The Chatham County Council on Aging
dedicates this
2020 Candlelight Reflections Booklet
to all the Caregivers and Care Receivers
we have had the opportunity of serving over the years.

We also want to thank the caregivers and staff members
who contributed their talents to this booklet.
Candlelight Reflections
Thursday, November 5, 2020

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Resolution of the Chatham County Board of Commissioners

Proclaiming November as Family Caregivers Month

WHEREAS, Chatham County wishes to join the state and nation in recognizing November as Family Caregivers Month and also as Alzheimer’s Awareness Month; and

WHEREAS, Chatham County acknowledges the vital roles of family and friends in caring for loved ones, including those with Alzheimer’s disease and children with special needs; and

WHEREAS, the national theme for 2020 Family Caregivers Month—Caregiving around the Clock”—speaks to the all-encompassing tasks of caregiving that can include shopping, meal preparation, household chores, transportation, and providing comfort and care; and

WHEREAS, caregiving can take a toll on the caregiver’s physical, emotional and financial well-being, including on those seeking to balance caregiving with a working career; and

WHEREAS, many family caregivers are experiencing extra responsibilities and stress due to COVID-19, as they strive to keep their loved ones at home while others find ways to remain connected with their loved one if residing in a long-term care facility; and

WHEREAS, Chatham’s 2018-2023 Aging Plan recognizes how our large and growing older population will require increasing support for family caregivers; and

WHEREAS, the Chatham County Council on Aging and others are striving to assist caregivers, even now in the face of COVID-19, by offering respite, virtual support groups, training, options counseling, Meals on Wheels, assistive equipment, incontinence supplies, and other assistance.

NOW THEREFORE, BE IT RESOLVED by the Chatham County Board of County Commissioners that November 2020 is proclaimed Family Caregiver Month and calls upon the people of Chatham County to join the Council on Aging in honoring and supporting family caregivers.

Adopted, this the 5th day of October, 2020.

Karen Howard, Chair
Chatham County Board of Commissioners

ATTEST:

Lindsay K. Ray, NCCCC, Clerk to the Board
A Prayer for the Caregiver

November is National Family Caregivers Month

Unknown and often unnoticed, you are a hero nonetheless.
For your love, sacrificial, is God at his best.
You walk by faith in the darkness of the great unknown,
And your courage, even in weakness, gives life to your beloved.
You hold shaking hands and provide the ultimate care:
Your presence, the knowing, that you are simply there.
You rise to face the giants of disease and despair,
It is your finest hour, though you may be unaware.
You are resilient, amazing, and beauty unexcelled.
You are the caregiver and you have done well!

-Bruce McIntyre
Basketball player
Lover of books
Poet
Class valedictorian

Sense of humor
Ice blue eyes
Lit up a room
Out of the box thinker

Excellent seamstress
Wonderful cook
Red velvet cake
Famous biscuits on everyone’s plate

Pen to paper
NC Poetry Society
Words that roll off the tongue
Hundreds of poems, haikus published and won

Sunday school Teacher
Community Leader
Employee
Farmer’s wife
Four children she loved and adored

I swallow hard to check back these tears of mine....
Ten years...this disease stole

Trying days and dreaded nights
Pots burnt
Oranges in freezer
Wedding rings gone
Kitchen crumbs
Bedroom messes
Pacing the floor
Wring those small frail arms

Humor shines
Draped in all necklaces
“All too pretty to leave one behind.”
Blank stares that say
“Who are you?”
“I want to go home.”

Unclear of who, what and where
But never ever forgot
Bowing her head and grace she said.
Physically, mentally, emotionally done

This disease has once again won....

By: Wynne Fields

In memory of Nina A. Wicker
I remember back in 2012 when I first started going to a support group, I was full of anxiety about what might be coming our way. My husband had had several strokes, and, although his physical abilities didn’t seem to be affected, his memory was severely impacted. I didn’t know how long we would have to cope with his vastly diminished capabilities. I guess I thought his memory would get better over time. And, in a way, it did. He eventually relearned what a refrigerator was, and he stopped shaving his face with toothpaste. Really, it wasn’t so bad for many years. I wasn’t worried anymore about all the things that I knew might be coming down the pike. Over time, my anxiety was replaced by acceptance.

As I came to know other caregivers with loved ones who had Alzheimer’s or other dementias, I realized that there is much you can do to make your lives more livable. The first one being the realization that most dementia is not going to change your life overnight (even though it did for us). You don’t have to panic. It is a process that takes a long time, and your loved one is going to be much the same as he was yesterday or last week. And you can take comfort in that.

The second thing I realized is that you can accentuate the good things about dementia (really, there are a couple). I remember before my husband’s stroke that we used to have arguments about what we were going to spend money on. My husband liked to spend money fairly lavishly, and I was a budget-conscious finance nerd. It sounds weird, but since my husband can’t make decisions anymore, we don’t argue about how we spend money. I enjoy not having that discussion about every choice involving finances.

Another good thing about dementia is that at some point in time, the person with the disease doesn’t realize they have it and that, too, is something to be grateful for. I used to worry that my husband would be anxious about his condition, but he really doesn’t see that he has a problem. That’s good in my mind, and it makes me feel like he isn’t suffering in a way. Unlike most other diseases, the “pain” of dementia is mostly felt by the caregiver, instead of both the patient and the ones who love him. Usually the pain of having a disease in the family is compounded by watching the patient wrestle with the adverse impact they know their disease is having on everyone.

The final good thing about dementia is that it has brought me some of the most meaningful relationships of my adult life. I have made friends with other caregivers and shared deep and profound conversations with them that I don’t
think I ever would have had otherwise. Even moving several states away hasn’t broken my friendship with my first support group. We call ourselves the “Forgetful Friends” and I count on them for support any time I am feeling down. I know I could reach out to them in the wee hours of the night and they would welcome my call. And, they understand all the conflicted feelings that come along with caregiving. I will treasure their friendship for the rest of my life.

It’s 2020 and I am still caring for my husband at home. He has declined since the early days, and I fear he has Alzheimer’s as well as having suffered from the consequences of his strokes. But, we are taking each day as it comes. I know he appreciates me because he tells me (at least 100 times a day) that he loves me.

I hope there is a treatment someday for dementia, but until then, I hope all the caregivers and patients can find solace in their lives. Always remember that there are people out there who can help.

Author Anonymous
Two Candles - by Jessica Bryan

It is fall, and the day is dreary, chilled by a relentless rain falling like tears,
That dampen my heart as I remove two candles from the cupboard.
Time...so much time has passed since my mother left us. Even longer since my father departed.
I think of them...my father and my mother. They are together now, hand in hand.
They are smiling and young again. There is no illness, worry or regret.
I light two candles: one for my father and one for my mother.
I watch as the flames grow and then sway in the small currents of air.
They seem to move as one, burning brighter as they swirl and twirl on the candlewicks.
The flames reach out and wrap around in a lover's waltz then part and flirt with the space that separates them.
I, mesmerized by the movement, become lost in memories of Mom and Dad dancing together so many years ago.
My last fond memory of my father; his eyes brimming with love, asking my mother for one last dance.
Telling her that she was the most beautiful woman in the world.
Two little old people, still deeply, fiercely, and beautifully in love with each other.
My mother's face, etched in deep lines smiles back at him...
She becomes a girl in her teens mooning over her handsome Prince Charming.
I am a witness to the purest and most timeless love between two souls,
I watch entranced, unable to turn away for fear that I will forget.
My father died a few weeks later. My mother lived on with Alzheimer's for 17 more years.
Now, as I light the candles in their memory, I cry.
It is not out of sadness, but from nostalgia. There is a deep yearning to go back just for a moment.
To remember them as they were...together...dancing.
It is a reminder to cherish our loved ones and to love them with all we are capable of giving.
To see them as they were when they were young, filled with love and hopes and dreams.
I look back at the flames that move and bend to silent music. Perhaps it is celestial harps.
And I know that they are rejoined, laughing together, and loving together always and forever.
A Family Circle of Caregiving Love

By Dennis Streets

I was always told that my Grandpa Streets had “hardening of the arteries.” He died when I was 12. Sadly I don’t have many recollections of Grandpa that are not clouded by his cognitive impairment. Grandpa was a western Pennsylvania coal miner who started in the mines at age 9 and retired in the mines at age 65.

My understanding is that soon after moving to Pinellas Park, Florida, he began showing worrisome signs. He would get lost walking his dog Skippy, and people in town would drive him and Skippy back home. I do remember how quiet he was in our family gatherings—only occasionally laughing at something my brother David would do. David could make us all laugh with his one-person plays. I especially recall one at Thanksgiving—one of the last times Grandpa sat with us at the dinner table.

My pronounced memories of Grandpa Streets, though, are the days and nights I would be present when Aunt Eva would be trying to manage his confused and sometimes combative behaviors—and then later on when Grandpa was bedridden, and Eva was doing her best to provide loving care.

I remember how upsetting it was to Grandma to see her dear lifelong partner roaming the house in the middle of the night acting as though he was wiring the mine. I was just 7—nearly Grandpa’s age when he worked as a miner—but I was so unsettled by what I saw.

What was most amazing about Aunt Eva, during the 10 years that she was the live-in caregiver for Grandma and Grandpa, is that Eva also taught elementary school that entire time. In fact, because Eva starting teaching in the coal mining town of Sutersville, PA as soon as she graduated from high school, she also had to earn her college degree at the same time she was Grandpa’s caregiver. I often wonder how Aunt Eva did all of this and more. Eva ended up teaching 48 and a half years—only retiring because there was a mandatory retirement age in our school district at that time.

Not only did Eva survive during this period of her life...she flourished in many ways. She had a tremendous sense of humor. She was active with a close knit group of friends. She took trips overseas, including Cuba. And Eva helped my brothers, sister and I achieve our education. She was our “second mother.”

Having never married, Aunt Eva eventually moved to Christmount, near Black Mountain, into a house next to my parents when they moved from Florida to the Tar Heel state.
Fortunately she enjoyed several wonderful years there—making vegetable soup, pickled eggs, ambrosia, and so much more. She made new friends, took a few more trips, and loved playing cards.

On one winter day, Eva fell at the front door of her house and broke her hip. This was the beginning of a long, but steady decline. In some ways Eva fit the profile of someone who might predictably end up living her remaining years in a nursing home. While still cognitively very sharp, Eva eventually required considerable personal care assistance. She became incontinent and frail. She was in a hospital bed in her living room for 3 years. At the age of 92, Eva died at home as had Grandpa Streets.

The caregiving that Eva began came full circle when my brother David left his teaching position at a local community college to become her caregiver, along with providing loving assistance to our Mother and Father as well. He devoted 11 years to enabling them to enjoy as much quality of life as they could at home. My Mother lived to age 87 and my Dad, 93.

David often says: “I never considered the caregiving a burden, but rather a privilege.”

After caring for my Dad, who outlived both my Mom and Aunt Eva, David applied what he had learned about caregiving to a new role. He became a certified nursing assistant and staff member of a retirement community. His humor, compassion, caring nature, knowledge and practical skills added immensely to those residing in the community assisted living unit.

When I hear about “essential” workers during this period of COVID-19, I cannot think of any two persons in my life who better defined what it means to be “essential” in a loving and caring family.

Brother David, infant Dennis and Grandpa Streets
When Can I Leave Yesterday?

In Honor of my sister-in-law “Shirley”

As I woke up this morning to another beautiful day,
With a gleeful heart I left my bed,
Then I was encumbered with the thought, is it really today or yesterday?

As I rambled for my toiletries, my mind could not recall,
What am I to do with these, should I use them at all?
So I will just leave them here, and use them yesterday;

For it’s in yesterday I do reside, I can tell of my courtships,
my marriage, my children... even the day I found salvation.
But when you challenge me with the thoughts of today or tomorrow,
Not being able to correspond is my greatest sorrow;

It was yesterday all my troubles seemed so far away,
When will I leave yesterday? I cannot say.
Being in your presence is enough,
though there may be times you can’t see,
for in yesterday, I’ll always need your love
until tomorrow sets me free;

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Gratitude

As I was contemplating what would be a proper submission for this Candlelight Light Reflections essay I was thinking of all the things that have happened in my life over the last three years since I became a full-time caregiver for my beautiful mother. Many, many things have changed and continue to change on a daily basis, some are beautiful and some are horrible.

The thing that I have come back to more and more is that it is something that should not and truly cannot be done alone. I have been so fortunate to have community support through the Council on Aging and their respite care program. That program led me to a wonderful caregiver named Rosa Lee who has become more of a friend and now more of a family member with us. The love and care that she has shown my family is immeasurable. Last Christmas she and her husband took Mom and I out riding around to see the Christmas lights out in the country. We have visited their Church and she knows my family members personally. Giving me the opportunity to get out of the house even if it’s just to the thrift store or the grocery store can have so much meaning when you are at your wit’s end with frustration over so many different things. Knowing I have someone that I can depend on and trust has been the most invaluable treasure I could have ever asked for and the amazing part is that it was offered without my even asking. When I came home from work and realized how much Mom needed a full-time caregiver it was for multiple medical issues. I really thought I was losing her at the time and being able to be here with her I know has made a tremendous difference in her overall health, and some improvements have been blessings medically but of course dementia doesn’t get better. Rosa Lee has had professional and personal experience with dementia and is able to give me her perspective which has also been a tremendous benefit to me and Mom. The funny thing is I didn’t even think I would need any help! I was very very wrong.

I just want to express my gratitude to this community and the Council on Aging and especially to Mrs. Rosa Lee Brooks for everything you guys have done to keep my mom home and happy and safe. (Not to mention covid-free) Hallelujah!

Submitted by Lisa Pollard
In Memory of Pauline:

There is a green chair on our screened porch where my mother would sit for hours, rocking and smiling at the trees, the flowers the scurrying squirrels and the twittering birds. She loved nature. Even after all of her memories faded; even after the smile was replaced with weary indifference, she would look out at the greenery and find peace. An expression of pure contentment would fill her face. I would bring her tea and cookies and she would look up at me with surprise and gratitude. To her, I was a kind stranger who had done something truly wonderful. She’d sip silently as I might join her for a moment, wondering about her thoughts, her feelings, her ideas. There was no conversation. Her words were meaningless sounds that escaped from her lips and were lifted by the winds to the drifting clouds...lost for a lack of understanding. I’d look over and smile, nod my head, and watch her rock away the hours, feeling a deep connection and a completeness in a way one cannot express in words.

When I think of those days, those years, I smile to myself just before I look out onto the screened porch. Sometimes the green chair will gently rock in the breeze and for a moment I think of my mother still sitting there. Then I feel the heavy tug at my heart. It actually cries before the tears fall from my eyes. That sorrow that moves from my chest, my throat. and then to my eyes...that compresses and expands, that brings exquisite pain reminding me how good it is to love someone even though it hurts so much to lose them.

Remembering...loving you then, now and always, my Dear Mother.

By Jessica Bryan
Present in this Moment

Liz Lahti

My dad is 92 and has been in an assisted living care facility for over a year and a half. He moved down to North Carolina from Michigan in 2016 to be closer to family. I recently read the book, “I Am Here” by Kevin Shape. He talks about caring for his dad and describes his journey as, I Am Here For You and For Me... I Am Here With You and With Me... I Am Here...

I pondered what these statements meant to me. After my mom died, it was difficult to not be able to help him out on a regular basis. Financially it made more sense to move him to North Carolina and I told my dad, I would be here for him. I would help him move and get settled in independent living. I would take him out for dinner, to get a haircut, to the store, the doctor and celebrate special occasions with him.

My dad had a tragic accident and broke his back in 2019. After going to the hospital and rehab, he did not improve, moved to an assisted living care facility and went on hospice. He has been bedbound since January 2020. I told him I would buy his supplies, take dinners to him, and visit him several times a week. My dad catnaps and keeps his television and lights on all night. He has no idea what time it is, so I started to get phone calls at all hours of the night. I was working one full time job but felt like I had two jobs caring for him. I was decided I needed to be there for me. I decided to not answer the calls at night and I started utilizing my husband and daughter to visit and deliver supplies.

My dad’s nickname for me is “Mother Hen.” I easily got into a routine caring for him. I would get his mail, sit with him during meals, take stock of his supplies, organize his room, do exercises with him, help him shave, do his teeth and put lotion on him. Then COVID hit. I was not able to see him in person and had to surrender his entire care over to the facility. It was one of the hardest things I had to do. I would occasionally see him on FaceTime. He had lost weight; his hair had grown longer, and he looked like Albert Einstein. I was now there with him in this new way, separated by a mere 3 miles. A camera was recently allowed to be placed in his room. I can now see when he is sleeping and does not hear the phone or when he tries to answer and is not able to. I can catch a rare glimpse of him when he is eating and can hear when the game show network is on his television.

I got to spend his 92-year-old birthday with him for a half an hour through a window. They Hoyer lifted him to his wheelchair for the first time since March and brought him downstairs. Restrictions were then lifted, and I had the pleasure of seeing him face to face one time before numerous cases of coronavirus hit the facility.

As I write this, I am here with me. I don’t try to hide my feelings and the tears tumble out. There are now 25 cases of COVID between the staff and residents where he is living. I am here between the memories of the way things were and the uncertainty of what the future holds. I am asking myself what do I do next. I listen for the answer while being present in this moment.
Now I Remember

By Susan Hardy

I remember...

Summertime...The red and white Buick as it appeared in our back driveway each evening in the summertime heading toward the garden on the hill.

My grandmother would gather the corn to later be canned at the cannery at the local high school.

My grandfather would gather the tough corn to later feed to the pigs in the backyard.

I remember...

Fall and harvest time for apples...The lively chatter in the kitchen as we filled the baby food jars with beautiful pink apple jelly.

My grandmother had prepared the apple jelly.

My grandfather had tended the apple trees on which the apples had grown.

I remember...

The first freezing temperatures...Being shown how to stuff the casings with the sausage we would enjoy on Christmas Day.

My grandmother had mixed the ingredients for the sausage using her sister’s recipe.

My grandfather had cared for the pigs who constantly escaped their pens.

I remember...

The first snowfall of winter...Eating oatmeal in the warm kitchen as we watched the birds eating their meal spread on the snow on top of the well cover.

My grandmother had prepared the oatmeal.

My grandfather had scattered the meal for the birds.

I remember...

The Sundays...when my cousins, aunts and uncles would gather at my grandparents’ home.
My grandmother would exchange comments about all the grandchildren with my aunts and my mom on the enclosed back porch,

My grandfather would exchange comments with my uncles and my dad about the sport they watched on the television in the living room.

I remember...

That Sunday in late fall... when the women were on the enclosed back porch and the men were in the living room.

My grandmother was crying on the back porch.

My grandfather was yelling in the living room.

That was the day dementia became real to me.

I remember...

January of 1990... The words my grandmother spoke the first time we headed to the nursing home to visit my grandfather.

And the words my grandfather could not speak.

I remember...

The day... my grandmother declined the offer to visit my grandfather.

The day... we realized my grandmother was the one who needed care.

The day... the doctors told us my grandmother had given her all and her body was not well.

Now I remember...

All the days before the nursing home... when my grandmother needed our help.

Now I remember...

All the days before the nursing home... when my grandmother silently cared for my grandfather and did not ask for help.

Now I remember...

All the days before the nursing home... when we failed to step in and give help.

Now I remember...

In memory of James & Addie Clark
Lessons Learned by the Caregiver
by Jackie Green

Where Do I Start?

My journey being involved with those with neurocognitive disorders, including Alzheimer’s disease, started when my mother started to display forgetfulness when she was in her early 60’s. Both her parents had suffered with the disease and by default, their care became the responsibility of my aunt and uncle. Mom would lose her train of thought when she was talking then she would say “Oh it will come to me. I’m not going to worry about it because it won’t do me any good”. Suddenly light switches were labeled for a house she had lived in for 40 years. But my family and I, like most families didn’t recognize it or didn’t want to recognize it for what it was because mom was handling things so well in general and we were all busy living our lives. After all, wasn’t memory loss a natural part of the aging process.

Lesson learned (looking back): This kind of memory loss is not a natural part of aging!

Mom’s memory got worse and worse. Her and dad argued more than ever in their 50 years of marriage because of the memory issues. Then my husband told me about an interchange between them and how clearly my mom was completely oblivious of a lengthy conversation he overheard her have with my dad. This didn’t make me love my mom any less. I think it made me love her even more. I really wanted to help “fix” her; help her memory; help her and dad not argue as much. I enjoyed any time I could spend with my parents even though we lived states away from each other. However, some moments were horrible!

Lesson learned: We can’t fix someone else, regardless of how much we love them.

Then my father-in-law, who was always methodical and prepared, showed up to bowling with me and the kids without his wallet. Instead he was carrying a baggie of change from the car. Very uncharacteristic and peculiar! Several months later, more symptoms and we’re told he was diagnosed with Alzheimer’s disease. My husband and I, both engineers, go to what we can control and start the research on this disease. Aha! My mom’s symptoms also fit this diagnosis! Holy moly what do we do now? Both sides of our family are facing this devastating disease.

With all the arguing between my parents, my husband and I decide we need to tell my dad what we know about AD and we think mom has it. My dad gets angry with us and vehemently denies it. But the next morning, he looks terrible and he said he didn’t sleep at all that night and what should he do. According to dad, her doctor knows she’s been forgetful but there hasn’t been any diagnosis. Although my father was given 3 months to live 9+ years earlier, my dad is dead 6 weeks after my husband and I tell him that we believe mom has AD!

Lesson learned: You can die from a broken heart!
Mom’s life is turned upside down in disbelief and grief. Her symptoms escalate drastically and our extended family’s lives change forever. When they were a team, dad naturally filled in the gaps of what my mom wasn’t able to do herself and we had no idea how bad it was.

Lesson learned: Spouses can cover up the symptoms of memory loss whether they want to or not. Unless you are living with a person with a neurocognitive disorder, you don’t know what it really going on. But if you are living in that environment, you can be so focused on how it affects you and trying to survive, that you don’t see the big picture.

We now have to figure out how to take care of mom and help her have the quality of life possible when she doesn’t really want our help. How in the heck do we do this when my siblings and I live in 3 different states? Naturally, we start “sharing” mom.

In the meantime, my father-in-law’s primary diagnosis changes from AD to terminal brain cancer. Within eighteen months after his initial diagnosis, which includes brain surgery, chemo, and radiation treatment, my dear father-in-law passes from terminal brain cancer, with the dementia symptoms associated with it. My husband and I stepped in to support his parents in every way we could because we were the only family in town. I became their advocate and was at all the doctor’s appointments. I spent quality time with my father-in-law, including when I would take him out to lunch to give my mother-in-law a break. I did much of his personal care and when I got up in the morning, I would say to my husband, trying to find a way to deal with the fatigue, “it’s time to go make the donuts”! It’s ironic, but even with how hard it was, I have some really great memories of that time and I wouldn’t change my involvement but would wish he wouldn’t have had to go through that! I demonstrated my love to him through every action I took. At times, it was really hard! He kept his sense of humor and many times as I tried to assist him by cuing him when he was walking, he would jokingly say to me “You’ other left, Jackie” and we would both laugh!

Lessons learned:

- How to assist someone who uses a walker. Remind them to “stay inside the walker’. Good leg up the stairs first, bad leg down the stairs first
- The importance of laughter
- How to patiently feed someone w/dignity
- The value of hospice, now called Transitions Life Care,
- How to change someone’s diaper when they are bedbound
- About the death process as he passed in his own home 2 ½ months after being admitted into the hospice program.
- How to support a wife losing her spouse and facing being alone in life when she never wanted to be! After all, she had moved directly from her parents’ home into her marital home.

Over the next 5½ years, mom stays with one family for a while, then changes locale with the weather. When it warms up in the north, she goes back up to upstate NY. When it gets cold in the north, she comes down to NC and spends 3-6 months of the year with us. We take her to our daughter’s volleyball
games in middle school and high school including out of town for the weekend long tournaments. It warms in the north and back up to my brother’s house she goes. My brother’s family reaches their breaking point, time to move mom again. My sister’s family can take her for a couple of weeks in the summer to enjoy time at the pool and the beach, time to move mom again. Still without a formal diagnosis, I take her to the Duke Geriatric Evaluation Team. Diagnosis: Mild to Moderate Dementia. They inform me that location changes and disruption of mom’s routine can make her symptoms progress faster, not to mention the severe stress on the families. But mom and dad never wanted to be “put in an old folks’ home”. My dad had tried to set them up so that they were financially secure and we want to honor their wishes. The Duke Geriatric team were the ones that suggested to create a medical binder to go with her to each siblings home. They also told us that even watching the news can be hard for someone who is not in their own familiar location because they don’t know whether the crime committed or the impending storm is across the state or outside their own door. I had to start laying the groundwork for her next transition into managed care and getting my sibling to be okay with it. Some were more concerned with the financial implications and “losing all her assets”. Enough said!

Lessons learned:

- A long time family physician may not diagnose correctly not because of incompetence but because of how long a person holds onto their social graces and can fool people for the first 10 minutes or so with “small talk”. It takes time and insight that a provider may or may not have.
- Some people can’t see reality versus what they want to see, especially when money is involved. Maybe that’s greed.

Mom gets to be too much for us to juggle between families when she strikes my nephew and is no longer welcome to live at my brother’s home. I remember the words of the Duke Geriatric Team that an adult living community would be better for her and our families. Another move for mom...More churn....More adjustments.

Lessons learned:

- Deciding to place a parent in an assisted living Memory Care unit against their wishes is one of the most difficult things you can do in your life!
- You don’t always get to choose your teammates in life.
- Appreciate the gifts that each sibling brings to the situation. The input may not be equal in terms of time invested and each person may not be able to handle all situations. Work as a team!
- Long term rifts can happen to sibling when they have to face this journey as a family.

Mom had been exposed to second hand smoke her whole life in the midst of her current battle, she is diagnosed with lung cancer. We feel that the only responsible thing to do is remove the mass surgically but not do any additional treatments. It sounds like a responsible compromise. Little did we know at the time, the devastating effect that anesthesia has on those with dementia, not to mention how she would react to being in the hospital.
Lesson learned:

- Oh! If only we knew better, we probably wouldn’t have treated the lung cancer and extended her life when she faced the devastating neurological disorder of AD! Perhaps cancer had been the Lord’s blessing in disguise that we didn’t see because we were in problem solving mode.

As her health care proxy, I received many disturbing phone calls: mom hit a woman in the back of the head with her purse during church service, mom’s being confrontational, another urinary tract infection and the bizarre behavior that can occur in the elderly as a result...Mom’s paranoid...Mom threw her belongings out the bathroom window and was trying to escape through the window...Twice....I apologize again and again to staff but also to family members and mom, herself. I just wish I could fix the whole situation!

Lessons learned:

- The staff didn’t take the behavior personally. They loved mom. But they had to inform us of what was going on and take appropriate steps.
- Some people only drink when they are thirsty and this causes dehydration in the elderly and can lead to Urinary tract infections (UTIs).
- UTIs can cause many symptoms in the elderly and sometimes you can’t believe it until you see it.

Her last full month of life was around Christmas, her favorite time of the year. She’s having recurring UTIs, having trouble swallowing, which brings on pneumonia. Her symptoms are progressing and her quality of life is bad. The decision is made to do give her another round of antibiotics to get her through Christmas because she would not want her family to have their holiday memories marred with her death. Right after New Year’s Day, I receive the phone call that she has stopped eating and drinking and it only a matter of days. So I jump in the car and drive up to upstate NY in the middle of a snow storm. My nephew meets me at midnight when I arrive at my mom’s skilled nursing residence. I spend the next 3 days in her room with her and comfort her and celebrate her. I leave the facility only once in 3 days to have dinner with my sister because she thinks I need a break. I lay down with exhaustion, listening to the labored breathing of the death rattle to awake a short time later to silence. I rush to her side, check her breathing that I know will not be there, notify the staff and call family members. It’s about 4 am. I then sit and hold my mom’s warm hand, stroke her warm, silky soft arm and talk with her until the funeral home comes for her. I walk out early that morning before dawn to light snow flurries.

Regardless of how hard all this was to see my parents and my family deal with these diseases, there were many more things learned!

Lessons learned:

- To cherish the person who was still “in there” regardless of the disease symptoms. They just want to feel safe, loved and valued.
• To stay in the moment with someone with memory loss, because it is the only moment they know.
• They aren’t doing things to manipulate, they aren’t doing things to control, they are losing control and they are doing the best thing they can.
• That I needed to do the best I could for them and that is how I could look myself in the mirror and knew I did the right thing.
• To set a good example for our children of how to care for parents as they age.

I had put my working life on hold for 8 years starting when my father-in-law had been first diagnosed with Alzheimer’s disease. When it was time to go back into the workforce, I was no longer an engineer or a small business owner. I was trying to figure out how I fit into my new world. I started helping a friend’s parents that was dealing with neurocognitive disorders. Then my former pastor needed some help due to his advancing age and health limitations, so I helped him as needed. My husband highly suggested that I consider making it a career to work with “old people” as he calls them, “because you are so good with them, Jackie”. After completing certification as a Certified Nursing Assistant, I decided I would be better equipped to help the elderly stay engaged, so I completed the Activity Director training and started a whole new career that I absolutely LOVE!

Lessons learned:

• We change and learn based on our life’s events, a new passion may result!

I went on to work for almost 5 years in a memory care unit and I found so much satisfaction and joy. I loved my residents and their families and they loved me. I was able to improve their quality of life. I validated their existence. I was able to support their families because I had already walked their walk. I would frequently tell family members when they were frustrated with the behavior of their loved one that it would be okay and try to approach each moment fresh because that is the only moment their loved one may know about. The family may beat themselves up because they didn’t react “right” and told me that I seemed to always know what to do. I would let them know that it is different when they aren’t your loved one and you don’t have all the history with them and the memories. I could approach their loved one with a clean slate each moment and could build on that moment not what came before and without worrying about what was next.

Lesson learned:

• How to help residents in a memory care unit enjoy their life, feel safe, valued and loved
• How to support families of residents and encourage them to enjoy the moment and feel that they did the best for their parents.
• We aren’t given instruction manuals when we have children. Likewise, we are not given instruction manuals when we have to parent our parents.

Part of my journey, was to learn all I could about neurocognitive disorders and especially how to prevent them. After all, my mother and her parents had all died with one. I became a Certified Dementia Practitioner. The medical community is still working on understanding these disorders and how to
prevent or treat, but they do know that what is good for the heart is good for the brain. So I encourage everyone I know to do what they can.

Being a long-term caregiver, I didn’t understand the value of taking my self-care. I was too busy surviving being a caregiver, parent of two teens and wife. So at the end of the caregiver journey, I was in severe knee pain and required my third knee surgery on my left knee. Without being able to exercise because of knee pain for so long came debilitating low back pain that was caused by complete lack of abdominal muscles. The other side effect of lacking core muscles was urinary incontinence. To that add the fatigue that came with undiagnosed hypothyroidism and the inability to sleep through the night because of all the above! I fought depression and my memory was shot. I was a mess.

But fast-forward to finding my new passion in life of working with seniors. With that came new excitement, movement, more meaningful socialization and purpose. More physical fitness came with changing jobs and teaching exercise classes for seniors 4-8 times per week. It took a couple of years to rebound but today I am healthier and physically stronger than I have been since my early 30’s. The urinary incontinence is nearly non-existent and my brain is functioning better than it has for many years. For the first time in my life, I can re-trace my steps if needed (maybe not 100% but more often than not!)

Lessons learned:

- You can rebuild your life after caregiving if you make the commitment that you are worth it!
- What’s good for the heart is good for the brain.
- Follow a heart healthy diet – The Mediterranean Diet or the DASH Diet are great for the brain!
- Physically exercise in moderation on a regular basis (Did I mention I am an exercise instructor now for seniors!)
- Get regular check-ups
- Challenge your mind--puzzles, new learning, new schedules, new skills (did I mention that my husband I are started a new life mission on a farm!)
- Get adequate sleep (I got a sleep study done and now sleep with a mouth guard)
- Quit bad habits like smoking, excessive alcohol consumption
- Avoid stress when possible (laughter helps this a lot!)
- Develop healthy coping strategies (change what you can, accept what you can’t)
- Socialize
- Practice mindfulness
- “Don’t worry, be happy!”
- If you really want to learn something, teach someone else!

This journey of caregiving was not easy. If my husband and I wanted to do the ethically right thing for our parents, we had to step up. It had its costs, physically, emotionally, mentally and financially. We know we gave it our best even though we made mistakes. Our choices were always in an attempt to do the right thing for our parents. Now we find that we can support others that find themselves in the same situations. We have already walked in similar shoes. That makes it even more worth it.
"A New Kind of Pain"

A new kind of pain
Has entered the land
Bringing hurt and turmoil
To everyone she can

This new kind of pain
Is woven in loss
No one is exempt
Sometimes a deadly cost

We will weather this storm
In the name of Jesus Christ
Who has and knows all
He's already paid the price

For this new kind of pain
Sometimes silently lay
It will attack anyone
On any given day

Her name is Corona
Covid too
We give her to Jesus
He knows what to do

With this new kind of pain
That don't want to stand still
But the Power of God
Will make sure it will

Sometimes it fails to launch
Because you don't know how
Screaming for direction
It will cause you to bow

To the One who knows all
In the earth and beneath
It's a new kind of pain
But your life He will keep

A new kind of pain
What can I say?
It's like rain without shelter
That has come our way

Tears of joy left the scene
Peace beckons it to come
To a reality of hope
For each and everyone

A new kind of pain
Is on a course of its own
Taking residence wherever
And you are not alone

Author, Reverend Claudia Greene
Illustrations on the cover and throughout this booklet.

Jessica Bryan's mother, Pauline Pulizzi, died in May of 2019. She was 99 at the time of her death and one month shy of her 100th birthday. The illustrations on the cover and throughout this booklet are samples of the drawings she was doing at the age of 96. Even through dementia, she was able to express herself through her drawings.

The artist, age 96