I was afraid I wouldn’t be able to get her into the house.” He managed, of course, to get her into the house and got her settled in bed.

The next day, my sister Judy was startled to see Mother so changed and took her right back to the hospital. She spent all afternoon there, and just like the day before, the emergency staff could not find anything wrong other than the already diagnosed Alzheimer’s.

That same Monday night, after the two emergency room visits, my father discovered that the Robitussin bottle, that someone had bought for my mother’s cough a couple of days before, was empty. It wasn’t hard to figure out that my mother had taken a swig of cough syrup every time

she coughed, since she obviously couldn't remember how often she'd medicated herself. Mother had been drunk as a fiddler, drunk as a lord, drunk as an owl, drunk as a skunk. My sons said, "Grandma Roboed!"

If I ever get like that, hit me over the head with a bat.

I will not hit you with a bat, Mother, nor will I hide you hugger-mugger behind walls, behind whispers.

When I was in graduate school at the University of Minnesota, I took several writing workshops with a man in his late twenties who always wore a knit cap pulled low over his forehead no matter what the weather. The fiction writer in me, combined with a natural suspicion, knew there was a story behind that cap. I associated it with mental illness. Probably he had a layer of aluminum foil lining the cap to protect his brain from toxic, life-threatening radiation from an unknown planet in a parallel universe. Probably he wrote science fiction. In any case, I always sat across the circle from him in case what he had was catching. In case I too would be struck with an uncontrollable urge to write science fiction.

I discovered I was right and wrong about him.

No matter what the course, he always read from a book-length manuscript, a prose narrated in the second person. It read something like this:

You said you thought a picnic would be nice, so I took you to the bluff at the edge of Minnehaha Park overlooking the Mississippi River. You said you liked tuna fish sandwiches the way I made them with sweet pickles and onion mixed in with the mayonnaise. I suggested that we rent a boat sometime and cruise along the river. You laughed and said you would buy me a sailor's cap. You let me hold your hand. You told me about the time your family went canoeing up in East Bear Skin and your younger brother could only paddle in circles. Then a little boy cried over dropping a paper kite into a puddle and you grew sad and insisted on going home.

It seems odd now that no one in the novel-writing class ever asked him what he was about, at least, not in any direct way that I remember. It wasn't until we were in Patricia Hampl's memoir class, after he read for the first time from this same manuscript, that she asked bluntly, "What are you doing?"

He told us that he was writing this for a young woman who had once been his girlfriend. She suffered from severe depression, and he encouraged her to have shock treatment. He, himself, had suffered depression, and shock treatment had helped him. (Aha, I thought, the knit cap!)

On the strength of his encouragement, the young woman did have shock treatment and was relieved of her depression, but also lost a year of short-term memory and no longer remembered him, nor was she interested in trying to renew a relationship. So this large volume of work was to fill

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in her memory of the past year—the year they had spent together—with the hope of getting her back.

His grief over the loss of her companionship and the futility of his project to reproduce someone else's memory seemed to pull the floor out from beneath our chairs and leave us suspended slightly above it. How sad and how impossible.

I think of that young man with the cap often now days. (And parenthetically, I must tell you that I have known other people who had shock treatment and who never wore stocking caps). I think of him because now that my mother has lost all memory of her life with us, I talk to her with the same second-person voice. I talk to her in stories:

“Mother, you were the umpire for the stake's Young Women's softball league. And you were good. You never hesitated. ‘Strike one!’ you would yell out.”

“Me?” Her past surprises her. “I did that?”

“Yes. We played at Hamilton School. Later, you were the athletic director for Park Stake.”

She shakes her head, amazed at herself.

“You baked bread twice a week and fixed us sandwiches for school. Vienna sausages were my favorite. You hid the Twinkies and fruit for Daddy's lunch in your sock drawer, so Gerard wouldn't eat it on the sly.

“Mom, you used to take me downtown to the Yardstick before school started to buy material for new dresses. The aisles were tight and the material stacked way above our heads. You liked the Bates cotton. You made me plaid dresses with white collars. After, we would walk down to JC Penny and buy a bag of cashews to eat on the bus on the way home. I always think of you when I eat cashews.”

Once while I was doing dishes and she and Dad sat at the kitchen table, I turned and said, “Mom, you won't remember this probably, but when I was a teenager, I was your best helper. I especially loved doing the dishes. Janie hated doing the dishes, but I *loved* it.”

Mother viewed me suspiciously. “I don't think so,” she said.

“Ha!” my father said. “Even *she* doesn't believe that!”

It is like John Bayley writes, that “memory may have wholly lost its mind function, but it retains some hidden principal of identification, even after the Alzheimer's has taken hold.” It must be true; otherwise how would she know I was lying? And how does she happen to know that *Wheel of Fortune* is on?

She knows the same way she still knows to wash the clothes and hang them out to dry. She still vacuums and cleans up the dishes. She irons. She stacks the mail into neat little piles though she can't tell the

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difference between a bill and a request for charity. Routine has become her substitute for memory.

Eight children and their spouses plus Mother's two sisters look after my parents who still live in their house, both of them ailing. We take in two meals a day. We take mother out on errands, take her shopping. Ted and Neal fix things and clean up the yard if they can beat Mother to it. Judy doles out the pills on Sunday nights and takes the pill bottles home with her, since one week all the pills were missing and it cost almost \$600 to replace them. We take Mother to the grocery store, but often she gets up early herself and walks down to the Smiths a block from her house. She brings the cart home. We take her out to have her hair done on Saturdays. We have them over to Sunday dinner. Mother's visiting teacher takes her to church every Sunday.

On Fridays I take her for a ride after dinner. We drive through Federal Heights, and she exclaims over the beautiful houses. We drive through the upper avenues—more beautiful houses. We drive down through City Creek. Every week, she says the same thing: "This is beautiful. I've never been here before." We drive past the Capitol. She looks with interest at this building that she says she's seeing for the first time.

She reads all the signs aloud: "The Church of Jesus Christ of Latter-day Saints." She points at every passing church.

"Stop, 4 Ways," she announces at a corner.

"No, I won't," I say and accelerate through the intersection. She laughs with glee, like a child, and so I do it at every stop sign.

My sister, Janie, discovered that Mother knew all the hymns after she put a tape of the Tabernacle Choir on her car stereo. So Mother and I sing on our drive. We sing "Redeemer of Israel." We sing an old Dutch song: "Louisa zit niet op je nagels te bijten—Bah, wat vies, Louisa!"

She is easy to please, this new mother. She likes hugs—maybe for the first time in her life. She likes treats: M&Ms and Hershey bars. She's always grateful like a pleasant child.

When we get back from our ride, I say, "Why don't you take a bath while I'm here so I can help you out of the bathtub." She does this dutifully. I watch TV with Dad and wait for her to call me. Then I hear her voice: "Janie, I'm ready to get out!"

"I'm coming," I say.

Sometimes she'll come outside and wave goodbye until I'm out of sight.

The point is that at this time of her Alzheimer's my mother still has a life. A life that has value. She is delighted by small tasks and favors, but she is, nevertheless, delighted.

In a surprising way, Alzheimer's has protected her against the realities of life. She takes the announcement of a tragedy, a friend's death, with

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the same equanimity as a birth announcement: just a slight lifting of the eyebrows. I now better understand the remark an elderly neighbor, suffering from Alzheimer's made years ago when she was told that her daughter had died of cancer: "Oh," she said, "I'm glad it wasn't me."

I am not naïve about Mother's future. I know this condition will worsen, that she will forget us altogether, that she may suffer delusions, that eventually she may lose control of limbs, bowels, and bladder. That she may become silent and stop swallowing. That she will die.

**Take me for rides
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I would rather not lose my mind; but if I do, I won't tell my sons to hit me over the head with a bat. Take me for rides and walks and let me eat M&Ms and Hershey bars. Keep the Robitussin and the pills hidden. Keep my hair cut and my body clean. Buy me a pair of red high-tops. I think I'd like that. And if I am one of the mean, nasty ones, then put me in the best care center I can afford and don't feel guilty. Enjoy me while I'm here, for as Elizabeth Berg wrote in *The Pull of the Moon*, "I too have forgotten the grass. But I used to do one-handed cartwheels and then collapse into it for the fine sight of the blades close up. And there was no sense of any kind of time. And I was not holding in my stomach or thinking what does my opinion mean to others. I was not regretting any part of myself. There was only sun-rich color, and smell, and the slight give of the soft earth beneath me. My mind was in my heart, anchored like a bright kite in a safe place." ∞