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Family and friends reflect



Julie Young recalls her days working for Child and Family Services Adult Day Center which was, for many years, the first and only program of its kind for frail older adults in Washtenaw County, Michigan. She states, “Planning daily activities for participants was constantly challenging, but it was also rich with opportunities for creativity, compassion and humor. I am grateful for them all.”

MEMORY OF A POEM

Julie Young

After lunch at the Adult Day Center (ADC), we always planned relaxing activities so the participants could rest or nap for a while. We listened to music, looked at books and magazines, gave manicures and polished fingernails, and played simple word games. I often read aloud – almost everyone seemed to enjoy the jokes in “Laughter is the Best Medicine” from the *Reader’s Digest*. For holidays and national days of commemoration I would read speeches, accounts of historic events, and poems to the group. I loved to read aloud and, although it is not a common activity any more, most of the elderly adults at the ADC had read aloud and been read to in school. Quiet attention focused on me while I was reading and, for a short while, I was the “teacher” for this small classroom of special students.

One of those was a petite Hispanic woman diagnosed with early onset Alzheimer’s Disease. She was still so young and had beautiful straight dark hair. Her sons had described her as a vibrant, happy person before the onset of the illness – wearing colorful scarves and jewelry, cooking great meals for the family, enjoying music, parties and family gatherings, driving a convertible. One of them said, “She just loved driving that car around...” Now she wore simple clothes – dull t-shirts and slacks. She seemed to be observing everything and all of us but without expression or much recognition. She hardly ever spoke.

On an afternoon near Valentine’s Day, I had chosen a few love poems to read to the group. The last one was Elizabeth Barrett Browning’s sonnet, *How Do I Love Thee?*. I had to memorize it in high school and still remembered some of the beginning lines and the steady rhythm of iambic pentameter. The meter is simple – one unstressed syllable, followed by one stressed syllable.

I began to read the first line, *How do I love thee?* and just as I was saying the next words, *Let me count the ways.*, I heard another voice in the room begin to recite the poem. As I continued to read this beautiful love poem aloud there was the murmur of each word, repeated by the other speaker, several beats behind the rhythm of the lines I was speaking. It was a soft echo of the poem from a voice I had never heard before. As I read, I glanced up briefly from the book to see who it was, *I love thee to the level of every day’s most quiet need*. It was the small dark-haired woman reciting the poem from memory. Her gaze was fixed. She seemed quite unaware of anyone around her. Her words were clear, but spoken only to herself, under her breath. I heard her repeat, *I love thee with a passion put to use/ In my old griefs, and with my childhood’s faith*. She remembered it all and never wavered or stumbled on line or word. I went on reading the poem to the last line and in the silence when I’d finished, I heard her voice alone, *I shall but love thee better after death*.

She remembered it all and never wavered or stumbled on line or word.



Alberta Sabin writes: “I have lived at the Chelsea Retirement Community (CRC) for nine years. My submission is fiction, but many of the details described in my story are from my experiences with my mother who had severe dementia. Several of my friends at the CRC now live on the campus for residents with Alzheimer’s and other dementias. I visit them a couple of times a month and they, too, have influenced my story.”

ALZHEIMER'S STOLE MY GRANDMA

Alberta Sabin

I was about 10 years old when Grandma came to live with us. Grandpa had recently died, and we found out from their neighbors that Grandma was leaving the house and getting lost.

Grandma was getting lost? Not my grandma. She was the smartest lady I ever knew. Well, so was Grandpa. He was a smart man. I loved to stay at their house, sometimes for a whole weekend. But that changed when we moved.

We were 200 miles away from them. Because it was so far, we only visited them at Christmas time. But Grandma made up for it. She wrote letters to me. I would write right back and she would too. It was so much fun. I felt like a big girl. I got lots of letters in the mail. None of my friends got as much mail as I did.

And then things changed. She didn't send me any more letters.

Grandma used to be a very good cook. I loved to eat at her house. She cooked so many yummy things. When I visited her, she let me help her. She gave me my very own apron to wear and I got to take it home with me. We would make cookies and cakes, and even bread. That was lots of fun because she let me knead the dough. I got a lot of flour on the table, and on the floor, and on me too. Grandma let me help even when I made a mess but she told me that if you are a good cook, you have to clean up your mess and wash the dishes you used. That was okay with me. I liked putting my hands in the warm soapy water. Grandma would read stories to me and she liked to hear me read to her. Grandpa would tell funny stories. Then we would all laugh. I sure missed him when he died. I cried and cried.

I didn't understand at first why Grandma had to move in with us, but I was very happy she was coming. It wasn't long before I noticed she had changed. She was not the same Grandma I knew.

One night she woke me up and asked me to help her find her bed. She got lost in our house. I couldn't believe it. We didn't have a big house. We didn't have a basement or an upstairs. We had three bedrooms, a bathroom, a living room, a dining room, and a kitchen. Our garage was outside the kitchen door.

When Mom and Grandma and I came home from shopping one day, Mom drove into the garage and we took the groceries into the kitchen. I helped put stuff away. Suddenly Mom looked around and said, "Where's Grandma?"

"I thought she came inside with us," I said.

Mom looked very worried and was looking out the kitchen window. "We have to find her," she said. You look in the garage. I'm going to check the back yard."

I looked all over the garage and she wasn't there. I started to cry and called to Mom, "She's not here!"

Mom was scared. I could tell she wanted to cry too. "Let's go out front. You go this way and I'll go that way. I'm afraid your Grandma is lost. She will be frightened. If you find her, give her a hug and tell her you came to bring her home. Wipe your tears, Honey, and try not to cry."

I walked as fast as I could. I was so afraid we might not find her. All I could think about was that maybe a stranger picked her up in a car and kidnapped her. I saw something like that on TV. I swallowed hard and kept blowing my nose to try to keep from crying.

When I turned at the corner of our block I saw Grandma with a lady I didn't know. I wanted to scream, "You leave my grandma alone." But then I saw that she was holding Grandma's hand and talking to her. I ran up to them and said, "Grandma!"

The lady said to Grandma, “Do you know this girl?”

“I sure do,” she said. “This is my granddaughter Bonnie.” She put her arm around me and kissed me on the cheek.

“I’m glad to meet you, Bonnie,” the lady said as she offered her hand. “My name is Betsy Garth. My daughter Jamie will be so glad to meet you. She hated moving away from all her friends.”

That night after supper I heard Mom tell Dad that she talked with Dr. Bromley on the phone. “He thinks Mother should be seen by a neurologist,” she said. “He sees signs of dementia. He says we have to be prepared for the time when she will need to be placed in a facility with staff who are trained to work with people who have severe memory loss.”

It was all so scary. I ran to my room and buried my head in my pillow. I cried and cried. After a while Mom came into my room. She rubbed my shoulders and hugged me.

“What is going to happen to Grandma?” I asked.

“We are going to take her to a special doctor, called a neurologist, to see how we can help her. You already know that she is not the same person you knew as a little girl. The best thing we can do for her is to love her just the way she is.”

The next week Mom took Grandma to see the neurologist. “Your grandma has Alzheimer’s disease,” Mom told me.

“What’s that?” I asked.

“It’s a disease of the brain,” she told me. “It makes people do things that usually they would never do. Remember how Grandma came to breakfast with her bra on the outside of her sweater? She thought she was getting dressed.”

I remembered when she did that. I thought it was funny, then. Now I wished I hadn’t laughed. I didn’t know that Grandma forgot how to dress herself.

A few weeks later Mom received a phone call. “That was the head nurse at Pleasant View Home. It’s a residence for people with Alzheimer’s,” she said when she hung up. “The director told me they have an opening, and I should bring Grandma to see it and to meet some of the residents.”

When Grandma saw it, she thought it was a very nice place, until Mom told her that was where she was going to live. Grandma cried and said Mom was mean and didn’t love her anymore. I knew that wasn’t true. But I also knew how Grandma felt.

The day Grandma was moved into Pleasant View was a sad day for all of us. Mom said Grandma cried and hung onto her so tight and kept saying she wanted to go home. The nurse told Mom not to worry, that once she got to know some of the residents and got involved in activities, she would be happy and begin to think of it as her home.

Mom visited Grandma every day. Two months went by and I finally got to go for a visit. When I walked into her room, Grandma was all smiles. “Look what I made for you, Bonnie!” She held up a picture of a flower she had pasted on a sheet of paper. On the bottom she wrote, “I Love You.”

Alzheimer’s stole my grandma from me. She changed. But I know she loves me. And I love her. I always will, even when she doesn’t know me anymore. She will always be my Grandma.

The best thing we can do for her is to love her just the way she is.



Anita Buckmaster's husband, Rick, was diagnosed in June, 2012 at the age of 61 with younger-onset Alzheimer's. Anita explains, "My mother also suffered from Alzheimer's and passed away almost six years ago. I have written some poetry for family, but never anything to publish. Since Rick's diagnosis, I have had words coming and going in my mind. This felt like the perfect opportunity to put the words into writing and share them with others."

MY HUSBAND IS LEAVING

Anita Buckmaster

My husband is leaving
I don't want him to go
This is so painful
But how can he know?

It began many years ago
On a blind date
It was love at first sight
It had to be fate.

The kids are grown now
It should be our time
This makes no sense
There's no reason, no rhyme

He's been my best friend
Makes me laugh, makes me cry
God must have a reason
I can't help but ask why

My husband is leaving
There won't be another
He's slipping away slowly
As did my mother

Alzheimer's is cruel
The worst of its kind
Who will buy me flowers?
The thought fills my mind

Love each other deeply
Every moment, every day
No looking back, no regrets
Nothing more to say.



Barbara Tucker is caring for her beloved spouse who has mild cognitive loss following a stroke in 2007. She shares, “We continue to make our way through the uncharted territory of the human mind and the unique opportunities it has brought for enriching our psychological, emotional, and spiritual journey together.”

LITTLE BUNCHES OF JOY

Barbara Tucker

“When you scratch my head, I think better all day.” It’s him, but the words, the voice, are from somewhere else. I have never heard this voice before.

I am astonished. If I’d only known. I well up, regretting all the times I have agreed so begrudgingly, just when I have finally settled into bed, just when there should be no more demands of me that day. And now this tiny glimpse, after five years of peering intently into the opacity of his mind.

This is a different place now – our own private journey. I look back to see we have left our mooring and are floating along in a place where others sometimes venture, but where no one has to stay, except the two of us.

But one where there can be these tiny gifts we give each other – seconds of clarity, born of kindness.

I want it to happen again. My logical mind tries to figure out how. I want another clue. Mine are all exhausted. Well, never mind. No one knows if or when or how, not even me, the expert on my spouse of 27 years.

We have only randomness.

No way to know what completely unpredictable thing will happen next. I am braced for the new trouble it will bring my way.

But I tell myself, “I’m quick, resourceful, up to the challenge.”

Nobody is that agile. Or resilient.

What I know now (or is it what I do now?). Control has no value here. Better to let down my guard and experience this life like giving over to a carnival ride. Enjoy the trip through the fun house, where perception may as well be reality.

Not “What the hell next?” but “What precious moments can we find?” Hover above. Watch for them, incubate, foster them.

And pile up little bunches of joyful experiences along the way.

Right after you take very good care to always be watchful to keep in place all the prudent precautions.

“What precious moments can we find?” Hover above. Watch for them, incubate, foster them.



Lauren Scott is a Midwestern whirlwind. She has a BA in writing from Knox College, and is an Interlochen Arts Academy alum. She lives in Chicago where she square dances and has adventures with her boyfriend John. This poem is dedicated to her grandmother, Dorothy Scott.

THE FAWN ENTERS THE WOOD WHERE THINGS HAVE NO NAMES

Lauren Scott

Alice thought, but nothing came of it. 'Please, would you tell me what you call yourself?' she said timidly. 'I think that might help a little.'

'I'll tell you, if you'll move a little further on,' the Fawn said. 'I can't remember here.'

(Lewis Carroll, Through The Looking Glass and What Alice Found There)

Tread carefully. Remember now:

hooves on meadow floors, your mother's tongue;
a fawn's memories must not slip away. How,
at dawn like warm milk, your young bones had sung

of hooves and meadow floors, of someone's tongue
wiping clear the frost settled on leaves. Let this
dawn like warm milk to your young bones, let it be sung
again and again. You must not forget you exist,

your name wiped clear, the frost settled. Let this
image of a fawn persist, snow spots on dark fur.
Again and again, you must not forget to exist
when names fall to earth like rotten berries. Spur

that image you are fond of, persist, dark spots on snowy fur
and—what was it again? Something warm and wet,
its name fallen to earth like a rotten berry. Spur
these memories quickly, run, the wood is dark, forget—

what was that word again?—nothing. Warm and wet
what you can keep within you until dawn.
These memories quickly run. The wood is dark. Forget
your want to know of what you are. Soon, that too will be gone.

Nothing will keep within you until dawn,
no fond memory. It all slips away now.
You know that what you are will soon be gone.
Tread carefully, if you remember how.



Shari Thompson writes: “Life is full of seasons. Care giving is my season now with my mom living with me. I teach special education in the public schools. My three daughters are young adults creating their own seasons of life. Writing this piece has given me a sense of connection and an opportunity to have conversation with written words. I appreciate the wealth of resources and support our community offers to all of us care givers.”

OUR PETOSKY STEPPING STONES

Shari Thompson

Mom held our little girl hands as we walked along the northern shore of Lake Michigan every summer looking for Petoskey stones. Her keen eyes could spot these sparkling pale grey treasures from a distance. We were delightfully excited each and every time we found a stone. When we dipped our fossils in the cool lake water the coral rays glowed like little suns.

Our world was small in those young years of childhood. People knew each other well, there was a sense of connection with family and friends who lived nearby. With time, like most everyone else, we grew up, our worlds expanded; we traveled and started our own families. Mom moved to Florida; Michigan became too cold for her as she got older. On her bedroom dresser she kept a few of our Petoskey stones. Our southern holiday traditions evolved. Spring breaks found us on an early six o'clock flight to Gramma's home in the sunshine and in the pool by noon. Mom's world now had sandy gulf beaches with beautiful shells. She had a good life, working as a nurse, enjoying the pool and her friends.

Five years ago during a visit we noticed some forgetfulness. There was no real concern, her home was full of active grandchildren and there were many distractions. A later phone call from her friend telling us mom brought her toothbrush over and asked for help making a phone call raised serious concern. We got her to make an appointment with the doctor. Watching mom struggle to draw a clock, remember three words, and spell backwards was heartbreak. She was flustered and nervous, she said she had not slept well the night before and that was the reason she did not do well with the questions asked by the nurse. The doctor said she could not drive anymore and would soon be unable to live by herself. Our world changed that day! Mom got angry! The doctor was wrong, she kept saying over and over. She accused us of taking over her life and controlling her. Life became difficult. How do we do this long distance? My sister and I ruminated WHO, WHAT, WHERE, WHEN, WHY? We called these challenges our Petoskey stepping stone decisions. Is there one right decision or several? The world of memory loss was unfamiliar, sad, scary, and emotional.

Our first Petoskey stepping stone decisions involved long distance care. This was short lived – too much worrying, too far away, medications, finances, vulnerability. Our worlds became Venn diagrams, connection evolving to disconnection. Once again we found ourselves on our Petoskey stepping stone, what now? This decision brought Mom to Ann Arbor to live with me. My balance on the stepping stone was becoming more confident. I can say the A word (Alzheimer's) without tears. Another step with Mom led us to the Silver Club, a wonderful place for her to be encouraged and engaged with meaningful activities.

This morning, holding Mom's hand, we walk into the U of M Memory Clinic for our appointment with the neurologist. I watch others coming and going through the clinic doors. Some people push a walker, use a wheel chair, a cane, some smile, others blink, stare, and glance at each other just like me. I wonder how they got here, who are they with, what was their morning like? Did they dress themselves, put socks over their shoes, brush their hair with a toothbrush, put lipstick on their forehead, pour cheerios into their coffee and try to eat them with a fork? Mom did. Our time now to see the doctor. I take Mom's hand and we walk to our room to wait. In comes the doctor, friendly greetings are exchanged. Mom is unable to draw the clock. The questions are asked, Mom smiles, gestures, and says a few unrelated words. When asked to spell world backwards, she laughs as if she is playing a game. I see no anxiety this time. We are told to come back next year. I wonder what life will be at that time.

The steps I take these days are small, redirecting, redoing, and restarting. Mom moves very slowly. At times I enjoy a laugh at Mom's creative sequencing. She is safe and happy. As challenging and consuming as this has been for me, I also am safe and happy. I share my poem with you and a wish for your stepping stone, decision-making journey to be graced with a hand to hold.

Our Stepping Stone World

W walking when waiting worthwhile wince wholesome winsome warm waterfall wonderful wishful willingness wonder whole why window words weak where wisdom weave welcome weather we windy watching

O ouch oversee obliging overlap open orbiting outdoors offering observing optimistic obstacle offer old onward oasis oddity odor ocean once overwhelmed

R raft rambling roundabout respiration relationships rays reasons rearrange radiance rather reflection railway rare receive refresh responsible rhythms roadways recurrent realize ravines resourceful remembering recognizing realm receptive running

L living losing lost longing lacing leaf listening leisurely lavender laughter light lingering language landscape ladder lasting little local life learning laundry later leading lattice leftovers leaving love

D daily duty dad display doctor directions dogs diagnosis dessert dancing delicate define daughter decline deciding data dainty drifting diligence detour delicious departure dressing dreamy doze dignity discussion diminish decorate distant distance



Sharon Greene recently retired from a career of 30 plus years in the Neurology Department at the University of Michigan. Here she writes about her mother.

HERE YESTERDAY, TODAY; NOW GONE AWAY FOREVER

Sharon Greene

My mother was here yesterday, today; now gone away forever

Let me tell you of my mother, Vivadean Alberta Greene. She was the strongest woman you would ever have seen.

She was a lady who used her hands to build anything all over her land.

She was a carpenter you see, and she built houses, speed boats, tables and chairs, wall shelves, wooden docks, and a toy box just for me.

Here yesterday, today; now gone away forever.

She was a hard working mother who had few jobs. First she was a self-taught accountant who maintained the bookwork for my father's first minority-owned business, Greene's Auto Polish and Body Shop in Jackson, Michigan.

Both Mom and Dad were born and raised there yet my mother would be the one to prevail there.

After a long and painful relationship, my dad left us and out went my mother's heart as if it were ripped.

Here yesterday, today; now gone away forever.

She raised three children with my father: one living in New York, Ronald; one in Ann Arbor, Sharon; and one in Jackson, Alvin.

She pulled herself together after many tears that I wiped from her face over the years. She had to make it on her own and maintain her life alone.

She established her own business, Greene's Cleaning Service, and she cleaned doctors and dentists offices all over Jackson for many years. As she dusted, scrubbed, mopped and vacuumed many rooms she began to have pain in her arms, hands, and knees, yet little did I know it was not the pain, but there were white matter changes and atrophy in her brain.

Then little by little small things she could not remember, "Did I take out the trash piled up at the door? Did I set the alarm when I locked the door? Oh my Lord, where are my keys?" These are the words she would say to me. She had such faith in God above and He protected her as His little dove.

Soon she began to get lost while driving and would tell us she was just looking at the trees and shopping for sales at her Goodwill stores. She bought so many things, too many to name, and she would say, "I can't remember why I have this, but it must be for one of my projects."

Here yesterday, today; now gone away forever.

On the weekends I could see the pain was getting worse and this was not a good feeling to me.

I work at the University of Michigan Hospital and fortunately for me it was in Neurology. I took her to the best neurologist there who ordered MRI's on her back that showed severe degenerative bone loss disease. This was in the 1970s. He suggested a small surgery and my mother voiced loudly, "I am not having no surgery; I will just keep taking my SSS tonic."

After many years it was difficult for her to walk and she scooted on the floor to keep from standing on her knees but she kept this from me. One day I came as she crawled to the door, and I said, "Back to Neurology you must go." "What is your doctor in Jackson doing to help you?" I said to her. She replied, "Do I have a doctor here? Oh yeah, I forgot my doctor is giving me pain pills."

She was on high doses of a pain killer, so of course I thought that was why she was so confused; but the pain killer was not the sin, the atrophy in her brain was growing thin.

Here yesterday, today; now gone away forever.

She then saw a doctor and the EMG test was performed. Boy, was my mother mad at me; another painful test you see. The muscles in her arms and legs were wasting away and the bones grew weaker day by day.

Yet another doctor saw her for her memory and he told me things I did not want to hear, but for me it was all too clear. Dementia was taking over her mind, and then things from there were always a decline.

My mother knew from that appointment that she could not hide her problems from me anymore and refused for me to take her so far. "I will get better; you see you don't need to take off work for me. I will take my pills and stay busy with my projects. I think better when I am alone." That was in the 1980s.

Here yesterday, today; now gone away forever.

Her body began to fail and she retired at the young age of 75! She gave her business to her granddaughter Dawn, and the Greene Cleaning Service has another generation of success.

Here yesterday, today; now gone away forever.

My daughter Traci now works for the U of M Hospitals, and we tried again in the 1990s. My mother saw her family doctor, yet to no avail. The story was the same except the dementia now had an awful name; it was the demon disease called Alzheimer's. The stages went oh so fast that it was like a wind storm and only God could calm the sea.

One last attempt was made by my daughter and me to see the best in Neurology. Her local geriatric doctor allowed us to make what we did not know would be Mother's last appointment in 2012 with the neurologist who wanted to try another medicine for Mom, but before I could even get the medicine filled, the demon of Alzheimer's stuck up its ugly head from the bottom of the sea.

She went from hospital to rehab, and finally God said, "Back to the bottom of the sea you dementia/Alzheimer's demon, Vivadean is coming with me." Her great-granddaughter, Taylor, and I put the Christmas tree in her room as her great-grandson, Aaron, rubbed and kissed her head. Taylor asked, "Do you like the tree?" Mother, only able to whisper, said "Pretty."

Mother was placed into hospice. She refused to eat or drink, and was drifting away. Each morning before leaving for work, I crushed her pills and used a syringe filled with Ensure to feed her.

Then finally on that lonely day God gave me hope as she swallowed eight cc's in one, two, and three large swallows without choking or gagging as she had in the previous days. I thought to myself, "Thank you Lord, she is getting better this morning," but the Holy Spirit of reality set in for me as I called the hospice number and asked for a nurse to come that day.

My oldest grandson, Anthony, was with me so I had to fake that I was reporting her vital signs, but I knew God fed her her last intake of nourishment before going on her long trip to heaven into her final resting with the Trinity.

One swallow for the Father, the Son and the Holy Spirit.. Amen. It is well with her soul. Her body was healed as God called her home in the time after I left for work at 7 a.m. and before her caretaker Carmen came at 10 a.m. She

passed with only her loving dog Sparkie at her bedside on December 10, 2012 and was placed to rest on December 17, 2012.

As my fiancé, Robert, held my hand while driving from Ann Arbor to Grass Lake, Michigan, he still had hope, but I knew Mother was gone.

Here yesterday, today; now gone away forever.

Her great-grandson, Aaron, rubbed and kissed her head.



Joanne Lord is a Clinical Research Coordinator, certified by the Association of Clinical Research Professionals since 1999. She is the dementia clinical trial coordinator for the Department of Neurology. Joanne enjoys working with patients as well as their families and plays an active role in all aspects of clinical research. She received her LPN from Marion S. Whelan School of Practical Nursing and her BA from Mount Holyoke College.

THEY DIDN'T TEACH ME THIS IN COLLEGE

Joanne Lord

Some may think goodbye is a simple word, I do not agree. The word goodbye is used millions of times a day. We use it when hanging up the phone, or when someone walks away, a coworker leaves our office, and in hundreds of other situations. I have discovered that the word goodbye is complicated, taking many twists and turns and causing many emotions. They didn't teach me this in college.

The word goodbye has certainly affected me in my career working with patients with dementia, both in Vermont and in Michigan. Some of my most difficult goodbyes involved leaving my job of five years as a study coordinator in order to move to Michigan. I fondly remember one study partner who gave me an angel with purple wings for Alzheimer's Disease to hang in my car. "Why an angel?" I asked. "To keep you safe as you drive from Vermont to Michigan." My angel is still in my car 13 years later!

The goodbyes were difficult because over time I had grown to really care for the well-being of my patients on a personal level, as well as professional. It's hard when they no longer come in, when they pass away, or when a trial is over. And when I knew I was going to be leaving, I wasn't sure what would be the best way to tell my patients goodbye. I knew it was not going to be easy. Would I say the right thing; would I use the right words? Do I tell them goodbye several times on different days and hope they remember, or do I tell them once for the last time and that is the end?

Some may ask why say goodbye to dementia patients when they don't remember? To me, this may be the one time they do remember. And I realized that if they knew I cared about them, that was the most important thing.

After working with patients for so many years, I also got to know their study partners and families. I enjoy talking with families and learning more about them, and getting to know families helps to keep them involved. Some were interested in knowing who I was as a person, just as I liked knowing more about them. I am always happy to share tales of my latest adventures horseback riding, my parents traveling around the country in their RV, or stories about my two nieces.

I became close to two couples over the course of several years. One of the wives, who was a patient, always wanted to know about my riding adventures. She asked the name of my horse. I would always respond, "It's Dusty," and several times during her visit she would ask the same question. I would respond the same way. Never a problem; I would just answer. I put the latest pictures of Dusty and me on my iPod and showed them to her. One day towards the end of the study, she came in all excited and said, "I know his name! It's Dusty." Well, I cried right then and gave her a big hug. She had finally remembered his name.

Another husband and wife in the same study were interested in my latest adventures. Our common interest was skiing. Soon we were comparing Vermont mountains to Michigan mountains, and we decided that Vermont mountains were much better! We always had something to talk about. The patient was losing weight, and I encouraged him to eat more. His wife kidded that she really did feed him.

As the study continued, I realized the patient was going downhill, and it was breaking my heart. I had a hard time seeing a previously vibrant man now unable to speak coherent sentences and unable to recall my name. When the study was over, I was once again saying goodbye and wondering, "How do I do this?" His wife and I both tried not to let the tears fall that day, but it couldn't be helped. They didn't teach me this in college.

I was not sure I would see that couple again. However, this past summer I had the pleasure of visiting them in their home. I was in the area visiting my parents and the couple invited us to their home. It was so wonderful to see them in their own environment. The patient was happy to see me, and once his wife reminded him of my name and where I was from, he did know me. He gave me a big hug as he sat next to me on the couch. He could not converse with words, but his non-verbal skills were sharp and expressed love, gratitude, and knowledge. Once again, tears were in my eyes as I said goodbye.

I look forward to the email messages that occasionally pop up in my inbox when this couple wishes me a Happy Birthday or a Merry Christmas. The last email included a picture of the patient dressed in a Santa suit at the day program he now attends. He had gained a little weight, and his wife was pleased that he actually filled out the suit. I love getting messages from them and keeping tabs on how they are doing. Although it still seems like a goodbye at the end of the email, somehow it brings me closer to them once again, and I wouldn't have it any other way.

I will continue working on dementia trials, building relationships with families, talking about my riding adventures, my parents RV travels, and my nieces. I am also still saying goodbye at the end of trials and at the end of a study visits. I wonder if it will get easier as time passes? As I get older? Wiser? More experienced? I don't know, and only time will tell. Practice can make it easier, but practice cannot make it perfect. Some goodbyes are harder than others. In fact, some are much harder than others. Sometimes the tears are going to come, and I can't stop them. They didn't teach me this in college.



Gail Fromes wrote this remembrance of her mother, pictured above.

MEMORIES OF MY MOTHER

Gail Fromes

My mother developed worsening memory impairments after three strokes over the course of a few years. All of the strokes involved her right brain. This very intelligent woman who once took an adult education course with me in personal accounting and was the first to answer every instructor's question, was now left with cognitive problems that were quite devastating.

When I came to visit her in the evenings at the nursing home, she would ask me what happened at work that day. I would tell her and then 30 minutes later, she would ask "What happened at work today?" Occasionally, she would cock her head to one side, look at me, and then say "Did I already ask that?" I would gently reply that she did, but I would be happy to go over it again and then proceeded to do so. Sometimes, after I started repeating the tale, she would say "Oh, I remember that part."

The hardest experience for both of us would occur when she would ask me to go get my father and bring him into the room. (He had died several years earlier.) I found myself trying to hedge and say he's not around right now, or he had to leave for a few minutes. I then tried to quickly move on to another topic to distract her, but to no avail. Mom would ask again and again until I finally had to tell her that he had passed away. "Oh, that's right," she would say with a look of grief on her face. Because of her memory problems, she had to face the terrible news of her husband's death over and over again.

At other times, her memory was very good, and she remembered the names of people and told stories of the past. She recognized visitors when they came by and often was the only one at her activity sessions who knew the answer to a trivia question. I once told her that a woman stopped me in a store to ask about a good seasoning for roast beef. I had no idea, but when I posed the question to my mother, she replied immediately, "a bay leaf." This was no surprise to me. She was a wonderful chef.

One night, she became very confused and thought I was her sister. She asked me how things were going in New Orleans where her sister lived. I told her who I was quite frequently, devastated that she no longer knew me. Finally, before I left for the night, she recognized me as her daughter and we talked and joked as usual. She died 30 minutes later.

My mother was fully aware of her loss of memory and was very frustrated by it. I was struck many times by the fact that she not only had cognitive problems but had the added hardship of being fully aware that she did. That never stopped her from trying to engage with people and having a positive view of life.

I will always remember her as a woman of great courage who, in spite of three strokes, left-sided weakness, and memory and cognitive problems, always had a smile for everyone she met. She will forever be an inspiration to me.

I was struck many times by the fact that she not only had cognitive problems but had the added hardship of being fully aware that she did.



Donna Zajonc writes: “During the winter of 2011, I lived in Tequisquiapan, north of Mexico City. There I renewed my friendship with Hector and met Elizabeth.”

HECTOR AND ELIZABETH

Donna Zajonc

From the taxi window, I saw a slightly stooped man walking on the dusty shoulder of the cobblestone road. A straw sombrero on his head bobbed with each step. He was wearing a rough wool vest bordered in black. He was carrying the weight of his world on his rounded shoulders. It was Hector.

Following him was a woman as unsure of her steps as her mind was of its function. The sun bleached the already-faded colors of her blouse and skirt, nearly erasing her from the scene. It was Elizabeth.

I asked the taxi to stop. They were on their way to visit Hector's friend Julio, who lived a few doors from me. They admitted to being tired and eagerly accepted the ride.

Julio had been a friend of Hector's since university days. He became a successful architect while Hector became a professor of literature, a poet, and a dreamer. Julio was one of the reasons Hector relocated from Oaxaca to Tequisquiapan with its quiet, cobble-stoned, bougainvillea-adorned streets.

The other reason was that Hector could no longer live in the house he owned near Oaxaca because his neighbor ran an under-the-counter, over-the-wall auto paint shop spewing toxic fumes which enveloped Hector's patio, seeped through the windows into his house, congested his lungs and reddened his eyes. So he gathered his dogs, Noche and Blanca, one under each arm, and boarded the bus to Tequis where he would benefit from clean air and Julio's warm friendship. In turn, Hector encouraged me to profit from the quiet life and clean air of Tequis. A change sounded exciting. After all, I had been wintering in Oaxaca for 15 years.

It was very shortly after Hector settled into his new surroundings that he received word of Elizabeth's precipitous arrival. Although Hector and Elizabeth's sister had agreed that a visit was a good idea, he belatedly realized that he was speeding headlong into becoming the keeper and caregiver of a needy person for the full month of February having only a small inkling of what she might expect of him.

The friendship between Hector, Elizabeth, and her husband, David, began in Oaxaca, where Hector taught them Spanish. They met with him twice a week, two months a year, for more than ten years. Elizabeth and David had settled into an Oaxaca life of lessons and wintertime friends. To them, Hector was both "maestro" and "amigo."

Now it has been two years since Elizabeth and David enjoyed those days in Oaxaca. David died shortly after their last visit and part of Elizabeth died with him.

A year ago Elizabeth attempted to renew her relationship with Oaxaca where she received the best support Hector could muster. However, she was unable to cope without David and without a good part of her cognitive capacity, and she returned to her California home within three days.

Now, two years later, Elizabeth arrived in Tequis and within days, she and Hector had developed a routine. They would breakfast together and walk to the Vienna Café in the center of the village where they bought cream cakes from a wiry Austrian who made and sold the cakes but never ate them, nor did he lick the frosting from his fingers. When I told Elizabeth the name of the café, she said, "Oh good, I can remember that. I was in Vienna once." At the Vienna Café, Hector would edit his poems while Elizabeth enjoyed the plaza.

Hector kneaded and nudged his poems while Elizabeth circled the square until she remembered Hector. She would hurry to find him and her sense of security. Hector would invite her to have coffee with him. Then they walked around the plaza together, had lunch and later returned to the café where Hector would make further adjustments to his poems while Elizabeth wrestled letters into crossword squares. At some point, she would get edgy and they would walk the plaza one more time, eventually going home for dinner.

Elizabeth's mind accepts new information with great resistance and retrieves old information with even greater resistance. Most often, she can't remember my name or Hector's. That she couldn't remember my name was surprising to me, although it shouldn't have been, as I wasn't a part of her Oaxaca life. For her, I was a new Tequis friend. However, the first time she couldn't remember Hector's name, I was the one confused. She was stumped and frustrated when she tried to remember it. She blurted out, "You know the man I'm staying with. What's his name?" I was shocked. I didn't believe that Hector was the name she couldn't remember.

She was good natured about it and laughingly admitted to forgetting nearly everything. When I told her a friend of mine was coming to visit and that his name was Bob, she said, "Oh good. I can remember that. That's the name of my brother-in-law." She was joyous whenever a name association would help her recall a name or place.

Regularly, Elizabeth and I found things to do together. One day we sorted her money. It seems she and Hector had gone to the bank the previous week and, shortly after, she told Hector that she lost her money. He told her that we have to be more careful, but accidents happen. A few days later, Elizabeth exclaimed, "Oh, look Hector! I found some money I didn't know I had." She agreed that sorting her money was a good plan.

We first sorted the peso notes into denominations of 5s and 10s. Then we stopped to study the picture of Benito Juarez on the 20-peso note. She remembered hearing good things about him. We both were interested in the 100-peso note issued to commemorate the 100th anniversary of the Mexican Revolution. One side featured the railroads (which sadly no longer exist) while the other side featured the valiant Mestizos who brought the revolution to a successful conclusion. We both thought Jose Morales, pictured on the 50-peso note, was very sexy. We found Sor Juana, on the 200-peso note. She was one of the most notable women in Mexican history, ranking in familiarity with La Malinche, the legendary concubine of Hernan Cortes. However, Sor Juana was an ardent nun, a prolific poet and a revered revolutionary.

After sorting, counting and chatting, Elizabeth put her little money, that would be Juarez and Morales as well as the 5- and 10-peso notes, in a little green wallet. She put her big money that would be the Mestizos and Sor Juana, in her big green pouch. Both of which she fit into an even larger green and beige striped carrying bag, which she bought the day she thought she lost her money. Her reasoning was that if she had something big enough to hold all her money, she wouldn't lose it.

On other occasions, Elizabeth and I would take the local bus for trips we jokingly called our trips to nowhere. We took the Number 3 bus, which goes very close to the area where I live. We took the Number 8 bus, which serves the neighboring village of La Tortuga. One day we took the Number 9 bus to the village of San Nicolas. Back in Tequis, we bought a map to see if we could find the villages we had visited and then we'd know we hadn't really been taking a bus to nowhere, but that we had actually gone somewhere!

On days I had Spanish lessons at the Vienna Café with Hector, Elizabeth would go for an amble around the square wearing her sun-faded blouse and skirt. Eventually she would return to confirm Hector's whereabouts.

When my lesson was over, Elizabeth and I would decide on an adventure. One time she bought a small notebook in which she wrote down the places we had visited on our bus trips. She apologized for her handwriting and with a chuckle said, "No one else can read it, but I can."

At other times, we shopped in the local market for food and flowers. When we finished buying everything from calla lilies in honor of Frieda to sweet smelling corn tortillas, we slid the bags and bundles into the back seat of the first suspensionless taxi in the queue and bumped over the cobblestone streets to my house. Once there, Elizabeth washed the strawberries and cilantro and together we'd pick pebbles from the dried beans. We always bought too much of everything, notably cheese. In Mexico, the cheese is good! And Elizabeth had a favorite. She couldn't remember that it was the cheese from Chihuahua that she favored, even when I yapped like a lap dog. She didn't recognize it by sight either, but she did remember the taste. When the lady selling the cheese proffered a bite-sized wedge on a torn piece of banana leaf and Elizabeth tasted it, she smacked her lips. We always bought some, and later we ate it with strawberries while we sat on the shaded patio making words with lettered Bananagram squares. The game, a stepchild of Scrabble, gave us both pleasure and cognitive exercise.

When it was time to draw some letters, I tried to teach Elizabeth to say, “Take five.” I’d say, “What do you say?” She would say, “Get some more,” with a questioning glance, and I would say, “Take five,” and she would smile and repeat, “Take five.” When it was the next time to augment her pool of letters, I would ask, “What do you say?” Her face would cloud over a bit and I would say, “Take five.” She would smile and say, “Oh yes. I forgot.” Even my wiggling five fingers did not help her recall. After one of the failed attempts, she sighed, “Oh, if my students could see me now.” Both she and her husband used to be middle-school teachers. A couple more tries and when, once again, I saw her face cloud over, I realized that for her to learn “take five” was not going enhance her enjoyment of the game one iota. I deep-sixed my “take five” initiative.

The days blended together. Elizabeth worked in her young people’s crossword puzzle book, while I used the Internet. Then we’d walk to have coffee in the plaza. I brought out the Bananagram squares. We made words. We’d “get some more.” She’d smile as she took five. Soon Hector walked by. We’d gossip and joke, share fresh orange juice and listen as the magpies began their late afternoon serenade. Their piercing song was a signal to Elizabeth and Hector that the sun would soon fall behind the surrounding hills. So they hastily left while there was still time for a turn on the plaza before walking home.

For me, Elizabeth was a pleasure, a treat to enjoy at my choosing. For Hector, Elizabeth was a pleasure and a responsibility.

After four weeks, Elizabeth would go home and Hector would be pleased with his effort, exhausted by his experience and apprehensive about what next February might bring.



Alvesta Smith wrote in remembrance of her brother, Timothy, who was born on October 7, 1937 and died on October 20, 2008. Alvesta wrote, “Tim’s absolute love and joy was his family. He was a loving and devoted husband, father, and grandfather. He lived his life determined and committed to being a good role model and demonstrating exceptional family values. He and his wife, Kathryn, had three children.

MY BROTHER

Alvesta Smith

My oldest brother, Caparton Timothy Evans, lived in Westchester County, New York. Our family who lives in Michigan would visit Timothy and his family from time to time. We would invite Timothy to come over and visit, but he never visited us here in Michigan until he became sick and unable to care for himself. Then we would go over and get him for six to eight weeks during the summer to help care for him. Once when he was around 60 years old, we visited the family in New York during the summer and our brother seemed quite agitated. He had a frown on his face and kept walking around the house. Finally, he went to bed while we were there and that was quite unusual. He would be the one to entertain and take us out to lunch or dinner.

He was a long distance truck driver, driving the truck from Connecticut down into New York City and across the George Washington Bridge into New Jersey. Tim was a dependable and on-time truck driver. The company could depend on him.

When I was a child we lived with our great-grandmother, Ida. She had been a mid-wife for a doctor in Virginia. We lived in the country and some days during the summer my mother would say to me to take Grandma by the hand and walk her almost to the end of the road while talking to her then turn her around and walk her back home. This was for her to get some exercise.

Great grandmother would sit in her rocking chair in her bedroom looking out of the window and see a one-legged man across the forest. I didn't know if he was working, sitting or what he was doing. She never said. But she talked about the one-legged man.

My brother was driving the truck down the New Jersey Turnpike one day and did not remember where he was. A policeman found the truck pulled over to the side of the road, talked with Tim I suppose and called the truck company in Connecticut to dispatch a driver to the New Jersey Turnpike to pick the truck up. Timothy was taken off the truck as a driver but encouraged to help train some of the younger drivers for a while, though he had a number of mini-strokes. Timothy lived for approximately 10 years with dementia.



Christine A. Yared is an attorney specializing in employment law, civil rights, and family law, including LGBT law. Her father, Woodrow A. Yared (1916-2004) was an attorney, as well as a district court and circuit court judge. He passed away in 2004, having suffered from dementia during his final years. Christine writes, “I wrote this poem after visiting Dad on August 27, 2004. Dad passed away on November 7, 2004, my mom's 85th birthday.”

FATHER

Christine A. Yared

Standing in the final hall
where great minds slip, strong bodies fall.

Black and white photos hung by the doors
illuminate their youth during the Second World War.

In his locked and dreary space,
fixed on his face.

an empty stare

As I approached the bed, his eyes lit bright,
I kissed his cheek, then hugged him tight.

I spoke of memories, love and pride,
these feelings and thoughts, to my soul strongly tied.

Tears streaming he cried in his heartfelt way,
he softly continued to say.

"Thank you, thank you,"

I felt grateful, 'twas not too late,
depth, the weight.

certain he felt the

I felt grief, our time was ending,
understood, this was my sending.

we both

THE PLAY

Christine A. Yared

(Telephone conversation on a Monday during the fall.)

Daughter: Hello.

Dad: Hi Chrissy.

Daughter: Hi Dad.

Dad: I need your help. Can you help me with a play?

Daughter: A play?

Dad: Yes. I need you to fill a hole.

Daughter: What do you mean?

Dad: I'm working on a play and I need you to fill a hole. Can you help me?

Daughter: Sure.

Dad: Good. You know where we practice, right?

Daughter: I think so, where is it?

Dad: You know, by the park in Cascade. Can you be there tomorrow morning at 9:30?

Daughter: Yeah.

Dad: Good. You should just wear blue jeans, a sweat shirt and tennis shoes because it will be muddy.

Daughter: O.K.

Dad: Thanks, I'll see you tomorrow morning.

Daughter: I'll be there. Bye Dad.

Dad: Bye honey.

At the time of this conversation, my dad was still living at his home with my mom. We knew he was struggling with Alzheimer's or some other type of dementia, but it was all still new to us.

He was still experiencing times when he was living in the present, aware of his surroundings and the events of the day. Of course, with time his condition became worse and it was eventually necessary for him to live in an assisted living home on a locked floor which was for people with similar conditions. At the time of the telephone conversation my dad had started to often talk about the past as if it were the present. When I answered the call and my dad first stated he needed help with a play, I thought he meant a theatrical play since he acted when he attended Ottawa Hills High School in Grand Rapids.

Yet once he added that he needed for me to "fill a hole," I immediately realized he was talking about football. My dad was the quarterback in high school. When I was growing up during the 1960s and 1970s my dad and I would typically watch a couple of professional football games together on Sundays. We would discuss the plays selected and he taught me how to evaluate how they were executed.

When I hung up the telephone, I concluded that he would probably forget about "the play" well before the next morning. Yet I was not certain since I was still learning about the symptoms and patterns of people with Alzheimer's and dementia. Even though it was a work day for me, the next morning I arrived at my parents' house at 9:30, wearing blue jeans, a sweatshirt, and tennis shoes. My dad answered the door surprised and happy to see me stating, "Chrissy, I didn't know you were coming over. Come on in." My mom asked why I wasn't working and I explained that I had some time and stopped by for a visit.

This incident provided a valuable lesson. On one level, his call was emotionally devastating. The call provided evidence that my dad's condition extended beyond forgetfulness or confusion during a conversation. I had to mourn the fact that I would no longer be able to have the type of intellectual discussions that we previously enjoyed. More importantly, this meant that my dad, a retired judge and World War II veteran who was a defense attorney for Japanese soldiers accused of war crimes, was losing his ability to enjoy life by doing what he loved – reading, learning and discussing history, politics, current events, and the events in the lives of those he loved.

Upon further reflection however, the conversation had the proverbial silver lining. My dad was in his element during our telephone conversation. He was working on a productive goal. In his mind he was either a coach or quarterback thinking about the next day's practice, roles that he enjoyed. There was a specific play he wanted to work on and he thought that I would be able to fill a hole which was needed to perfect a play. He thought I could help, located and called my telephone number, explained what he needed and when we ended the call he was pleased that he met his objective.

The telephone call was analogous to a child engaging in make-believe play. For the child, play which is done in a safe, supervised environment is a form of creative engagement which is healthy, enjoyable and educational. As adults we all engage in play in the form of games, hobbies and various social activities. Of course without dementia, we are aware it is play and can move seamlessly between play and the other aspects of our lives.

Yet given my dad's condition at the time, and having witnessed his pain during the times he was acutely aware of his decline, the telephone call and my visit the next day was a brief opportunity for joy. While he was planning the practice, and during our telephone conversation, we were engaging in a form of play that related to an activity we previously enjoyed together. At least during that brief time, he was finding satisfaction and not focused on his disease. Of course, I was also flattered that I was on his team roster.

Another lesson for me was that there is no reason to try to correct a person with dementia who is engaged in a harmless activity or has an incorrect understanding about specific facts. If the activity or words do not create danger or harm anyone, it is valuable to let the person stay in their moment, whether they are coaching a football team or directing a Broadway production of South Pacific.

This experience also allows me to express my wishes should I ever have to live with this disease. If at some time in the distant future, I call you to plan my tennis strategy in my upcoming Wimbledon match against Arthur Ashe, do not tell me that Arthur died in the 1990s or that I have neither the talent nor health to win my assisted-living center's tournament. Instead, encourage me to rush the net and hit to Arthur's weak side.

When you visit me and I think you are President Eleanor Roosevelt seeking my advice about whether we should use a newly developed secret weapon to end the war with Japan, do not waste our precious time trying to convince me that Eleanor was never president. Instead, I will expect you, being the President, to direct your Secret Service contingent to clear my room while we talk.

Finally, be sure to listen carefully and do not presume you already know my advice. My dad was born in 1916 and never wore or cared for denim blue jeans. That telephone call was the first and only time my dad told me that he

wanted me to wear jeans.



Frieda Morgenstern writes: “As a very private person, nothing short of aiding in an Alzheimer’s project would make me want to evoke earlier events in my life. I am a freelance writer, and particularly enjoy doing profiles of people, which I have done for years and continue to do now.”

A SISTER'S PERSPECTIVE

Frieda H. Morgenstern

My sister developed Alzheimer's under my unsuspecting eyes. We were always close, through childhood and adulthood, different in our choices of events in our lives, which I attributed to individual preferences. I still miss her very much, or the person I remember so fondly.

My sister and her husband had an extraordinary marriage, so in tune with each other that few friends or outsiders permeated their blissful existence.

After her husband passed away she moved to a retirement community in the Rancho Mirage area of California's desert to be near her son who lived nearby. We kept in touch by emails and phone calls, although her communications were gradually troublesome to me because her son traveled a good deal through his business, leaving her to be dependent on the residents of her facility for companionship. I invited her to visit me in my retirement facility in Ann Arbor – an eye-opening step.

My son, who lives nearby, picked her up at the airport and helped get her settled in my apartment. To show her what my life consists of, we visited such places as shopping areas, the bank, as well as the drug store when she wanted to renew her prescriptions. I introduced her to my pharmacist, whom I have known for many years, so he could give her personal attention. This is when my heart skipped some beats as she drew out of her purse (with great difficulty) a batch of papers that turned out to be copies of her prescriptions. To give her privacy, I shopped elsewhere in the store while she made her purchases. I finally met her in one of the aisles where I found she was doing pirouettes and singing blithely.

Our facility has a community get-together once a week and I introduced my sister to many of our residents. My sister went to the bar, where only wine is served, and there met one of our illustrious Chinese experts to whom my sister attached herself because she evinced an interest in going to China. When this lovely Chinese lady went to her apartment to get some maps and information for my sister, as quickly as possible I came to the rescue, before the fourth glass of wine could be spoken for.

Only a few more instances to make me wonder at the cognitive imbalance my sister was undergoing.

We went to the mall because my sister had always loved shopping. We shopped at different departments, while I asked her to stay at the department where I left her and said that I would pick her up in a short while. When I returned, she was nowhere to be found. I canvassed several aisles, had her name called out on the loudspeaker, finally had the store guard look for her in the store and out into the mall. She showed up, package in hand, cheery and singing in one of the store aisles. My heart was in my mouth.

One day I took her for a ride to show her how lush and green our city is. She looked around, frowned, and finally said, "I don't like this area." Did she miss California sunshine? When we visited my son and daughter-in-law's house she made this tremulous observation "It's too confusing." Were more than two rooms upsetting for her?

When she and I got on the elevator in my building, she delighted in pushing all the buttons, while I cringed. She liked to go down to sit in front of the building so she could greet all who came in or out, though I had told her that no one sits in front of the building except when a car or cab is picking them up.

When she first arrived for her stay, she refused to sleep in the guest room but wanted to join me in the master bedroom where I have an oversized king-size bed. Was she reliving our youth when we had to share a bed? One afternoon as she was napping, I reached over and patted her head, feeling strongly like the big, protective sister that I had always been, but now powerless to know what else to do to help her, beyond submitting to medical know-how.

Sibling affection is noteworthy; when Alzheimer's intrudes it can be devastating.

I will always miss the sister I knew.

My heart was in my mouth.



Pam McCombs writes: “My father was diagnosed with Alzheimer’s disease in 2004. I have used writing to help me cope. I wrote “Stewart A” originally as an example of a ballad for my first-year writing students. I revised it for the memory loss anthology to help others understand the progression of this disease.”

STEWART A

Pam McCombs

Dad/Grandpa/Boppa lives independently
in a facility, with two parakeets.
One yellow, one green that he whistles to
before breakfast, dinner, and supper.

Now, he loves bingo,
eating mixed cheerios
and wearing Hawaiian shirts

Dad/Grandpa/Boppa, born 88 years ago
Stewart A, the twelfth of thirteen,
the youngest son, lived on a farm in rural America.
He grew up watching, catching, and caring for all kinds of birds.

Now, he loves bingo,
eating mixed cheerios,
and wearing Hawaiian shirts

Dad/Grandpa/Boppa joined the Army Air Force in 1941,
was stationed near Chattanooga. He flew many times,
as navigator, across the USA in a B24, but never left the states
because of the Sullivan brothers in WW II.

Now, he loves bingo,
eating mixed cheerios,
and wearing Hawaiian shirts.

Dad/Grandpa/Boppa has Alzheimer's Disease
and doesn't remember what he did two minutes ago.
But, he can play bingo with two cards, goes down to the dining room to eat and knows his room number 204.

However
Four years have passed and now he is almost 91!
Dad/Grandpa/Boppa only has one bird.
Tammy, the yellow one, he still loves to
whistle to, when we remind him.

He still loves bingo, but has to be reminded.
He still eats cheerios, but doesn't care if they're mixed.
He still wears Hawaiian shirts.

Dad/Grandpa/Boppa has to be escorted to all his meals.
He sits in the lounge watching TV and
sometimes he gets lost going up to room 204.

He still loves bingo, but has to be reminded.
He still eats cheerios, but doesn't care if they're mixed.
He still wears Hawaiian shirts.

Dad/Grandpa/Boppa needs lots of support
to live independently, needs lots of help to remember
when to eat,
when to play bingo,
when to go to bed.
Alzheimer's is slowly eating away Stewart A

He grew up watching, catching, and caring for all kinds of birds.



Carol Burton reflects: “As I approach the age of my elder family members and recall earlier years, I often wish I could apologize for the ignorance of my youth and my lack of appreciation for their experience and their fortitude. I am trying to salute them now with occasional memoirs such as this one.”

HOMEMADE PHANTOMS

Carol Burton

These days I often ruminate, particularly on the commingling of life and death and memory. In my seventies now, I am experiencing the failures of old age—the losses of body skills and form, interest and desire, the sharpness and detail of memories. No surprise there, beyond the common astonishment that one has actually become an Old Person. How the hell did that happen? Where did that younger self go? What's left?

That's a question of special interest to me because of the dementia-related memory loss in my mother and paternal grandmother, i.e., both sides of my family. I saw the waxing and waning of both these women—what they were in their prime years and at their deaths—and all sorts of existential questions arise. One I'm asking is, what is left of you when you've forgotten everything? What part of one's being is the most immanent, elemental, the last to go?

Grandma was from a German-American community, the first-born in her family. Conjure up a stereotype and there she was—a bossy, large-boned, sturdy woman who worked hard and took her homemaking and her religion seriously. She was masterful in cooking and the textile arts, and her garden was a complex symphony of color and fragrance. Her home was clean, clean, clean and decorated with wallpaper she hung herself, quilts she sewed, and ironed linens with lace edgings she crocheted. She was stout because she also enjoyed the culinary creations that made her “Pa” happy—good farmer food with lots of meat, potatoes and sugar. She was active in her Lutheran church's Ladies Aid Society, went visiting after the services on Sunday, had no use for shyster lawyers, and could tell you what Jesus wanted you to do in all areas of living. I didn't know until I was in my twenties that she was also quite jolly at parties and sometimes downright funny with a woman's grouching kind of humor.

She came to live with my parents after she was widowed, which was a trial for my mother a, shall we say, casual housekeeper, who hadn't been to a church in a long time. Grandma became dangerous in the kitchen, had a child-like fascination with red and hoarded odd red things, took off her clothes in the front yard, and wandered down the country road to “go home.” She made little sense in her conversation, which was laced with German and then became nonsense interspersed with stock social phrases like “How's your family?”

So what was left of the woman at the end? I recall a couple things that were perverse expressions of her former self. For one, she cleaned. She tried to wash off a bruise mark on her leg, and she scraped the dark finish off a chair down to the bare white wood with her fingernails. She also liked to socialize. I remember sitting with her in her little room, and she told a good story. It was total gibberish, but her timing and inflection were perfect and her laugh explosive at the punch line. She had me completely engaged, and I laughed heartily and sincerely at the proper time. I never enjoyed her company as much as that afternoon.

My mother lived with my husband and me for several months before she died. It was a trial for us, too. Perhaps the most difficult thing was putting our expectations in reverse. We are both teachers—we work for improvement, and lack of retention is a sign of failure for us. We had to start looking for negative changes in her abilities and not be disappointed when they appeared. Was she just being lazy and avoidant or had she really forgotten how to take pills or flush the toilet? She lost more of her adult self as the months passed, onion-like layers sloughed off, leaving a being who was more childlike, artless.

Some traits persisted as others fell away. I like to think these were the most fundamental and intrinsic parts of these women—the essences that float about in our recollections and analyses of them. For my grandma it was nourishment, work and social interaction. Her appetite finally yielded to her illness, but otherwise she enjoyed all things with food—preparing, offering, and eating. She had a strong sense of rightness about how a house should be run, how people should behave, and how hard work was necessary to that rightness. She kept her hands busy and talked, talked, talked. That was what she was to the end—busy hands and something to say.

For my mom it was laughter, personal beauty, nurturing, and naughtiness. Her naughty streak was there from childhood on, according to the family legends. Not meanness or criminality—mainly bedwetting, lots of beer, and

dirty jokes. She lived thirty years as a widow in the country and always had a huge variety of company of all ages. She was an easy touch and people took advantage of her hospitality and good nature, but they also checked up on her and just adored her.

Things she loved until the end—colors, windows with scenery, nature shows on a non-stop television, looking pretty, jokes, and me. Although she couldn't remember my name, she did know that I was her Baby. In her last hours she smiled vaguely when I told her I was going to curl her hair and when my husband asked his daily silly question, "Would you like a kiss, Madam?" And when I told her she could let go, within two minutes she died. Here was this shell of my mother, unable to call up anything from her body or mind, and yet she was still there and is still here with me now. I don't know how else to say it. Not breath or heartbeat, but something of her nature persists playfully beside me. Hi, Mom.

I look at scraps of paper they wrote on—lists, recipes—and handwork they did and I am just so regretful that I was too busy to siphon off their thoughts and memories while they were still accessible, too callow to appreciate how many thousands of stitches and meals and gifts and love notes made up these women. I'm left to distill them into phantoms that I carry in my head, that I talk to as I drive, that I embellish as I approach their final ages and understand them so much more.

And I wonder how I will be remembered, how I want to be remembered, how to create my own ghost.



Deb Mecks is a married first-time grandmother with two grown sons. She is a temporary administrative assistant for the University of Michigan Health System. Deb received her BA in Journalism from Wayne State University ('87) and is applying to the U-M master's degree program for the study of Creative Writing.

WHERE HAS MY LOVE GONE

Deborah Meeks

My husband was driving as we glided down the I-75 freeway headed to a branch of my mother's credit union in Lincoln Park, Michigan. My mom was in the back seat. "Where are we going?" she asked again for the fifth time.

Patiently and respectfully I answered her for the fifth time, "To the bank, Mom, to get the power of attorney papers notarized."

"Oh," she responded.

I knew she didn't remember why we were going to get power of attorney papers notarized, which is precisely the reason why we needed to get the papers notarized. Mom had been diagnosed with dementia one year prior. She kept the diagnosis to herself until she could no longer handle her day-to-day business without my help. I had been joint on her bank account for years. Now I had taken over paying her bills, but I needed to legally have her power of attorney so her creditors would give me confidential information about her accounts.

The inertia force from the car climbing up the Rouge River bridge forced me to sit back in my seat. I bobbed my head to the music coming from the radio. I wanted to sing but couldn't because I was trying to hold my breath so I wouldn't inhale Southwest Detroit's distinct smell – a mixture of gasoline and burnt rubber. "Where are we going?" Mom asked again, this time with more curiosity. She must have smelled it too because when I turned around and looked at her I laughed because she had her nose scrunched up. I answered her yet again, "To the bank to get the power of attorney papers notarized." I had to talk loud because her hearing was failing also and she refused to wear her hearing aids. "This don't look like the right way," she said as she looked out the window at the skyline filled with factory chimneys blowing out stinky factory smoke.

I continued to study her wondering, how could this frail little lady sitting in the back seat of the car dressed in a frumpy pink jogging suit and dirty sneakers be my mom? Just two short years ago she was a maverick. A fashionable maverick who would have never been seen outside in a frumpy pink jogging suit or dirty sneakers. As a matter of fact, after we handled our business at the bank we had to stop by Dietrich Furs, in Detroit's New Center area, to get her mink coats out of storage.

I was getting a crook in my back as I studied her from the front seat. We were going down the bridge now so I straightened up in my seat and looked out my window while humming to a song on the radio still pondering to myself, how could this be the same woman who was a much respected church musician whose choir members called her 'The General' behind her back because she was such a perfectionist. Now here she was questioning me about where we were going and why, like my sons used to do when they were children.

In 1963, my mom divorced my father because of his unforgivable behavior. Well, she could have forgiven him, but she felt life is too short to be dealing with his mess, and she sent him packing back to his mother's house. Three years later she bought a nice two-bedroom house with a remodeled attic on Detroit's northwest side. This was unusual behavior for a woman back in the 60s, especially a Negro woman. Most women of the day, especially minorities, got married and became housewives. They didn't have their own money, they were not extended credit or financing, and they dealt with the drama that their husbands threw their way. But my mother had a good job teaching music in the Detroit public school system. She was a role model in a time when the second wave of the women's movement was just beginning to swell.

Mom commenced to raise my sister and me as a single mother. She provided us a middle-class lifestyle without the help of social services. I never missed a meal and our school clothes came from Hudson's (now Macy's) and Saks Fifth Avenue. She was the perfect role model for me as I found later in my life I would need to make my own way as a divorced single mom. I am not boasting. I want you to understand that the woman who raised me and my sister, and the woman who I am now giving care to, are two different people.

The initial reaction of my family to my mother's dementia diagnosis was panic. She is the eldest of five siblings, and they were not used to her not being on top of her game. It also became evident that Alzheimer's/dementia was a family illness that we all would be dealing with in our senior years. My great aunt and one of my mother's brothers suffered from dementia before they made their transition. In an attempt to try and find answers on how to deal with her illness I signed up to do the Alzheimer's Walk at the Detroit Zoo in the summer of 2012. I had fun at the event but trying to rally people was not a rewarding experience. The family I expected to be all in with me, wasn't. Oh well, live and learn. I still get the Alzheimer's email newsletter to keep up with medical information.

After Mom was diagnosed she immediately became my responsibility. She has one brother that lives in Detroit and the rest of our family members live in New Jersey or California. I love my mother and I would not trust anyone else to take care of her. I squeeze in checking up on her between being a wife and an employee. My sister, who lives in New Jersey, is concerned but can't help me, so my husband is my team partner.

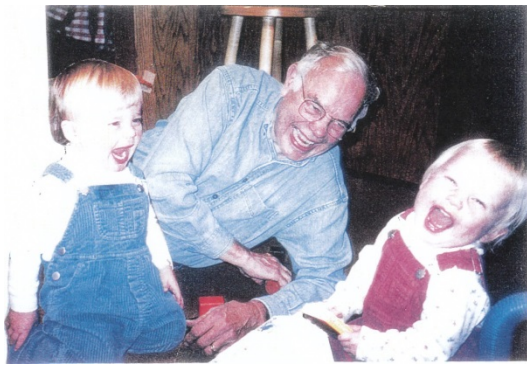
In the beginning, my non-Michigan family members would call me in a panic when they would call Mom and she didn't answer the phone. They immediately thought something was wrong and would beg me to drive from Westland to Detroit to make sure she was not sick, hurt, or dead. With gas prices being high, me making that fifty-mile round trip every time they got nervous soon became unfeasible, especially since they were not sending me any gas money. So, I immediately had to let them know I would not be speeding down to Detroit on a whim anymore. My husband and I visit her twice weekly and call her in between visits. Once I explained to them that Mom didn't answer the phone because she simply didn't want to talk, they calmed down. They didn't like it, but they calmed down.

With that under control, now we worry about her driving. In the beginning of her diagnosis she drove everywhere even though she has bad hearing and cataracts in one of her eyes. I took her to the doctor and he said the cataracts were not ripe enough to remove, and if she felt comfortable driving then she should drive. I don't agree with him, and my family wants me to take her keys. I, on the other hand, think the Secretary of State should do its job and deny her license renewal this year. I emailed SOS and asked what test they have in place to make sure seniors are still healthy enough to drive. In short, they explained that if she doesn't pass the eye test then she won't be getting her license.

To make my life easier, I am now about to move my mother into a unit in my condo subdivision. She doesn't have enough money to go into senior housing. When we first mentioned moving her a year ago she refused. Now as the dementia takes over I think she is welcoming the idea. My husband and I were thinking of moving to a bigger condo or renting a house, but the thought of packing up two houses and then loading it all on a truck left a nasty taste in our mouths. Besides, I think it will work out better having her own place. That way when family comes to Michigan to visit her they can stay at her place and visit for as long as they want.

So, as the three of us glide through life together I don't know if I'm doing everything right, but I am doing the best I can to keep Mom happy. I've made it a point to tell my sons to get them prepared for the day when they will have to care for me and their stepfather. My boys taking care of me? Oh geez! I better start getting myself prepared mentally.

I want you to understand that the woman who raised me and my sister, and the woman who I am now giving care to, are two different people.



Katherine Stribe shares: “Since the time that my husband Ralph and I heard he had Alzheimer’s, we decided we would talk about his condition openly with people. Thus, here is the Christmas letter I wrote in 2010 to family and friends.”

GOOD NEWS/BAD NEWS

Katherine Stribe

The bad news is Ralph is declining in his Alzheimer's.

The good news is he has kept his pleasing personality.

The bad news is Ralph can't understand the commentators on TV.

The good news is we enjoy watching Bill Cosby and other comics.

The bad news is Ralph can't put words together to join in conversation.

The good news is he loves having people around.

The bad news is Ralph doesn't do woodwork anymore.

The good news is he goes to Silver Club where he paints, sings, and has lots of fun.

The bad news is Ralph's knees and shoulders give him pain.

The good news is he doesn't mind doing the exercises to strengthen them.

The bad news is our traveling days are over.

The good news is we can go to plays, concerts, and grandkids' flag football, softball, and basketball games.

The bad news is Ralph has to put up with me doing all the driving.

The good news is he tells me I'm a good driver!

The bad news is Ralph can do little for himself.

The good news is he tells me he loves me and he appreciates all that I do for him!

The bad news is we don't do a lot of talking.

The good news is we do find a lot to laugh about.

The bad news is Callie's family and many of you live far from us.

The good news is we have Andy's family, neighbors and friends around here who give us lots of support.