

# **Voices of Alzheimer's**

## **Book Excerpts**

*Research Hits Home*  
Michael S. Wolfe, Ph.D.

Over ten years ago, I began working on Alzheimer's disease. My colleagues and I went on to make important discoveries about the molecular basis of the disease, with implications for new therapeutics. These discoveries eventually brought me to Harvard, elicited international speaking engagements, and earned me a reputation as a leader in the field. Nevertheless, I seemed to be virtually the only person who did not personally know someone with the disease. And with 4.5 million Americans afflicted with Alzheimer's, including almost half of all people over age 85, the chances of not knowing at least one person with the disease was quite slim.

All that changed during the past year. My own father, at the relatively young age of 65, began to voice concerns about memory problems. A former police officer in New Jersey who took early retirement and moved to Florida, my father loved to tease me about the warm, sunny climate he enjoyed while I weathered the winters of New England. Finally away from the harsh winters and his difficult and often dangerous job in the Newark area, Dad was free to play softball and golf to his heart's content. For a while, I dismissed his concerns about his memory: we all forget where we put the car keys from time to time, but as we get older we tend to read more into these momentary lapses than is justified. Living in a retirement community and having a son working on Alzheimer's also may have overly sensitized him, I thought. He was still quite a young guy, and the odds of him having a real problem were extremely low. In fact, at his age the chances were only about 1 in 100.

During the course of our lives, our bodies, especially our brains, produce a small protein byproduct called amyloid. As we get older, we are less able to clear out this byproduct, and it builds up to toxic levels in the brain, disrupting the connections between nerve cells that we need to think clearly and process memories. My colleagues and I discovered one of the enzymes responsible for producing this toxic byproduct and have been working to understand this enzyme better. Such understanding should help in the development of agents to block this process. Indeed, two agents that target this enzyme are now being tested in humans for their ability to slow or stop the progression of Alzheimer's. The hope is that such agents will lower amyloid and prevent Alzheimer's in a manner similar to how cholesterol-lowering drugs prevent cardiovascular disease.

At some point during our weekly phone conversations, I realized that Dad did have a real problem and should consult with medical experts. As a Ph.D. chemist, I did not qualify, and anyway could not assess my own father's situation objectively. A year ago, he went to the Mayo Clinic in Jacksonville where he underwent a series of tests for his memory and attention. He was diagnosed with mild cognitive impairment, typically the prelude to Alzheimer's. Indeed, he was prescribed medication that I knew was for Alzheimer patients.

It was hard to say whether this medication was helping, although at least it did not seem to be hurting. The current medications for Alzheimer's have limited benefits. Although they stimulate the critical connections between brain cells and can lead to clearer thinking, they do little or nothing to stop the underlying problem: the inexorable loss of these connections and the brain cells themselves. I was well familiar with the limitations of these drugs, this being my primary motivation for working on the problem in the lab. How frustrating it was (and is), having dedicated my career to solving this problem

but not being able to help my father.

His difficulties have become more serious during the past year, prompting a follow-up visit to the Mayo Clinic this past July. I flew down to Florida to accompany him on the trip. In many ways, this was a wonderful visit. We had more conversations in the span of three days than I could ever recall having before, probably because we never had this much time alone together. We also played chess, one of our father-son things to do over the years. In spite of his problems, he played a competitive game, which I found encouraging. We also had a few chances to throw a softball together, gradually ramping up the speed to challenge each other, just like old times.

But the trip was bittersweet. I watched him struggle with the one memory test I was allowed to sit in on. The neurologist gave the sobering diagnosis: very mild dementia, probable Alzheimer's. And his recommendations for certain lifestyle changes (driving, paying bills, having someone check daily about his medications) brought the point home that this problem was only going to be getting worse, that we should be planning accordingly. I had the surreal feeling of watching our own lives as if in a movie. This couldn't really be happening...it's too soon and too fast. Our work in my lab and other labs around the world had not yet advanced to the point where something could be done. Now the point of the research we were doing had clearly hit home.

We are in a position where, given the funds and the commitment, we can eventually prevent and treat Alzheimer's. How soon that happens will depend on the level of support and the depth of the commitment.

In the meantime though, I can still do something for Dad: I can be there for him, accept where he is now, and help him adjust to the changes that will be occurring in the coming years. After reading the stories in this book by others who have gone through this experience, I am encouraged that we can indeed make the most of what we have, where we are. This is not a movie. It's real life, and we must accept it and even embrace it as much as possible. One day, one moment at a time.

*Dr. Wolfe is Associate Professor of Neurology at Brigham and Women's Hospital, a teaching affiliate of Harvard Medical School where his work has focused on understanding the molecular basis of Alzheimer's disease and identifying effective therapeutic strategies. In January 2006 he founded the Laboratory for Experimental Alzheimer Drugs at Harvard Medical School, which is dedicated to developing promising molecules into drugs for the treatment of Alzheimer's disease.*

*No Kidding*  
Charles E. McGhee

No kidding. I've been told I have Alzheimer's. That's a disease. I've been trying to remember if I have ever had a disease before. I'm 72 as I write this. Two years ago, Norma Jean, my wife, asked me if I would talk to our family doctor about my memory lapses. That resulted in a referral to a psychiatrist, who did a few cognitive tests and asked me a few simple questions like what time it was and what day of the month it was. He concluded a probable diagnosis of mild Alzheimer's. I remember my mother telling me I had had scarlet fever as a child. I remember having my tonsils removed. That was no fun. I've had my share of flu, diarrhea and the itch. But these are not real diseases; each is more of a nuisance. Alzheimer's, now that's a real disease!

After that doctor's visit, I went home and did internet searches on Alzheimer's disease. I've always been a student. I studied engineering before entering the Air Force. I was trained as a flight simulator technician and served four years, but I really wanted to earn my bachelor's degree. I met the sweetest girl on earth during my first deployment. We were married within eleven weeks, just before the

Air Force sent me to Morocco. For eighteen months we planned our life long distance. My wife supported my decision to leave the service and complete my degree, even though it meant changing her career dream to become a nurse. I always felt like we both earned that bachelor's degree. I have been a student ever since. I like to learn and this is why I had to find out about this disease.

Alzheimer's cannot be definitively diagnosed without an autopsy. That means the doctors are guessing. At the time, 2004, the literature estimated a diagnosis accuracy of fifty percent. That meant that I had a one in two chance that the doctor was wrong! I told the doctor this and offered to wager with him that he had made a bad diagnosis. He wouldn't take me up on it. (Smart, because how could I lose a bet like that?)

Now, two years later, more educated and sort of convinced that I do have the disease, I'm working on keeping what I've got, regardless. At the family gathering on the Christmas after the diagnosis, I told Norma Jean I wanted the children to know the diagnosis. Not the grandchildren; some of them would be too young to understand. I felt we needed the children's support, and it was only fair that they be part of what was to come. Norma Jean needed to get used to the idea of being a caretaker. I had to learn to make her role as easy as possible. It's been a little bumpy. But we have piloted this ship for fifty-one years together, and we can learn to bring this ship to a safe and peaceful landing.

Now, a year after telling the kids, life is good. We're getting a lot of wonderful support from them. I am enjoying badgering the doctors by telling them it's Tuesday, May 18<sup>th</sup>, 2006 before they ask me. Oops! I just looked at my calendar and May 18<sup>th</sup>, 2006 is not on a Tuesday. Oh, well! Life goes on...

*After serving in the United States Air Force, the writer worked in electronics engineering before entering a career in the ministry. He was nearly seventy when he was diagnosed with Alzheimer's.*

*Mothering Mother*  
Carol O'Dell

"Letter to Self"

Dear Carol,

So far, you've been taking care of your mother for a year and a half. You've stuck it out through crazy times, angry times, tender times, through hospital visits and home health visits and while everyone else comes and goes, you've stayed. You haven't had a vacation and no more than two days away this whole time.

I know you: I know that when your mother dies, you're going to feel guilty. You're going to think that you should have been kinder, not in a rush, that you should have done more with her, taken her more places, insisted the kids be nicer. I know you're going to miss her and wish that a million things had been different.

I want you to know you did the best you could. You remained faithful. You grappled with every decision. You let her into your life and your home, you and your family did what most people wouldn't even have considered doing, much less done. People aren't perfect, and if they try to be, then they're not real. We're not supposed to get it all right. Remember, you had to balance this with being a wife and

mother. It's only natural to want to move forward and be more interested in your children—in those who are living. That's how the human race survives.

Remember, her emotions were always on an ever-widening pendulum, and Alzheimer's took them to frightening heights and devastating lows. You learned as a child that you couldn't trust her with your heart, although you kept trying. It just wasn't ever possible. That's okay. You know she loved you. And you loved her.

So go...love your children. Love your husband. Live life. Learn and grow and help others. Let it go.

Remember all the kindnesses - how Phillip built her apartment and put up her pictures, whatnots and books, how you tried to make it as much like home as you could, even before you did your own home. Remember stopping just to buy Klondike Bars for her. Remember the hot washcloths and how good she said they felt. Remember kissing her goodnight on her forehead, holding hands in the car and how much she loved getting her toes done. Remember how much she made you laugh and cry and want to scream.

You always knew you were alive with her. Remember.

#### "Letter to Mother"

Dear Mother,

I never wanted it to turn out this way. You, lost in confusion; me, overwhelmed and not knowing how to reach you. When you moved in with us, I was naive enough to envision us sitting by the river, me holding your hand, you nestled under a lap blanket, and the two of us sharing memories of my childhood and your childhood. Somewhere in this idyllic dream, you'd doze. I'd feel the pressure of your hand loosen and I'd know you were gone. I would kiss your forehead and whisper, "I love you," as you began your journey home.

A fairy tale, I know.

The reality is that I tiptoe into your room each morning and hold my breath, watching for the rise of your chest. Not that I want you to die; rather I fear that you have. Your life seems futile. Your days consist of not much more than a series of meaningless actions and reactions. Are you now more driven by instinct? Do hunger and thirst and a need to be covered up and warm rule you in your wordless world? Am I trying to decide if your life is more or less valuable than mine? Who am I to say? Does this sound cruel? I don't mean for it to.

I wake each morning to view the remnants of your destructive night. I pick up the nightstand, the telephone that is no longer plugged in. There's a mound of clothes on the end of your bed that you've taken off the hangers. More work for me. You've taken everything off. Your skin is as white as the whole milk you drink, your eyes remain closed, shunning this world.

I thought you'd be different. I thought I'd be different. I didn't expect this. I miss you. I miss what little we had. I miss your humor, your laughter. You still laugh sometimes....

Integrity is what you do when no one's looking. I wonder how I measure up. It's not that I do cruel things - it's that I don't seem to be able to relax, to sit down with you, talk, read the Bible to you. I'm scared so I just keep on my feet. I want to help you make a scrapbook, watch some old TV show, anything that brings you a bit of pleasure. But it's too late. Those things no longer mean anything to you. Each day passes and my family needs me, but you need me too. I want to write, go for a walk, clean out the refrigerator, take a bath, anything to avoid you.

I haven't put you in diapers yet. You wet everything, and yet at least you still try to use the potty chair. I just can't do that to you—or me. I'm afraid the diapers will give you permission to give up. I know that day is coming, and I'm helpless to stop it, just another step in your descending world.

I guess what I resent the most is the endlessness of the situation. It's easy to be kind, loving and caring when there's a cut-off date. Cancer often makes people valiant. Families rally around loved ones and last wishes get fulfilled; but this just seems to run into oblivion. I fear the possibility of years of your existence, staring off into space, randomly screaming while I perform the duties of diaper changes, sheet and night gown changes, wondering why.

I tell you I love you, especially at night. I try not to let a night go by without telling you. If you could hear me, understand me, step back to see this whole picture of our lives, I think you'd be proud of me, of us. We've made a good family. I love you still. I love that you loved me. I love that I had a mother.

*Carol O'Dell's literary works have appeared in numerous magazines and anthologies including Southern Revival Anthology, Margin Magazine, Atlanta Magazine, The Pisgah Review, Timber Creek Review, and AIM—America's Intercultural Magazine. She teaches creative writing and speaks on writing, care giving and adoption issues. Carol's book, "Mothering Mother: A Humorous and Heartbreaking Memoir" will be released in April, 2007.*

## **Voices of Lung Cancer** **Book Excerpts**

*I Miss My Friends*  
S. Epatha Merckerson

I'm one of five children in my family. We all smoked cigarettes. Not by example (my mother was never a smoker), but because that's what you did when we were growing up. You could smoke anywhere and advertising for smoking could be found everywhere: in the movies, magazines and television commercials. I smoked cigarettes for 23 years but quit in February of 1994, about three years after one of my sisters was diagnosed with lung cancer. Debbie is a lung cancer survivor because of a chance trip to the doctor. She thought she had bronchitis. Early detection saved my sister's life.

Yvette Hawkins and Billie Neal were two of my best friends. They were young, intelligent and vibrant women. They were funny and sensitive and creative. Yvette and Billie both died of lung cancer. By the time each of them had been diagnosed, the cancer had metastasized and they had only enough time to put their affairs in order. I was with Billie two days before she passed away and I was with Yvette when she took her last breath. I'd never seen anyone die before.

After my friends passed away, I began to learn more about lung cancer through organizations like the Campaign for Tobacco Free Kids and CancerCare. I became angry. There's so much to be done in the fight against lung cancer, first and foremost removing the stigma that comes with the disease: now we all know one does not have to smoke to get it. If information had been disseminated, if funding had been allocated for lung cancer research and tools for early detection years ago, my friends might still be alive today.

I'm honored to have been asked to be a part of *The Healing Project* and I will continue to use my voice in any way I can to fight for lung cancer awareness and the importance of its early detection. *The*

*Healing Project* has allowed me the opportunity to once again shout the names of people who brought enormous joy into my life.

I miss my friends.

*Ms. Merkerson is the star of the acclaimed TV crime drama "Law & Order." She has a long list of credits and honors including an Obie Award, a Helen Hayes Award and nominations for the Tony, Drama Desk and Image Awards.*

*Elisabeth*  
Misha Segal

*"Everything happens for a reason and even if sometimes things seem to make no sense, the future reveals why it happened." —Elisabeth Buchhalter Segal*

I grew up listening to those words by my mother Elisabeth; my mother, who was also my best friend and inspiration to my work as a composer.

Elisabeth was born in Vienna on October 31, 1920. (Many years later she would learn that day was celebrated far away by an entire country dressed up in funny costumes. She was tickled!). As a teenager, Elisabeth was Austria's table tennis champion. At the age of 17 she played against one of Germany's toughest competitors. Elisabeth won the first set, at which point her opponent threw her racket at the table, uttering, "I will not play against a filthy Jew". Thanks to the anti-Semitic propaganda machine, all Jews had been degraded into an unclean caricature of hooked noses and large lips. A gasp could be heard from the audience at the opponent's revelation: it was hard for everybody, including the judges, to believe that this young Austrian blond beauty, who looked to them more like Rita Hayworth's sister than the propaganda they were so familiar with, was really a Jew. Elisabeth's membership to the sports club was revoked there and then. In 1938, Hitler invaded Austria. Elisabeth witnessed beatings on the street, men dragged by their beards for all to see. Her own skin melted off her fingers from being forced to scrub the streets and Nazi army barracks with lye and acid. Her parents, prominent business and property owners, refused to leave but urged their daughters to run. Grete, their oldest, made it to Australia. Elisabeth's first attempt to escape was thwarted. Her second attempt at the end of 1938 was successful, but very difficult: she and several hundred others traveled for more than two months on three different small, dirty boats manned by pirates who helped themselves to jewelry, shoes, whatever they could get their hands on. Final destination: The Promised Land. The last boat anchored about 10 kilometers from the shores of Nathanya. It could not get close to the British soldiers guarding the beach; they were known for turning in Jews "illegally" attempting escape from the Nazis. But Jews already inhabiting the land tricked the Brits with drink and women, creating a distraction just long enough so all could jump ship and swim to freedom. It took several hours to account for everyone but they all made it.

*That was my mother.*

Elisabeth lost her parents to the Nazis but found strength to start a new life in Israel, where she met my Russian father and where I was born. She learned to laugh and live again. Her spirit could not be broken. In fact, after the war she was sent to Austria as part of a ping-pong team to represent the newly born state of Israel, the only girl amongst 11 men. She beat the Austrian champion in an exhibition game. Being just a few years after the war, the audience was still full of Nazis. The Israeli team wore the blue and white flag of their country, the Star of David, on their shirts and jackets. Elisabeth writes in her memoir, "...the same symbol they called 'Judenstern' which we had to wear as a sign of degradation and an invitation for anyone to abuse and torture us. Now we brought honor and respect to our beloved symbol and our flag."

*That was my mother's spirit.*

Elisabeth went on to lead a wonderful, rich life, traveling around the world, learning 5 different languages, doing international business and settling in New York City. It was many years later, in 1995, that Elisabeth was diagnosed with lung cancer. She had been coughing for a year. Her doctor insisted she had a pulmonary infection and so kept her on antibiotics for several months. When her condition did not improve, she insisted upon an X-ray. That's when the tumor was discovered. It was big and delicately placed. She came to Los Angeles to have an operation to remove the affected lung. The operation was fruitless: the cancer had spread to the lining of the lung and removing it would not solve the problem.

Her first oncologist gave her 6 months to live. As soon as he uttered the words "You should start preparing..." Elisabeth got up and walked right out. "Where are you going, Mama?" I asked. "He can start preparing" she said, "I am not going anywhere, definitely not in six months!"

We found another oncologist in New York, Dr. Isaiah Dimeri, who was more encouraging. Elisabeth stayed around for six years, almost an unheard of victory, considering that the disease was quite advanced. Dr. Dimeri became one of Elisabeth's best friends and remained my personal friend long after Elisabeth left. "She is one of a kind," he used to say. "If I had a bad day, Elisabeth would force a smile on my face. She would give *me* encouragement when it was *she* who actually needed it the most."

*That was my Mama.*

How did she do it? Straight from the hospital, on the way home, a day after open lung surgery, Elisabeth asked me, "Aren't we stopping for coffee?" She never let her physical condition interfere with her life. She never complained. As a matter of fact, after a chemotherapy session, Elisabeth would "spite" the cancer and go to a Broadway show or a concert of the New York Philharmonic. I would come for visits in New York and she would out-walk me. "Shouldn't we sit down a second?" I would ask after a 35-block walk on the Upper West Side. She'd look at me as if I'd just suggested the unthinkable. "Mishinka, if we sit down, we're going to be late for the movies...."

Over the years, we visited each other often and quite frankly, she was taking this much better than I was! I did everything I could for her; researched the latest treatments and clinical trials; accompanied her to important doctor visits and of course, played piano for her (if you are familiar with my *Female* CDs, that is the music I played for her), but it was she who kept the light shining long after the darkness came in.

*That was Mama.*

In the last year, Elisabeth was forced to slow down so I asked her to move in with me, my wife and our baby. Kicking and screaming, she left the city she loved. Upon arrival in Los Angeles, Mama, of course, continued to take care of me, ordering my (now ex) wife around if she fell short of her standards for how the house should be held; staying up with my friends and me until 2AM, drinking wine, talking politics and art.

It was only in the last 3 months that she became everything I didn't recognize my mother to be. Yet, her eyes still shone and painful as it was, her smile could still light up a room.

One night in the last week before she departed, she was feeling especially sick. She asked to see her oncologist from Cedar Sinai so I called him. He came to the house, checked her and told me this was the end of the road. When I called the next day to thank him, his assistant was dumbfounded: "Dr. Natale went to your home to see Elisabeth?" she asked. "Yes" was my answer, "and I wanted to thank him, it meant a lot to her". "I'll be darned," she said, "I have been working for him for over ten years and he never, ever made a house call." Later I asked Dr. Natale about that. His reply was, "I have never had a patient like Elisabeth before. I would come into the room and she would insist on finding out how I was doing. She never complained, was never phased by her condition. I came because I knew that if Elisabeth needed to see me, she must have really been in bad shape, so I *had* to see her."

Mother's Day, 2001 marked the day Elisabeth Buchhalter Segal left our lives. The next year, to honor what would have been her 82<sup>nd</sup> birthday, I played a concert at Cedar Sinai for the cancer patients. Dr. Natale saw Elisabeth's picture on the piano and his eyes welled. That concert was the first of many around the country and none of them would have happened if it weren't for Elisabeth. Even after her departure, she's giving, giving, giving to other people. Elisabeth did not "fight" the disease. Her victory lies within the fact that she wouldn't grant it any importance. "My life comes first. Diseases—they come last on my priority list."

"Elisabeth Buchhalter Segal was my mother, my best friend, forever my inspiration...and maybe yours, now, too.

*After studying film, philosophy and music at Tel Aviv University, Misha apprenticed under 20th century master composer Dieter Schönbach in Germany, studied composition and conducting at the Guildhall School of Music in London and graduated from the Berklee College of Music. In his native Israel, Misha's jazz, rock and pop influences helped change the face of popular music, garnering numerous #1 hits. His classical compositions have been performed by the Israel Philharmonic and the Israel Chamber Ensemble. Misha has created, composed and conducted scores for a variety of feature films including The Phantom of the Opera, and the all time favorite kids' movie, The New Adventures of Pippi Longstocking. Also to his credit are numerous works for the small screen, which earned him an Emmy Award.*

*His solo piano collection, Red, White & Blue 'Female' is the core of Misha's Beauty Found in Unlikely Places concert series. The concerts and the music were inspired by his mother, a woman with an unbreakable spirit. Through these concerts, associated media interviews and Public Service Announcements, he forwards his mission of educating the public on lung cancer awareness issues and raising the quality of life of those fighting the biggest battle of theirs.*

*Now I Understand*  
Barbara Terrell

I get it. No, I *really* get it. It took almost three years and a bout of breast cancer, but I now understand my mother-in-law, Julie.

I always thought that my husband, Eric, had married the exact opposite of his mother. Julie raised two children and never sat still. Her days were filled with charitable committee meetings, church activities, and Jazzercise; my days were filled with work meetings, church on Saturday nights and dog walks. Julie kept her petite figure by eating nothing but fruits and vegetables and low-fat foods; I believe eating pizza every day covers all the food groups. She raised her kids to eat healthy and stay active; I feed her son Lucky Charms for breakfast. She dressed like she could grace the cover of a fashion magazine, accessorizing with imaginative southwestern jewelry or scarves; I live in blue jeans and turtlenecks and have been known to show up at work with no earrings and two different colored socks. Yup, we were as different as night and day.

Eric and I had been married for about a year and had just spent the holidays with Julie and Bob, Eric's dad. Julie was vibrant and healthy, but had a touch of laryngitis, which she laughed off as being due to too much talking. She'd been hoarse for a month, and after a day of skiing decided she should probably go to the doctor. Then came her phone call. I instantly knew something was wrong; when I answered the phone there was no small talk, Julie wanted to talk to Eric right away. The doctor had taken a chest X-ray and made a grim discovery. She had lung cancer. Eric held the phone to his chest and silently cried.

Shocked and wanting to be involved as much as possible, Eric and I drove from Denver to Santa Fe and went to see the doctor with Julie and Bob. I felt like an outsider at the oncologist's office - my family dies of heart attacks and strokes. How does one handle cancer? When the doctor told us that the cancer was inoperable and had been found outside of her lungs, Bob, Julie, and Eric knew what that meant. Julie's sister had died of lung cancer a few years earlier.

From that day, I never heard Julie complain about having lung cancer. (She did complain about wearing a wig that made her head itch, and about having so many doctor appointments.) When her chemo schedule permitted, she kept going to her committee meetings and when she was feeling strong enough, Jazzercise. She loved being around people and keeping busy. She rarely varied her routine. Julie stayed up all hours of the night, as if she had to squeeze thirty hours into every twenty-four. Eric and I were puzzled. We wanted Julie to spend more time with her grandchildren and frankly, with us. Instead, Julie planned the yearly garage sale fund raiser for her pet charity, American Association of University Women. We tried to visit her once a month, but it always seemed like she was busy; I felt as if we were interrupting her schedule. But she always made sure her plans never interfered with our visits.

Julie was very resilient. She made it through chemotherapy. She made it through radiation treatments when the cancer went to her brain. Julie then volunteered to take part in a clinical trial for the new drug Iressa, which gave her six months of Indian summer: remission. Then, two and a half years after her initial diagnosis, the cancer was back with a vengeance. Bob was devastated when he had to call hospice.

Eric and I spent two weeks with Julie while she was under hospice care at home. There were times when she wasn't lucid. Other times, she was the old Julie, trying to organize and plan. Julie was worried she was putting everyone out and, of all things, that she had bad breath. It was during one of her

lucid times that she insisted Eric and I take a few days and go on a long-planned vacation. I thought she was nuts but she insisted. Not wanting to upset her, we tearfully said what we believed would be our last goodbyes and left for two days. We were nervous wrecks, calling and checking on her several times a day, racked with guilt, afraid we wouldn't be there when she and Bob needed us.

During our return to Santa Fe, Julie had slipped into a coma. We were told the end was near. I was sitting with her, holding her hand, telling her about the Indian ruins we'd visited and how we wished she had been with us. Her breathing became erratic. I ran and got Bob, Eric, and Julie's sister, Francie. We were gathered around her, touching her and telling her how much we loved her when Julie took a rasping breath and was gone.

I always wondered why Julie was so determined to maintain her schedule and to make sure that everyone maintained theirs. In a way, I felt like we'd been gypped out of spending more time with her. Try as I might, I couldn't understand it.

Fast forward three years. Eric and I were sitting in a \$2 movie theater watching the Johnny Depp movie *Finding Neverland*. During one scene near the end of the movie, the mother insists that her kids go to a play, even though she was dying. Throughout the movie, she tried to make sure that everything was as routine as possible for her kids, trying to shield them from her suffering. Her death scene so reminded Eric and me of Julie's death that we both started to cry uncontrollably. And then, a light bulb dimly flickered to life in my mind, a hint of a thought.

A few months later, I had my own shocking phone call. I was diagnosed with DCIS, ductal carcinoma in situ, an early stage of breast cancer. I had bilateral lumpectomies and four lymph nodes removed, followed by five weeks of radiation treatments. While my prognosis is totally positive, I discovered that cancer is all-consuming. Cancer swallowed my life, and then spit it out and I'm still trying to clean up the mess.

During my recovery, I was fanatical in proving to myself that I wasn't any different, that I could still handle my usual routine. Three days after my surgery, I cleaned out the refrigerator. Six days after surgery, I went on a two mile hike. The next day, I went on an annual elk hunt with my father and hiked five miles before driving four hours back to Denver. (I don't carry a gun; I take scenery photographs.) I wasn't going to let a little thing like breast cancer make me cancel a 21-year family tradition!

Every day I worked full-time. Every day I did physical therapy so I could raise my arm. (I had lymphedema, which made it difficult for me to use my left arm.) Although it was embarrassing to be caught by co-workers standing in the bathroom looking like the Statue of Liberty trying to stretch out my arm, I kept telling myself I'd be back to normal soon, to hang in there, to keep a positive attitude.

*Normalcy*: that was what I craved. I wanted to be able to exercise like I used to. I wanted to be able to close my car door with my left arm. I wanted my husband to give me a chest massage because I'm sexy, not because he needed to break up my scar tissue. I didn't want to be labeled a breast cancer survivor, but just a normal person doing normal everyday things. Then, the dim light bulb in my brain that had flickered on at the movies started to shine at 100 watts. *Normalcy*: that was exactly what Julie had coveted. She just wanted to be a normal person, not someone dying from lung cancer. Suddenly, Julie's behavior made perfect sense.

I guess we weren't so different after all.

*Prompted to start writing non-fiction by a bout with breast cancer, Barbara has been giving corporate presentations since 1987. Her goal is to help others realize that they can make it through challenging times with humor. She lives in a suburb of Denver with her computer guru husband, a shy yet neurotic German Shepard, and a CT she calls "the evil one."*