

Surviving Alzheimer's: A Care Giver's Story

I have often been asked what made me decide to write my book. To be honest, it never started out to be a publicized work. I began to write my thoughts a few days following my mother's death to ease my own personal grieving. Writing and journaling has always been an outlet for me so I used it to ease the pain. During the course of my mother's illness, my father took daily notes regarding her condition. Sometimes a line or two was all he would enter maybe saying she would not eat today, or this was a good day, but there were also words of hope, followed by discouragement and pain. After 15 years of caring for her, Dad had quite a stack of notes. After Mom died, I asked him if I could look them over and it was through his writing along with thoughts of my own that I based a memoir that I presented to him and a few close family relations. I was then encouraged to take my story a step further for others to read with the hope of offering some understanding to others in similar situations. But this is the story of one Care Givers journey. Many others have had to make different choices and agonizing decisions to follow their heart and suit their needs. I can simply offer what I witnessed as a daughter. Writing this book also gave me a chance to fight back in my own small way by speaking out and raising awareness of this gripping disease of sad good byes. The relentless symptoms only become worse with time, wearing down its victims and anyone else personally involved. The disease itself is shameless and shows no mercy to those afflicted. But it doesn't end there. It is cruelly passed on through a mutated gene to family members to reignite its thunderous course. I'm sure most of you are well read on the symptoms and dismal diagnosis of the disease but I am here to share my mother's experience and to honor my father's devotion towards her.

My parents met in 1941 while my mother was in nursing school. A classmate introduced her to my Dad on a blind date and the rest was history. Ironically enough, the first date they had was a trip to the same lake where she spent her last days. They were married in 1945. My mother had become an RN. During the war, they were beginning to draft nurses, so the joke has always been that my mother 'had' to get married to dodge the draft. It was a small quiet ceremony; in fact my father went to work the next day. He was employed at the Enterprise Foundry in Lew. that was founded by his father in the early 1900's. They married and had 3 daughters. Life had its hardships but they always seemed to find a way through the hard times. My mother was raised on a farm in Farmington and knew the value of a penny. She had many talents and was successful at anything she set her mind to. Her skills included knitting elaborate sweaters, sewing beautiful clothes, upholstering, furniture refinishing as well as excelling in such sports like tennis, golf (hole in one at Fairlawn), skiing and I even remember the time she participated in an all women's broom hockey game. All of these skills and memories were gradually swept away like dust by the shadow of Alzheimer's.

It was not until 1988 that my mother began showing signs of confusion and indecision. The 3 of us had grown up and had moved out of the house so I was not fully aware of how it started but my father remembers all too well. Mom had always been the book keeper of the family and suddenly she became unable to properly write out a check. Numbers did not make sense. Simple forgetfulness was blamed on getting older but it became more of a concern as events became more serious. One day my parents had gone grocery shopping. They unloaded and packed away several bags of groceries. It was only a few moments later when my mother asked where the groceries had gone. She seemed to know there was something wrong at this early stage because she began writing things down and clipping out articles on memory loss. She once told me “not to get old because it’s just not fun.”

My father is from the old French Canadian generation. Very strong willed, methodical, proud and hard working. House cleaning, cooking and raising children were not a part of his agenda. Women’s lib was unheard of at the time and my mother was just as happy in her place at home with the children anyway. It was a compromising union of give and take that worked well for them. When the diagnosis was made, changes took place that my father would never have thought possible had he the chance to peer into the future. As she became unable to perform familiar tasks, he took on the responsibility of managing the household but still tried to engage her in the routines as much as possible. They made beds together, folded clothes, washed dishes etc. I suppose his motto was ‘Hold on to as much as you can for as long as you can.’ My mother had always kept a spotless house and even during her illness she still found the urge to scrub and polish. My father saw her scrubbing and wiping the kitchen sink one morning using repetitive motions. He told her she was doing a “great job” and she replied, “I learned it from you!” In spite of this tremendous role reversal, he was determined to do everything in his power to offer my mother support, love, respect and devotion while preserving her dignity until the bitter end. This was so important to him. Mom always looked neat and clean wherever they went. It made his life look simple. No one witnessed the early morning baths, the physical transfers from bed to chair, the falls she took, the daily dressing and personal care that took place. When she became incontinent, the issues became even more complicated and taxing but he never complained.

One of the earlier doctor visits involved a local neurologist who encouraged Dad to get his affairs in order and start making arrangements for my mother. He blatantly spoke about AD in the presence of my mother. Dad was very sensitive to this and it only managed to strengthen his resolve about keeping her at home. Although he understood that someday, something may happen to him and she would be forced to live in a nursing home, he was adamant about giving up on her if there was any way he could keep her at home with him. In the end, he was allowed this meager luxury. She died peacefully in the serenity of their summer cottage by the lake.

There is a book for Alzheimer Care Givers appropriately titled 'The 36 Hour Day'. The title says it all. Care Givers have very little time for themselves and are constantly in a state of alert. To make her care possible at home, several modifications were made... PCA, handicap van, w/c lift, remodeled shower, lift chair, ramps.

For the victim, there's also a stage of shame and covering up. My father in law suffered from Alz. and on the day he was to be evaluated, he asked to bring along his little book that he kept of himself with resumes of his accomplishments to show the doctor so he wouldn't think he was 'ignorant.' It must be so difficult when you know things are not right but can't understand why. Patience, understanding and compassion are so important at this stage and one of the best ways to express this is through touch.

Words don't always make sense and thoughts are soon forgotten but the message through touch is so meaningful and simple to give. When I stayed with my Mom to relieve my Dad, I would often massage her legs, her arms, her shoulders. There seemed to be so little else to offer and it did seem to have a calming effect. Sometimes the patient will develop tremors or perform repetitive motions. A soothing touch can relax these impulses and reaffirm that someone is there. But the best piece of advice I can offer Care Givers is to take care of yourselves and accept help when it is offered. Sometimes people don't know what to say and will ask, "Is there anything I can do?" Use this as a golden opportunity and make the suggestion yourself. Tell them you would like the chance to go to a movie, visit a friend or family member, go to the library or just out for a walk. My Dad always wanted to do it all and it's fortunate that he survived as well as he did. I wish he could have accepted more help because the care is exhausting. His determination must have carried him through although caring for a loved one at home is not always the best choice or even physically possible. Keeping Mom at home was Dad's personal wish, but as I mentioned before, this decision is not for everyone. Sometimes a care giver can offer more and be more effective when there is some distance between the patients. The break may allow a better perspective and more energy to spare.

There was a time when I worried that my father would wear himself out before my mother and I knew how much he wanted to keep her at home so I told him that if anything ever happened to him first, I would take Mom into my home instead of placing her in a nursing home. But instead of the gratitude I expected, my father had me announce in the presence of my sisters that I could not promise such a thing. He had the foresight to know that we cannot always follow through on our best intentions and he did not want to me to feel guilty about an impossible decision in the future.

We all tried the best we could to share the responsibility of my mother. Once my sister thought it would be a good idea to take her to the Y for a swimming session at the pool. She seemed to like it but at one point, my sister could not see her anymore. Mom had decided to get out of the pool, got herself half dressed, wrapped her wet suit around her wrist and walked home which is about 2 miles away through intersections and busy traffic. I still don't know how she found her way home but she did manage to arrive

safely. A minor consolation. My sister was in a panic and called the house to inform my Dad only to hear my mother innocently answer the phone.

There was a stage when she developed endearing child like qualities but unlike a child, memory and learning were absent. She began addressing my father as Daddy and became enthralled with babies and stuffed animals. Dad needed to hold her hand when they went out to prevent her from wandering off.

There were many other bitter sweet moments during the course of this raging disease.

About 6 months prior to her death, Home Health needed to be involved when she developed a sore at the base of her spine. Visiting nurses came weekly or were called as needed. Dad observed every task they performed so that he would know how to do it himself if necessary. He kept immaculate records of her daily care with personal comments or changes that occurred.

Near the end, she kept losing weight in spite of what she ate and began having difficulty swallowing. Sometimes it would take an hour to feed her a little yogurt, applesauce or Ensure but Dad never complained and never rushed her in any way. In fact, he would encourage her to open her mouth and praise her as she swallowed the sips of fluids. He wanted to control her destiny but ultimately he instead became controlled by the vicious grip of her disease.

During the most devastating final stages of her disease, Dad was constantly at her bedside, reassuring her of his presence by holding her hand, patting her hair and speaking in soft tones. He often kissed her and openly cried as he sat on the small stool by her side. Sometimes, her eyes would remain opened, other times they would stare blankly in the distance but he remained at her side and continued to share her bed every night. The day she died and was laid in her casket was the first time Dad was forced to leave her completely alone and it broke his heart.

For these reasons and many more, I dedicate my book to my Dad, my inspiration and life time hero.

In closing, I would like to read a poem I wrote about how I believe my mother felt during the worst stage of her life.

Do not try to find, where I have gone,
I'm someone different, far beyond.
And although I may look to be quite the same
I am slowly forgetting your face and your name.
I've lost the ability and the means
To express the horrible way that I feel.
But your words and your touch, I do sense
They bless me with love and confidence.
Please be patient and repeat in kind
Respond as if for the very first time.
And if I pretend that I already knew,
I'm just trying to hide my shame from you.
And there will be times when I'll seem not to care,
But blame my disease for being unfair.
I wish words would come to help you understand
But my voice remains silent and my heart is in your hand.