Living in Twilight: A Daughter’s Alzheimer’s Story’ Part I, August 2010

By Nancy Daly

*“I know this voice- who are you?”*

*“I’m your daughter- I’m your daughter.”*

They took her car keys away last June. She was driving with her son on a busy boulevard at rush hour with her adored granddaughter in the back seat when she couldn’t remember how to drive. He told her to turn off her blinker and she turned off the car- impossible to pull over in traffic. She cried, “Stop yelling at me, I know what I’m doing!” But she didn’t. Twenty agonizing minutes later, they arrived home. Her son shook his head and said sadly, “The keys, Mom-, just give me the keys.” It was only the first task that would be gently taken away from her.

Slowly over time, her family adjusted. She was a gourmet cook and they were her designated sous chefs. Holiday dinners used to be course after course of exquisite dishes- the mushroom cream soup at Thanksgiving, the plum pudding at Christmas. It was poetry in motion as she stirred one, supervised the dicing of onions for another. She barked out orders while sipping wine and tossing scraps to the collies that raced through, prancing to be let out and back in again, the granddaughter scampering in avid, giggling pursuit. But Christmas was never to be the same again. She started a fire in the kitchen by placing a plastic cutting board on a lit burner because she couldn’t remember that heat came from it. Recipes she used to know by heart for decades were bungled and changed, “I know what I’m doing! You all leave me alone!” And it became clear that Christmas would have to build new traditions- new memories- a simpler feast. No more books as gifts as it was becoming impossible to remember from one page to the next, one paragraph to the next what she just read. She was the third member of the family to have a master’s degree in English Literature. They would now have to move her pieces in board games- as the ability to count “one, two, three . . . six” was fading- never to return.

There is no sense of time with Alzheimer’s. The same question will be asked several times over and over again. The phone can ring at 2 in the morning, 4 in the morning. It can ring five times in 20 minutes- but you have to answer it each and every time because that might be the one conversation in which she still remembers you and knows your name. Her family had entered a tunnel of confusion and uncertainty that was narrowing rapidly. There was no hope. There was only decision after decision to be made. How do you make the remaining time as light and joyous as possible – until there is no light- there will only be dusk.

*“I’m handing the phone to- to- my husband- what do you call him?”*

*“Dad- I call him Dad. You see, your husband is my father- he’s my father-“*

There will come a time when the Alzheimer’s patient will not be able to dress themselves, to comb their hair, to bathe. It isn’t that they are physically incapable of buttoning a button or brushing their hair, they simply don’t remember how.

*“Can you help Mom get dressed? She’s having a little trouble.” I entered rather cautiously to find her worriedly pacing back and forth, fumbling with her skirt and blouse- muttering to herself, “Something’s wrong- something’s wrong with the- with the- the- thing- something’s wrong…” And I look- it’s on backwards. Her skirt is on backwards and it is inside out. The buttons are all open-she couldn’t remember how to button them. My mom, the one who taught me the rules of accessories: “no white shoes before Memorial Day or after Labor Day- make sure your stockings are never darker than your pumps; and make sure that your shoes, purse and belt all go together and patent is for summer.” My mom who prided herself on dressing in her best outfit for church had forgotten to brush her hair and was in tears that her cuffs were not fastened. Our roles were now switched- I spoke soothingly as I helped her finish getting ready and directed her down the stairs to my father who was waiting patiently, then darted into the powder room to hold the hand towel over my mouth. She cannot hear me cry- it would confuse her, so I have to cry in silence.*

Their sense of time and space will diminish- until nothing is familiar- not even their family.

*“Oh, the dog is barking- how is your dog- who is she?”*

*“Baileys- her name was Baileys- but she died, Mom. Baileys died in October.”*

*“Oh, poor doggy . . . who are you?”*

With Alzheimer’s you lose them twice. You lose them when they don’t remember you anymore and you lose them again when they die. My childhood memories have now been bumped up to Technicolor, and I clutch at them- because for her, they are now fading into shades of grey. Without her verification- without her shared memory of the time that I was learning how to write and wrote my brother’s name on the wall so that he would be the one who got spanked instead of me or the time I had to be carried on to my Dad’s ship because my hand got caught in the car door- they are slipping away from me. For the joy of remembering, of being able to say to me proudly, “You were only three, but you didn’t cry- you were so brave!” My childhood champions are going. Those memories are mine alone now- I can no longer share them with her- and I fall asleep repeating them. For now, I am the sole keeper of my childhood. I alone remember.

*“I wanted to ask you- where is your real father?”*

*“That’s him, Mom- that’s Dad- that’s my father. “*

*“Oh, no- that’s not your father- that’s a cousin-where is your real father?”*

*“Mom- please- I promise you- that man is my father. He’s my father-“*

*“Oh. . . Who are you?”*

It is true that Alzheimer’s is a fatal disease- but it can be a slowly progressing one. It can go in cycles. Weeks can go by and all of a sudden you hear it- your name- a word you were convinced you would never hear again with certainty and ownership- your name spoken by your mom. But- there it is. It can manifest itself very differently in each individual. There is a musician in Los Angeles, who no longer remembers his own family, but he can play hours of music on his beloved guitar by heart, the memory is in his fingers. The mind may falter, but his artistry- the gift of his music is timeless- he is an artist- always.

*“We are going to England. Your mother wants to see it again, so, we thought we’d go over for a few weeks.”*

*“Yes- I want to see . . . to see- that place-you know- water . . . it’s- tea- the tea place.”*

And I listen so carefully now to every word she says- because I know that there will come a time when there will be no words. She will stop speaking, in time. There will be a time when she no longer knows me. She will be gone from me, even though she is right in front of me. Alzheimer’s will rob me of not only my mom, but of years and years of time, of memories shared, and I will be left with silence. So, I listen now, and we share laughs and gasps of wonder over *Harry Potter* together- hum along to the soothing carols of favorite Christmas music as that is a language that can carry through the fog of this disease. And I know that I can say “I’m here” with a touch and a hug- and somewhere inside her; there will always be an echo of who I am- her daughter.

Living in Twilight, A Daughter’s Alzheimer’s Story- Part II, August, 2011

It was 1:30 in the morning when she rang the bell of her next door neighbor’s house.

*“Will you take me to London? That man next door- he won’t drive me to London. Will you take me to London?”*

By now, everyone up and down the block was on alert. If you see Mrs. D walking up and down the street, go get her husband- or the next door neighbors- and just be calm. Agree with her, whatever she says, and try and guide her back to her house. She would wander restlessly, to the dining room to knock feebly on the window- sometimes in the front yard- sometimes across the street; tottering in hesitant steps, anxious, frightened- calling for my father.

*“Rick! Rick! Where are you? Where are you? Come help me!”*

*“There’s your house, Mrs. D. There’s your house- and look- there’s your husband. He’s right there- that’s your husband.”*

*“No, no, it’s not- it’s- oh, yes- yes, of course! Nice to see you! We have to get going. We have to go to . . . that place- we have to do that . . . “*

Most of the time- it was only a matter of moments before a kind neighbor would gently reroute her and she would return to the haven of home, safe and sound. But other times, she would burst out of the door, driven by blind terror at not knowing where she was or misplaced anger at my father. She would flag down a stranger and shriek, “Call 911! There’s a strange man in the house and he’s beating me!” Six police cars would show up, and my dad would have to explain, “It’s alright, officer. My wife has Alzheimer’s. Everything is fine, no one is being hurt.” Five times the police were called- five times my father would have to be interviewed to determine- once again that no abuse was taking place while my mom shuffled back and forth mumbling, “My head- my head hurts. There’s something in my head- and it’s wrong.” This is Alzheimer’s.

I cannot even begin to describe the horror and heartbreak of watching and listening as your own mother loses her mind.

I had researched and found a home health care company that was very dedicated, very knowledgeable and the answer to our prayers; an experienced nurse to provide assistance to my mom and a much needed break for my dad. But she refused to have a stranger in her house. This was her world and the walls of familiarity were narrowing. She spent her days in parallel time, reliving past memories of 10 years ago, 20, 40, 60 years ago as if they were yesterday, moving objects around as her shattered mind tried to recreatefamiliar tasks; putting silver knives in with the linens, clutching her dinner plate and her purse as she made her faltering way to the garage, “It’s time for church- we all have to get in the car.” And my dad would gently, patiently inform her- no, church was on Sunday, and it was dinner time now; let’s all sit down and have dinner. And she would, for a moment, join us- her eyes darting fearfully from one to the other- searching to remember names, faces. But she would jolt up again; take a few steps and call, “Rick! Rick! Where are you?” and we would all take turns trying to steer her back to the table, rushing in to place ourselves between her and the stove because accidents were becoming more frequent and we lived with the constant fear someone would get hurt- again.

My father ended up in the hospital three weeks before Christmas. The stress of taking care of my mom caused him to black out in the middle of the night. Hitting his head as he fell, he was knocked unconscious. It was hours before my mother found him. But because she no longer knew how to dial a phone, she staggered up the street until she found a neighbor who could call an ambulance. My brother and I spent hours tracking down friends to take shifts in the waiting room with my mom until my brother could get there. We couldn’t trust a busy hospital staff to keep an eye on her. How could she be expected to understand let alone remember any diagnosis, any instructions for my father’s recovery, when part of the time- she had no idea who he was? This is Alzheimer’s.

By the time I saw my parents again in July- her weight had plummeted to 85 pounds. She could no longer dress herself. Piles of clothes would be discarded until we could find a combination that she liked and that fit- everything was falling off her fragile, skeletal frame. My dad would try anything to get her to eat; her favorite soups from the specialty grocery, eggs just the way she liked them, fresh toasted sourdough bread with sweet strawberry jam. My parents are from the mid-west and my dad is a grill master. He would try over and over- flank steak- her favorite, sausages, pasta dishes- anything. Nothing tempted her. Her appetite was failing; most of the food on her plate made its way to the dog. She needed help cutting her meat; silverware was overwhelming at times. Spoons were safe, knives were perilous. Each night, it took us over two hours to get her to take a bath and go to bed. She would stumble throughout the house in her underwear- lost, terrified, wailing, “Get away from me! Don’t touch me! I have to go! I have to get this done!” She would pound on us with her fists, “NO!!!”, only to collapse sobbing moments later, “Help me! Help me!”

This is not my mom. This volatile, violent, ghostly figure is not my mom. No, this is not my mom. But this is Alzheimer’s.

At first, it seemed she had no idea who I was. When I tried to prevent her from walking in front of a car in a parking lot, she had screamed, “Who are you? Leave me alone!” But that night, two hours into trying to lead her back up the stairs for the third time- she glared at me, reached out and struck me, “You’re a horrible girl! You left! You moved! Go back where you came from! I hate you!” My father whispered, “Don’t do that. Don’t cry. She didn’t mean it.” Then kindly, but firmly, he coaxed her up the stairs.

And I let it burn through me- her loss for the daughter I was supposed to be, her frustration at the daughter that I am- it is spiking, piercing, rending every aspect of my being. I am “the one that left” . . . “the one that moved to California” . . . I am “the one who is doing that acting thing.” It wants to hack at me, this grief- it wants to bring me to my knees- I will not let it. I ruthlessly shove it down and bury it. I will think later. I will feel later. I will eat later- sleep later- years later if need be. I am here to take care of my parents.

The next day as I wash dishes, do laundry, slip into bathrooms after she uses them to wipe surfaces down with disinfectant wipes and make a game out of squirting everyone’s hands with sanitizing gel- the bathroom has become a mystery to her. I trot up and down the stairs and in and out of the back porch with cups of tea and help her get dressed- re-dressed- all the while keeping an ear and an eye out to guide her back from slipping out the front door, on guard for any objects that have been carelessly left and need to surreptitiously be returned. She turned to me as I was massaging her shoulders;

*“Where is your mother? Where are your parents? We would love to write to them and tell them what a lovely, helpful young woman you are.”*

*My dad, who had brought my mother down the stairs to apologize to me the night before tries to remind her, “She’s our daughter, dear; that’s our daughter.” She shakes her head and says, “Oh, no, I don’t think so.” It doesn’t penetrate- she has completely forgotten who I am.*

We finally had to put my mother in a medical facility in order for her medication to be stabilized before moving her into assisted living. The day my father took her to the medical facility was one of the worst, most wrenching days of his life. She raged. She cried. She tried to escape out the front door. She lashed out and hit one of the attendants. She was spiraling downward. My dad had always said, “She is my love. I cannot leave her.” And now, every time he has to leave her side and go home to their house of more than 40 years without her, she cries- and cries.

This is Alzheimer’s.

On the day that I was flying back to Los Angeles, as my brother and his family loaded up the car, my father gave me a strong hug. “Thank you, dear. Thank you for taking such good care of us. You were a great help. We love you.” And my mom stepped up with the bright, friendly smile of a gracious hostess, “Oh, yes, you were! We want to write your parents and thank them. . . You’re so pretty.”

I have just been slammed with a sledgehammer- I cannot breathe- but I cannot let this hit me now. So, I grit my teeth- and bear it- through the bright chatter of my brother and his family, through the hurried hugs and pats as they drop me off at the airport- through check in, through security, through the long corridors of the airport- until I reach the anonymous safety of a lone café table can I finally drop my head in my hands and cry.

I had to wait until my mother had Alzheimer’s- until she didn’t know me anymore before I ever heard her say to me, “You’re pretty.”

Alzheimer’s is not a solitary disease. It affects entire families- circles of friends, co-workers. It may not be every other thought you have, but it will be every third or fourth; “My mom has Alzheimer’s.” It is a cloak that you wear constantly. And some people will leave your life abruptly- or just fade away- and that has to be okay. There is a shadow and a loss in your life that is growing ever darker, ever deeper. There are times you are living in a hurricane of dread and pain; and for some- this will not be what they signed up for- as your lover, as your friend- and they will leave you. But at the same time, you will find that there are champions in this world- there are guardian angels- who reach out with comfort, support and faith. They will stand by you and walk with you. They will be your harbor; your shoulder to lean on- to cry on, “Is there anything I can do? I’m here for you”- and they mean it- and they are.

So, I would just request, if you have a daughter- in the spirit of making her day a little brighter and putting a glorious smile on her face and in her heart- in the next few moments, hours, days- no longer than a week- go to her, hug her and make sure you tell her-

“You’re pretty.”

“Living in Twilight- a Daughter’s Alzheimer’s Story- Part III, August, 2012

*“Yes, well- Christmas will be a little different this year without your mother here in the house with us. But I’ve arranged for us all to have a Christmas dinner with her at the Lutheran home. So we can all have a special dinner together with your mother.”*

*“Dad- Christmas isn’t a location- it’s wherever we are together. That’s Christmas.”*

By the time I came home for Christmas, my mom had been moved to a rehab facility and was in a wheelchair. I thought I was prepared. I wasn’t. As we walked into the lobby, there she was with her caregiver, a true angel on earth, Ingrid. Dressed in a bright red Christmas sweater, warm pants- her feet shuffling on the treads of her chair- she smiled brightly at everyone as they walked to and fro. I knew that smile well- that warm, welcoming, gracious hostess smile. I had seen it thousands of times at dinner parties as she circled around, making sure everyone had enough wine- had someone new to meet and talk to- that all was well and everyone was comfortable and having a wonderful time. As I approached her, she lifted her hand to me- and nodded- smiling sweetly. Another visitor- how lovely, her smile said.

She didn’t know me.

For two days, I chatted non-stop of how we were preparing the house for Christmas, decorating the tree- how we were gearing up for the increase in noise when my niece and her dog would arrive with her “staff”- which is how our family would sometimes tease my brother and sister-in-law. My mom smiled- spoke in brief phrases- always charming, always listening carefully to every story, every memory I shared- which were embellished by my father as he added in details I might have forgotten. But still- every time I said- “That’s right, I’m your daughter.” She would nod and smile. But it was the kind, polite greeting of a social gathering, not a true recognition- she still didn’t know me.

On Christmas day, I told my father that I wanted my mom to have some kind of a church service on Christmas, so we wheeled her into the chapel of the facility- right down to the altar. The wonderful gift of having gone to the Episcopal Church all of your life is that you can recite most of the prayers by heart. So, I channeled my own priests from my own church and fumbled back and forth through the service as best I could. I arrived at the prayer- “Thou shalt love the Lord thy God with all thy heart, with all thy soul and with all thy might” and leaned over to make the sign of the cross on her forehead. My mom reached up- clasped my hand, looked me straight in the eye, smiled and said very lovingly-“You’re my little girl.”

And there it was- she knew me. My Christmas wish came true. My mom knew me on Christmas.

It was the last coherent sentence she would ever say to me in person.

May 7th, 2012- My father had found a CD player for my mom for Christmas and she loved to hum along with Christmas music- her favorite. A dear friend of mine- Heather- was working with her every week as a music therapist. And my father was thrilled that in those hours that Heather was there, my mom would sing along with her- her eyes lit up, laughing joyously- glorious hours of music and lively company. As the weather grew warmer, my parents would sit outside in the garden- holding hands and listening to music- humming along and sharing smiles-pockets of paradise in the midst of sadness as spring slowly came in.

My dad called me that day as he did every day. “This is your father, I’m with your mother- do you want to talk to her?” “Of course!” and the phone was passed over and I bubbled just as I used to- “Hi, Mom- it’s your darling daught!” and as clear as a bell, I heard- “Oh, hi, honey- how are you?” She knew me- it was said just as she used to say it- same tone, same smile. So, I burst forward and prattled on and on about auditions- clutching at this moment of- “she knows me!” until I could sense she was getting tired. I promised her- “But I’ll be there in July for your birthday, Mom- I’ll be there! I love you.” I heard a very faint- “I . . . you” and the phone was taken away.

May 8th, 2012- Late afternoon, I was in the recording studio I had set up in my living room closet and the phone rang. No. I know I stopped breathing. NO. Do not answer it. I don’t know why there was this grip of dread. Because after yesterday, I was so sure- I would see her for her birthday. I had been saying to my dad for the past month, “Gee- it sounds like Mom is getting better- her spirits are up- it sounds like she’s getting better.”-I was so sure- so absolutely sure, I would see her in July.

*“This is your father. I was with your mother- a few hours ago. I was visiting your mother just a few hours ago and they just called to tell me that she had died.”*

And the world stopped- and stayed there. It all just stopped. Weeks went by- six weeks in a haze of grief and wrenching, crippling pain- my mom died- my mom died from Alzheimer’s. Emails and cards, messages and loving posts of support on facebook- suspended in time- in the midst of this fog, one thought kept hammering in my brain. I had vowed to her- “I’ll be there for your birthday in July”. I had no idea that her memorial service would be held two days before that.

It was empty- my mom’s side of the closet was empty. I had begged my brother to leave her clothes for me to go through. I was tersely informed*-“There’s too much stuff in this house and we have to get rid of it- we can’t wait for you to get here.”* There was very little left. I looked at the empty hangers, the gaping drawers in shock- the pretty summer dresses, elegant jackets and lovely suits for church- my mom’s pride and joy in wearing stylish outfits- shoes, purses to match- almost all gone. I had wanted that last service to my mom- a daughter’s rite of passage- to go through her favorite clothes- to remember each holiday vest she wore while supervising each course of Christmas dinner- to decide what should be kept or given away. But it was almost all gone- already packed to be taken away. Later that day, I found a few drawers that had been left untouched. So- I was able to go through and hold a few gloves, a few handkerchiefs- a scarf or two to my face and have my walk down memory lane. “This belonged to my mom- this belonged to her mom”- my family history in linen, satin and lace. “Mom? I’m your daughter- I’m taking Grandma’s gloves home with me- and your favorite dress that you wore to my wedding- Mom?” Silence.

Due to the storm in the area, my mom actually ended up with two services. The first being the blessing of her ashes followed by an impromptu reception at my parents’ house and the actual formal church service was held the next day. My cousins from Colorado and Missouri all pitched in- “We gotta help out our cuz!” Circling with platters, rapidly doing dishes and helping collect wine glasses and napkins from every corner of the house-“Try the basement! We’ll bring out the Christmas stuff if we have to!” Neighbors dashed back to their houses to bring ice and cups for the unexpected home reception- and through it all, I could feel her smiling- “Oh, how nice- just as it should be- one more party in the house.”

How do you say goodbye to your mom? How do you honor her? How do you define her legacy? A loss of a mother is so very profoundly felt by a daughter. For now- the one who took me shopping for prom dresses, who taught me to always write a thank you note- who instilled in me the joy and delight of being a warm, gracious and welcoming hostess- who led this family of literary titans to have hundreds of books spilling from every wall in every room of the house- she is gone and the house is so very quiet without her laughter and her marshalling of the troops. As I read through my words the morning of her service, it struck me- all of my trials and triumphs as an actor- “to always set the bar high- and when you reach it, you set it even higher”- the drive that pushed me to move across the country and start all over- “good is not good enough- not when you have the capacity to be great- so, never settle for anything less than greatness”-are all part of my legacy of growing up an artist in my family- resilience on the road less traveled by- a gauntlet with a gift in it.

With all of the last minute changes of my mom’s service, my father heard my eulogy for the first time that day and cried. My cousin Sarah gently offered him Kleenex and kept a comforting hand on his shoulder. After I finished, I sat down next to my dad and reached for his hand. He kissed my forehead and said- “Well done, peaches.”

I knew then that she heard me- as that was the nickname my mom used to always call me.

And finally, now- I can remember her- before she began to fade from me, before the last few years as her mind spiraled away into confusion and terror- before her body slipped away until she spent the last few months smiling brightly from a wheelchair- she was my mom. The last time she looked at me and knew me- the last time she knew I was her daughter- was on Christmas day.

This was Alzheimer’s.

In July of 2011, I founded Actors Unite to End Alzheimer’s for the National Walk to End Alzheimer’s in honor of my parents. I wanted to build a community of support, awareness and compassion for my fellow actors and anyone who has or who has had a loved one with Alzheimer’s. For the first two years, we had four teams- New York City, Los Angeles, Washington DC and Miami. It happened to every team in every city- as we walked the course, other actors would notice our team and actors’ union signs and run up to us- “I’m an actor, too! Can I walk with you?” We were walking in glory. Articles were posted on dcmetroarts.com, backstage.com and broadwayworld.com as other actors around the country responded- “I’m walking in Chicago! I’m walking in Virginia!” In its first two years, the 100 members of Actors Unite raised over $50,000. It is truly amazing as 85% of our donations ranged from $5-25. In 2013, I decided it was time to become a full national team. In light of that, we expanded our name to Actors and Artists Unite to reflect the actors, artists, production crew, writers, directors, friends and family members that make up this wonderful team- each and every one is a champion in their own way. As someone said to me after my mom died-“You have been carrying this torch and now, you must run with it.”

Nancy Daly is a working Actor, Voice Over Artist and Writer who lives in Los Angeles, but still considers herself an East Coast lady at heart. She is a member of the Actors’ Equity National Council and the Founder and National Team Captain and National Team Coordinator of Actors and Artists Unite to End Alzheimer’s. Her families’ names have been changed to protect their privacy.

Actors and Artists Unite has twenty eight teams registered to date for the National Walk to End Alzheimer’s of 2013.

The remaining teams include-

Saturday, October 19th- Long Beach and San Diego- first year!

Sunday, October 20th- New York City- third year as a team!

Saturday, October 26th- Washington DC and Hollywood, FL- third year!

Sunday, November 3rd- Los Angeles, CA- third year!

Anyone can start a team in their own city under our national team name. Find us at [www.alz.org/ActorsUnite](http://www.alz.org/ActorsUnite) and our team page on facebook- Actors and Artists Unite to End Alzheimer’s.

Our motto is- When Actors and Artists Unite, the world can shift. And sure enough, it does. So, come join us. Everyone is welcome. We take care of our own and as we Irish say- slainte!