

# The CAREGIVER

Newsletter of the Duke Dementia Family Support Program

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SUMMER 2019

## WOMEN AND DEMENTIA

By Lisa P. Gwyther, MSW, LCSW



Dementia poignantly, powerfully and disproportionately changes women's lives. Dementia alters roles, relationships and fundamental beliefs about caring. Women in support groups report drawing from unanticipated wells of strength, resilience, humor and compassion when they share their stories and reflections.

Since 1980, *The Caregiver* newsletter has featured stories from women charting unknown territory in caring. Yet, despite forty years of newsletters produced by women and including women's stories, this *Caregiver* is our first theme issue on Women and Dementia.

The March 2019 Duke Dementia Family Support Program's Triangle-Area E-Newsletter celebrated Women's History Month by requesting stories from our readers about women's lived experiences with dementia. Responses came from women who are quietly making history living with and caring for and about their families. Then in May 2019, we celebrated Women's Health Week by requesting Dr. Johnson's review for this newsletter of what is known and what can be done to protect women's health from risks associated with dementia.

Stories connect us and reduce isolation, stigma and misunderstanding. We hope the stories and reflections in these pages encourage readers to learn from each other, just as you do in support groups. Stories matter.



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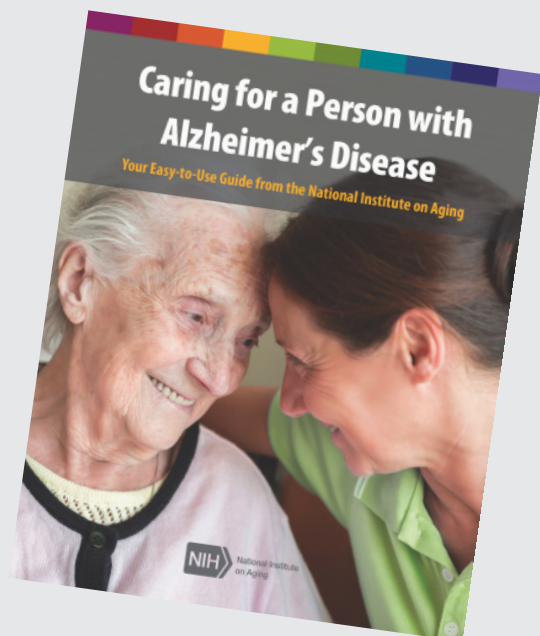
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## CARING FOR A PERSON WITH ALZHEIMER'S DISEASE: YOUR EASY-TO-USE GUIDE

Get Alzheimer's caregiving information and advice in this comprehensive, easy-to-read guide. Learn caregiving tips, safety information, common medical problems, and how to care for yourself.

Download or order your free copy at the link below. Available in English and Spanish.



<https://order.nia.nih.gov/publication/caring-for-a-person-with-alzheimers-disease-your-easy-to-use-guide>

# WOMEN AND RISK FOR ALZHEIMER'S DISEASE

Kim G. Johnson, MD

Duke Neurology Division of Memory Disorders

Alzheimer's disease affects women in unique ways. Women are more vulnerable to Alzheimer's disease than men, but we are unsure whether female gender itself is a risk for developing Alzheimer's disease or if other factors are involved. We know two-thirds of all Americans with Alzheimer's disease are women. This may be because older age is the greatest risk factor for Alzheimer's disease and women live longer than men. Also cardiovascular disease is a risk factor for Alzheimer's disease and of people with cardiovascular disease, more men in mid-life die than women. So men who survive to age 65 and over may be healthier with less Alzheimer's disease risk than women over age 65. Another factor may be education. Lower education is a risk factor for dementia and more women may have Alzheimer's disease at this time due to lower educational attainment in women who are over age 65.

However, we are learning of increased risk based on gender and genetic risk as more research suggests possible genetic and metabolic causes for Alzheimer's disease. A 2017 study in *JAMA Neurology* looking at 57,000 patients ages 55 to 85 compiled from 27 research studies shows women ages 65 to 75 with one copy of the apoE4 allele, the main genetic risk factor for late onset Alzheimer's disease, have increased risk for developing Alzheimer's disease compared to men. These same women also have an increased chance of mild cognitive impairment between the ages of 55 to 70. Interestingly, there were no differences between the sexes in patients who had two copies of the apoE4 allele.

New research presented at the Alzheimer's Association International Conference in 2018 shows that exposure to sex hormones over a lifetime may play a role.

Women with three or more children had a 12 percent lower risk of dementia compared to women with one child, women with a first menstrual period at age 16 or older had a 31 percent greater risk of dementia compared with first menstrual period at 13, women with natural menopause at 45 or younger had a 28% greater risk of dementia, and women with overall shorter total reproductive periods had a 33% elevated risk of dementia. These population studies support studies suggesting that progressive loss of estrogen associated with female aging may have interactions with

insulin and brain glucose metabolism which leads to increased cases of sporadic or non-genetic associated Alzheimer's disease. The hypothesis involves loss of estrogen creating increased inflammatory states which lead to a loss of synapses between nerve cells.

Women may also be at increased risk for dementia based upon higher rates of depression and anxiety among women compared to men at all ages. We know that having depression or a history of depression increases the risk for Alzheimer's disease. There is a link between the number of depressive episodes in a lifetime and risk of dementia. Therefore, treating depression with therapy or medications should be a public health priority. Depression can also arise after a dementia diagnosis. Ensuring patients over age 65 with and without dementia stay active socially in the community is important. Social isolation is associated with risk for both depression and Alzheimer's disease.

The course of Alzheimer's may have a different trajectory for women compared to men. An article in *Lancet Neurology* in 2016 summarizes differences in presentation between women and men. Among women and men with Alzheimer's disease who are

*Women are more vulnerable to Alzheimer's disease than men, but we are unsure whether female gender itself is a risk for developing Alzheimer's disease or if other factors are involved.*

*continued on page 4*



## WOMEN *(continued from page 3)*

positive for the apoE4 allele, women demonstrate more severe behavioral disinhibition. Women live longer than men with Alzheimer's disease and have more mood symptoms and disability. Men show more aggressive behavior and have more medical conditions than women. There is some evidence that women with Alzheimer's disease treated with the acetylcholinesterase inhibitors donepezil and rivastigmine have less cognitive decline compared to men. This effect may be due to the effects of an estrogen receptor. On MRI scans among patients with Alzheimer's disease, women have faster progression of hippocampal atrophy than men; however, men have more white matter disease in the brain.

Women not only are diagnosed more with Alzheimer's disease but they also are three times more likely to care for a family member with Alzheimer's disease. Sixty to seventy percent of caregivers are women. Several studies show adverse effects of caregiving on personal health and economic factors. A survey cited in *The Shriver Report: A Woman's Nation Takes on Alzheimer's* shows that all caregivers have 8% higher health care costs than non-caregivers. Sixty-two percent of caregivers have increased emotional stress and 40% of caregivers develop significant depression or anxiety. Specifically, three quarters of women caregivers express concern over their ability to maintain their own health. Women caregivers are especially vulnerable to economic effects. 19% of women caregivers quit work due to caregiving demands and 20% transition from full-time to part-time work whereas the same is not true for men. Only 3% of male caregivers transition from full-time to part-time work.

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Women can take steps to reduce their likelihood of developing Alzheimer's disease or dementia. Recent research studies point to the importance of prevention starting in midlife and possibly at birth. The invisible effects of preclinical Alzheimer's disease are occurring decades before symptoms occur. To prevent Alzheimer's disease women and men should strive for

healthy lifestyle with ongoing physical and cognitive activity, a healthy diet and adequate leisure time. *The Lancet*, a British medical journal, published a review of dementia in late 2017 which found that 35% of all dementias are attributable to low education, midlife hypertension, midlife obesity, diabetes, smoking, hearing loss, late-life depression, physical inactivity and social isolation. Epidemiologic studies show that controlling blood pressure and keeping blood glucose consistently in a normal range are important to preventing Alzheimer's disease.

A Mediterranean diet, high in vegetables, fruits, rice, whole grains, olive oil and low in meats (especially red meat) has been shown to decrease the progression of amnesic MCI and to Alzheimer's compared with other diets. Physical exercise, intellectual stimulation or leisure activities in high amounts over a lifetime are associated with reduced risk of dementia. Lifestyle choices and habits beginning before birth and established throughout the lifespan may reduce the likelihood of developing Alzheimer's disease. Improved socioeconomic status during the gestational period and early childhood is protective for late-life dementia risk.

Treating depression with therapy or medications could delay the onset of dementia in select patients. A study in 2018 in the *American Journal of Psychiatry* showed that treatment with a selective serotonin reuptake inhibitor (SSRI) antidepressant for greater than four years in patients with mild cognitive impairment and a history of depression delayed progression to Alzheimer's dementia by approximately three years.

The discovery of the biomarkers beta amyloid and tau are important to our understanding of the progression of Alzheimer's disease. The overarching mechanism behind the disease is still uncertain; however, we know that beta amyloid is deposited in the brain decades before clinical symptoms occur. Later the tau protein appears in brain cells which indicates the presence of

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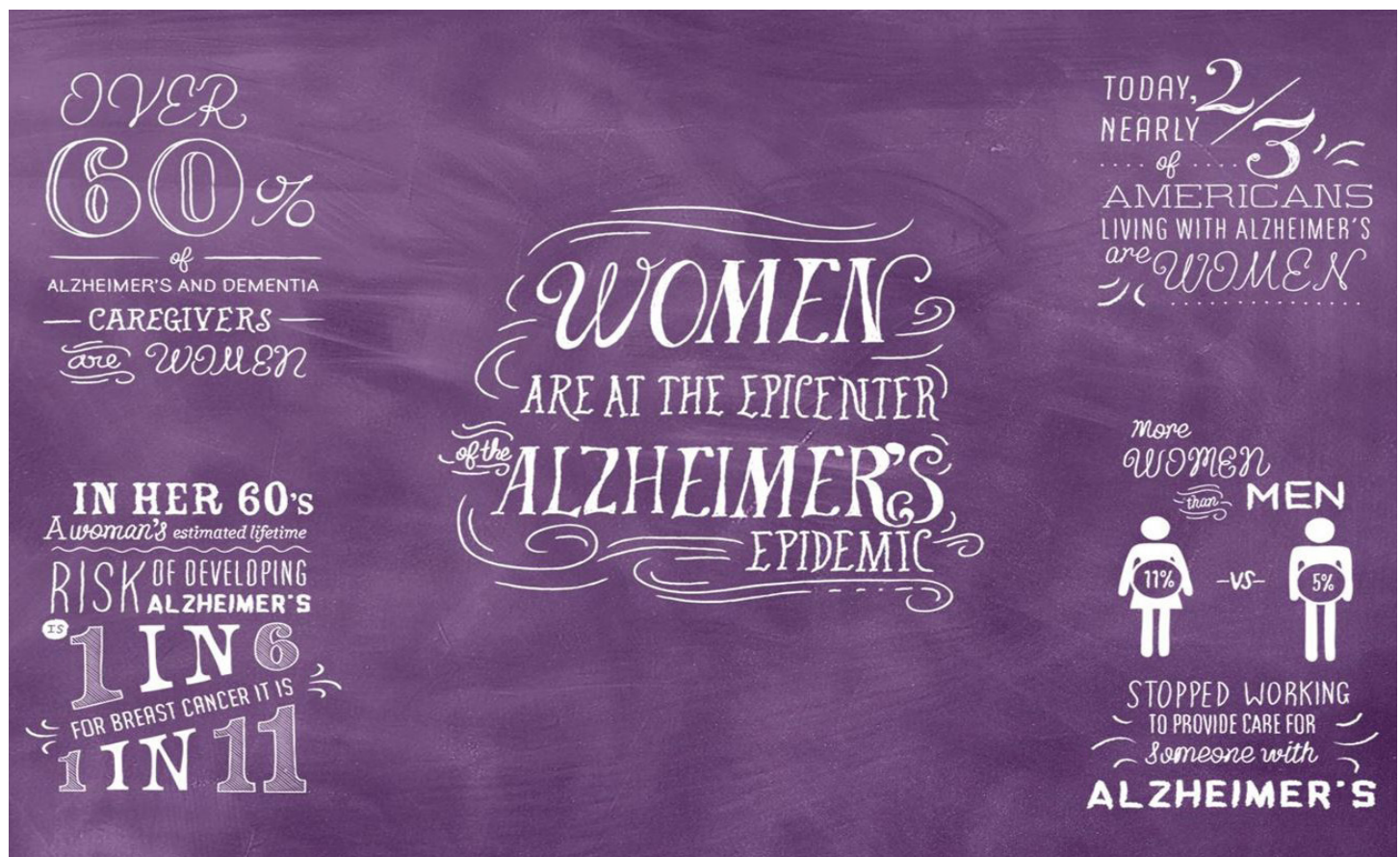
## WOMEN *(continued from page 4)*

neurodegeneration or cell death. Cognitive symptoms start to appear afterwards.

Knowing that signs of Alzheimer's disease show up in the brain decades before symptoms of cognitive decline hopefully will lead to increased prevention strategies for women enacted on a global scale. Alzheimer's disease is a global public health problem and expected to increase in high income countries and greatly increase in low income countries over the next 50 years. However, not everyone with biologic evidence of Alzheimer's disease in the brain will develop symptoms of cognitive decline in their lifetime. Education, access to healthcare and a lifestyle with decreased stress are protective. People with higher education have higher cognitive reserve and develop symptoms of dementia more slowly than people without this reserve. Mindfulness and meditation programs to increase resilience in response to stress are also important. Research shows a resilient personality profile is associated with lower risk or delay of clinical dementia even in persons with AD neuropathology.

Diagnosing Alzheimer's disease accurately and early allows women to make their own decisions and plan for their future while they are still able. The certainty of a diagnosis can relieve anxiety when patients and families know something is wrong with memory and cognition. Interventions to delay the progression of disease and increase support for patients and families can reduce cognitive and behavioral symptoms.

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# WORDS OF ENCOURAGEMENT

By Kim Chu



They are so easy to miss, these full-hearted, split-second glimmers of connection. In our little corner of the universe, time stands still. The way my young son looks at my mom is filled with pure love. He doesn't know what used to be. It's not the "long goodbye" for him; it's simply hello.

At 64, nine years after her diagnosis, my mom seems so far away. For years we were grasping at answers, until she received her diagnosis during my senior year of college. Her spirit was morphing, and so were her facial expressions. The color in her voice was fading, but the warmth in her eyes remains.

Twice she seemed to understand that I was pregnant. The first time she said, "I'm sorry I won't be able to talk to it much." The second time she asked, "Did he ever see you?" We wanted to be surprised, and didn't find out the baby's gender. But in that moment, she seemed to know. Our son was born on my birthday. It took weeks for her to even notice him. Now she says, "You're so good," to him almost every day.

You never know what each moment will bring, so keep climbing to the next. That's what my mom is teaching me on this caregiving journey. We savor the seconds that glow and dance. The ones that sparkle and fizz with

life, stopping time in its tracks. I'm learning to breathe through the seconds that turn us inside-out and shake the ground beneath us. Those are the ones that make us even stronger than we were before.

*You never know what each moment will bring, so keep climbing to the next. That's what my mom is teaching me on this caregiving journey.*

Last year my goal was to capture one-second video clips of every day spent with my mama while waiting on baby. Now I'm working on a [100-day photography project](#) to capture these days of ours: the messy, the magical, and everything in between. Chasing her light behind my camera is helping me to notice bits of color I was missing before. May we all seek and find at least one second of light in every single day, even when it seems unimaginable.

*Reprinted with permission from Kim Chu, the author/daughter of a woman living with FTD and The Association for Frontotemporal Degeneration (AFTD) Help and Hope, April, 2019 newsletter.*

## 26.2

By Pam Anderson



When I met my husband-to-be, he had taken up running with the goal of qualifying and completing a marathon. As an engineer and a man who loved competing in sports, I soon learned that his goal was carefully plotted out and executed with grit and determination. I asked him recently what the hardest part of training was, and without hesitation he said “doing it!”

Anyone who has ever taken on the challenge of long distance running will tell you that the training is time consuming and critical if you hope to get to finish the race. We wove the training into the rhythm of our lives. Jobs, kids, social and professional activities were given their due. We shared the responsibilities. Together we met his goals. Several years and 12 races later his interests changed and long distance running gave way to short runs and walking with me.

Today we’re engaged in another sort of marathon – the long road of Alzheimer’s.

Initially, the subtle changes meant that the balance of duties that we’d shared as a married team began to tilt in

my direction. I took them on and powered on. As a year or two passed, the heavy heart that promised to overtake my joy in life began to play out in vague and persistent health issues. I wasn’t sleeping. I was constantly worried I’d forget to pay the taxes or the water bill! I was doing 95% of the driving. Medical and legal appointments took on the look of a weird sort of social life. I knew the statistics about caregiver burnout. I was heading for a crash. I needed help. That first realization made me wonder where that would come from outside of family. What a surprise and reaffirmation on the goodness of people when we began to share our story and struggles. Strange as it is to write, our circle becomes exponentially larger every time we open up.

It’s a long road – Alzheimer’s. It takes stamina and a belief that we can make the distance. There is no prize at the end for anyone. However, there is hope. My husband has grieved the heavy load placed on me. There are still many moments when he expresses his gratitude for our life together. I think about his determination to run 26.2 miles...I use that these days.

*What a surprise and reaffirmation on the goodness of people  
when we began to share our story and struggles*

# DISCLOSING MY DIAGNOSIS

*By Judy, 2015*



I would like to begin by reading something I shared at a prayer meeting at our church last year.

In April of last year, Dan and I began a journey that we never expected to take. Dan especially, was becoming more and more frustrated by my inability to remember things, so we decided that I needed to see a doctor. After extensive testing by a neurologist, I was diagnosed with early-stage dementia and was placed on medication. We then began learning all we could about the disease and how to cope with it.

I am now in early-stage Alzheimer's and decided recently that I would like to share this with all of you, before it becomes too obvious. There are some things I can't do as well as before, but right now I am still able to cook, clean house, etc. I can drive to a few places that I go to on a regular basis, but that may not last much longer. It won't be too long before I will be relying totally on someone else to do the driving, and Dan will be learning to cook. Recently, our daughter found out about an eight-week program based at Duke University for couples in our situation. A group of professionals led the sessions, but each week a different speaker with expertise on a certain aspect of the disease also comes to speak to us. The information is very helpful to all.

After that, we break up into two groups. One for the spouses, who are called "caregivers" and one for the patients.

The spouses are given information and methods of coping with what they are going through. In the group for the folks who have the disease, the leaders have us

share our feelings and talk about coping mechanisms that may be helpful. We are now about half-way through with the sessions, and are finding it very helpful for both of us.

Dan and I have been reading a book about Alzheimer's and in one chapter relating to disclosure, a lady decides to tell her friend that she has Alzheimer's and her friend's response was, "Well, you don't look like you have Alzheimer's." You see, even humor can be found in such a situation as the one we're going through now.

I've asked our minister not to put my name on the prayer list just yet. He will know when that needs to happen. Thank you for hearing me tonight, and please don't be feeling sorry for me either...I'm looking forward to some good times ahead.

Since the time of my disclosure to the church, I have studied and learned more about this hideous disease and how it affects not only the patients, but also the patients' families, as well as their friends. Currently, five ladies in our church have this disease.

I know that a lot of research for a cure for Alzheimer's is ongoing, but so far, none has been found. For a time, I was hopeful that a cure would be found in time to help me, but I'm afraid that won't happen.

My neurologist has now told me that I should not continue driving. Even before my diagnosis, I got lost on two different occasions while driving alone.

I'm so concerned for my husband, our adult children, and our grandchildren. I've learned that as the disease progresses, an Alzheimer's patient's personality can drastically change. I am so afraid that when that happens, it may be very hurtful, even ugly.

I also know that a time may come when my husband has to place me in a facility for folks in my condition. Right now, the future looks very bleak.

I thank those of you who have begun this task force against Alzheimer's in North Carolina. I urge you to give it your all so that one day a cure will be found and this monster will be annihilated.

Thank you for hearing me today.



# A DAUGHTER WONDERS..?

*By Maureen Wertheim*



As my mom's caregiver, I have been advised to journal as a way to cope and remember. I always thought writing was work. I was very sure that I will always remember. Will I? Do I need to be worried about a disease that I now know too well and not by choice? I never imagined what to expect when I made the abrupt decision to move my mother in with me. When my daughters look at me, is there an unspoken fear that they will have to care for me in this way?

My journey as my mom's caregiver over the last several years seems to be moving toward an end. At 87, she is less and less able although, except for hearing loss and trouble speaking later in the afternoon, she looks physically healthy. Do I celebrate this as a success of the care I have been able to provide? How do I face the fact that I never thought my direct care would last years?

Then there's the guilt. Does it really matter which ethnic group or religion has the corner on the guilt market? My guilt feels unique to me because I am the child of a Holocaust survivor. My mother was in hiding from ages seven to 14, then reunited with her family in the US, and she married and always lived in the neighborhood that I grew up in. Our mother-daughter relationship from childhood was unusual. I always felt like the adult so caregiver was not exactly a new role for me. Her strict and very structured way of life was and continues to be her survival mechanism. Her rules for neatness and cleanliness and her insistence that there is only one right way to do things has probably helped her continue to function in ways that may have been lost to her disease. Chopping uniform pieces of vegetables

or remaking a bed in a hotel (and more recently in the hospital) are still current examples of her earlier self. However, her slow methodical behavior can still drive me to tears. I believe eating is a sign of life and she does it slowly and meticulously over hours. Her language is impaired, but her words suddenly come out loud and clear in negative situations like, "Pick that up." She doesn't know my name one moment, but she calls my name out clear as a bell when she hears a close clap of thunder.

I have learned that smiles work. Telling my mom to use the bathroom with a smile makes the process slightly easier. Using positive expressions like "fresh clothes" versus "dirty" makes changing easier. I strongly believe my skills as a mother and my desire to do everything and not miss out on life has kept me very organized. I know I am caring for an adult with an insidious disease. But caring for my daughters with an organized diaper bag and laying everything out prior to a bath or meal prepared me to create smooth transitions now when I am caring for someone who once cared for me. When I made the decision to get pregnant, I was unsure if I could deal with diapers. Hormones kicked in and it was second nature. Hormones or something have kicked in again.

I tend to be someone who jumps in, does what is needed and then, if time permits, thinks about it and processes it later. I often remind myself that if I do something that my mom is not happy about, she will nap soon and forget. And in that moment, it is a blessing. Maybe we caregivers are all "survivors" when it comes to the journey that makes up our lives?

# WHERE'S MY MOM?

By Lisa Fournier



My mom was diagnosed with dementia in 2003. I saw it first. She had always been “absent-minded” – losing her glasses, forgetting where she put her car keys, and so forth. This was different. We happened to be alone on my porch one day and I said, “Are you okay? You seem to be forgetting more these days.” Although I asked calmly, I was expecting strong denial from a woman who had always been “in charge.” Instead, she said, “I know” in a very quiet voice. I knew then that something wasn’t right. Mom happened to have a doctor’s appointment the next day, so I drove her. Surprisingly, she let me come into the examination room with her. This would never have happened before. The doctor gave Mom “the test.” I was shocked. She couldn’t remember the date, the season, and other items. I thought, “Now what do we do?” For 14 years, Mom and I went on a journey together – living with dementia.

When I first started full-time caregiving in 2009, it was full of the normal, harrowing stories. Mom was burning the food, the neighbors bilked them out of some money, tax returns weren’t getting done, and so forth. At first, I felt guilty for not rescuing her and my stepdad before this. However, I have come to realize there is never the “right” time. They were both the oldest children in their families and had lived through the aftermath of the Depression and World War II. They were used to doing whatever was necessary. I stepped into my role with full responsibility of the administrative tasks – doctor visits, paying bills, grocery shopping – right into my mom’s shoes. I was convinced everything needed to be organized, including the people. After all, my mom was supposed to be in charge, not me – right? In the meantime, my in-charge mom relinquished all

responsibility, and none of us were used to it. All I could ask is “Where’s My Mom?”

Over time, Mom had to move into a facility. I bought her several pads of drawing paper and colored pencils and she began drawing out her life in pictures. Pictures of her childhood, where she lived, lots of flowers from her garden, and other far-away memories. I believe it was especially therapeutic for her after my stepdad passed away. During this time, I saw glimpses of my mom – not as “my mom,” but the person she was at her core. Although there was no distinguishable event, I realized instead of missing “my mom,” I was given an opportunity to appreciate her for who she was right then, and not somebody with a label of “Mom.” Somewhere along the way, I dropped my expectation of “Where’s My Mom?” Mom, this lovely creation from God lived out the very essence of who she is in the last decade of her life. She was a blessing to others, speaking words of delight into their lives. When I would visit her, we would hold hands and be still and present with each other. My mom passed away in December 2017. I am her baby – she literally called me this name until she couldn’t anymore. It used to drive me crazy. When I was little, I would stomp my foot and say, “I am NOT a baby!” Now, I’d love to hear her say it again. In the last few years, when Mom couldn’t express in words her feelings and emotions as clearly as she once could, this was a word wrapped up in deep meaning of what she felt about her and me – the full tenderness of a mother’s love to her daughter.

Although the caregiving path is a hard one, there is a blessing when you decide to glimpse into the person living with dementia as who they are, and not their former role. Dropping expectations and being present with somebody is powerful. Looking back, I was able to see my Mom for who she really was as a person – down deep. She is a part of me that I carry through every moment.

Where’s My Mom? In my heart.

*Lisa has her doctorate in Strategic Leadership from Regent University and teaches social entrepreneurship at Virginia Tech. Currently, she is working on her master’s in Aging and Dementia at Texas State University, aiming to help individuals, families, and communities demystify the stigma of dementia.*



# CONSTANT CHANGE

By Roberta J. Cruz

“There are opportunities even in the most difficult moments.”

- Wangari Maathai



To take a moment and reflect on my experiences as a caregiver brings up feelings of pure exhaustion. There is so much. A snapshot of my situation when I became my mom's caregiver: my son was fifteen months old and still nursing; my husband was in the midst of his internship year in Pediatrics; I had been working from home taking care of a friend's baby; and we had been living in NC for over two years with a growing network of friend support, with our closest relatives in Washington, DC.

Culturally, I have a sense of what is expected of me in caring for my mom. Most days, that weight is more than I can carry by myself because many things seem out of my control. My caregiver experience as a woman, daughter, wife and young mother has been rooted in supportive relationships, compassion, love and persistent practice.

My mom immigrated to the United States from the Philippines in 1974 at the age of 29, ultimately finding an accounting job in New Jersey. Then, from New Jersey to California, she, along with my Dad, raised my older brother and me. She worked tirelessly as an accountant and as a mom. Even at a young age, I knew and felt that she worked too hard because she suffered a stroke at the age of 51. She did the best she knew how to “have a better life” here in America, despite the challenge of my father's frequent absence and gambling. Throughout my adolescence and into adulthood, she often reasoned

and minimized her struggles by saying that, “things could be worse.”

Balance is relative. I have always struggled with work life balance. Having my Mom as my first teacher in life, I've had a strong tendency to work tirelessly and place a high value on others' perceptions of my contribution. Often, the projects that seemed most fulfilling have left me overwhelmed and exhausted emotionally. However, my experiences with pregnancy, labor/delivery and motherhood had been different than any other project. It had been a culmination of many life lessons of how to move from the dark and find light, of how to ask for help, stay active and of how to make friends and partner with people who support my growth. For the first time in my adult life, I had found a rhythm...I felt balanced.

A year and a half later, while visiting my parents in California, it became clear that my Mom could no longer care for herself. My dad, brother and Auntie were not in a position to care for her. After a two week unexpected, abrupt transition period, we became an intergenerational household—an experience I had always wanted and imagined ... just not like this.

So many emotions! I recall many times checking in with George with and without tears, in laughter and in exhaustion, “Is this really happening? Are we going to do this? HOW do we do this?” My biggest fear was the

*continued on page 12*



## CONSTANT CHANGE *(continued from page 11)*



impact of caring for my mom on my ability to be present and available for my toddler son and husband. George's biggest concern was that it would be one big failure that maybe we wouldn't be able to help and the process of trying would be more harmful to our family. Yet even with these concerns, we agreed that we couldn't leave my mom alone, knowing that something catastrophic would likely happen soon.

Life as a roller coaster—a useful visualization from pregnancy that came in handy during this intense period of transition. The highs and lows, turns and flips, accelerated moments and periods of anticipation of the unknown are inevitable. In those moments of anticipation and chaos, how do I respond? How do I want to live? Not wanting to remain stuck and anxious, I relied on some efforts that have helped me gain momentum in the past: letting go of expectations (compassion towards myself), focusing on my breath, movement through dance, and sound boarding with trusted friends as well as being open to new information. Additionally, the concrete act of writing checklists, reviewing and prioritizing tasks became essential to feeling a sense of accomplishment in a time of feeling overwhelmed.

By this time, George and I had known each other for almost 15 years, in a relationship for nine years, and married for five years. We've had innumerable growth moments over the years, so there was definitely a solid foundation of trust and confidence in each other. In moments where emotionally, the weight of caregiving (the actual act and the logistics around care coordination for my mom) was too much for me, his perspective,

strategic approach and compassion helped me find my breath and strength.

Prior to the transition, we had plans to grow our family and try to have another child. The added responsibilities and uncertain circumstances made it clear that it was not the “right time.” George reassured me that if growing our family caused too much stress or anxiety, having one healthy child is a blessing, and that he would support whatever direction I wanted to take our family planning. Since we both have older siblings, I wanted my son to experience life with a sibling. It was also clear to me that if we intentionally did NOT try to get pregnant, I would have a strong resentment towards my mom. This is something I knew I did not want. The confusion and frustration of experiencing a miscarriage was short lived. I was pregnant several months later. Our daughter, Eva Joy, was born in December of 2016.



Constant change. Life continued to be full. When my daughter was two months old, we transitioned my mom to an assisted living facility in California so that my family could have a break from caregiving to focus on our growing family and George's professional training. After three incidents of mom leaving the facility in five months, we moved her back to live with us. Responsibilities grew and changed with each additional family member, as each kiddo met a growth milestone and Mom's illness progressed. The weight of negotiating the relationship between my mom and other extended family members and friends continued to weigh on me.

The funny things about taking care of a parent and infant/toddler age children are the humorous and

*continued on page 13*

## CONSTANT CHANGE *(continued from page 12)*



sad parallels that come with it. Exploring childcare/preschool options for my son coincided with my search for adult day programs and potential residential living options for my mom. Finding someone to come into our home to assist with my mom's care paralleled our need for childcare. My daughter's interest in potty training began around the same time that Mom began using Depends. Never a dull moment. I am amazed to witness the growth and decline in life within our intergenerational family.

Even with a solid relationship with George, we couldn't do it on our own. We needed help. I needed help. Seeking professionals to work with us in or away from our home was a skill that we had to practice. Finding a professional to work with (whether a primary care provider, a therapist or a babysitter) is like dating. It takes effort, time and patience. I learned to rely on gut feelings and instincts at the interview stage.

Our partnerships expanded as our family situation changed. As I learned of each new resource, I was eager to make a connection to see how it may fit into our much needed support network. Friends and family would check in on us from afar, and yet I needed an actual community of people close by whom I can see and speak with in person. So, I leaned on the many new friends in NC—kind neighbors with generous hearts, other mamas from childbirth preparation classes or mom and baby circles, the staff and caregiver friends at Duke Family Support Program, Charles House Association and the Durham Center for Senior Life, the staff and family friends made at Beth El Preschool, Nounou's Garden and Learning Outside, former

coworkers from my time working at 9th Street Bakery and Whole Foods, the inspiring and motivating folks at the Durham and Chapel Hill/Carrboro YMCAs and all the other kindred spirits who lifted me up along the way. If someone was willing to listen, I was ready to share our situation and all its vulnerabilities, hoping that in doing so, I would feel lighter and not alone. And at the same time, if our situation can help others find perspective in their lives, even better.

George and I often reflect on how fast we "grew up" in this process of becoming parents and caregivers in such a short intense season of caregiving. Making decisions was often daunting, yet knowing what we did NOT want helped us move towards the best decision for our family in any given moment. Communication with



each other, with other caregivers in support groups and other experienced professionals in the elder care world reminded us that we needed to be fluid—to practice letting go and always be ready to shift.

It has been almost a year since we made the cross country move back to San Diego, where George is wrapping up his training. I'm thankful to say that we've found supports relatively quickly since our return. All that practice has been helpful. With Gus in transitional kindergarten, Eva at a preschool three times a week and my mom's schedule between the memory care adult day program and an amazing private care provider, I've been able to find a rhythm once more. I've made a space to process and grieve the loss of my mom and the relationship that I'll never get to have with her. What gives me hope are my relationships with my husband, children and friends, as they move towards continued growth, an expression of kindness and an exploration and appreciation of life.



# JUST BECAUSE

A timeless poem written by a 16-year-old granddaughter for *The Caregiver*, Volume 7, Issue 3 (1987)

One of my Grandmas  
Gives me hugs  
And sends cards in the mail  
On my birthday  
And sometimes  
"Just Because"  
One of my Grandmas  
Can't remember  
Who I am  
Or what day it is...  
So I give her hugs  
"Just Because"

The above well describes my feelings after my grandmother was admitted to a nursing home, and our family life was returning to normal. When my grandmother lived with us, giving her hugs was the farthest thing from my mind. I can vividly remember the tension level rising at our house after Grandma came to stay with us. I also remember the frequent arguments between my mom and dad over the care and workload distribution. My parents are the foundation of our family, and when they seem less stable, we children sense it. We knew that their arguments had something to do with this tall, gaunt and mysterious woman who followed us from room to room.

As a 10-year-old, I was angry at her for disturbing our family life, but mostly for monopolizing all my mother's time, energy and attention....I spent most of my time in my room or at play practice. Because we lived in the country, there were no

girls my age with whom I could talk and escape the constant questioning:

"Who are you? Why are you in my house? When do we eat?"

I not only felt angry but guilty...because of my negative feelings for her. I thought a girl my age and her grandmother should have this close, special relationship...

There were tender moments...like the times we would walk around the block, see a "Davis" sign and we would simultaneously break out into a chorus of one of the many poems she taught us:

"Fire! Fire" said Mrs. McGuire

"Where? Where?" said Mrs. O'Hare

"Downtown" said Mrs. Brown

"The Good Lord Save Us!" said Mrs. Davis

She recited poems like this up until her last days. They will always be a symbol of the enjoyment we gave to each other—her glimpses (however shadowed, cloudy or into the past) in exchange for the fun and excitement (however chaotic or hair-raising) a family of seven has to offer a polite, civil old lady.

When I remember my grandmother's poems, her dry wit and the times when our family all laughed (and in the end, cried) together, I can't help but feel a warmth and smile "Just Because".

**My mother, Willene, is 94 and she has dementia. Two years ago she dictated this letter to one of her caregivers as a birthday gift to me. I will treasure it always.**

*Dear Celeste,*

*Happy Birthday.*

*I love you very much. You are a very nice daughter. You are the best daughter that ever lived. You take such wonderful care of me. You do everything very nice. You wash, you cook the dinner and clean. I wouldn't change you for all the world, because you are so thoughtful. I do not know if it is out of place, but I hope you live to 100. That is a compliment.*

*Lots of Love,  
Willene*



# LEEZA GIBBONS: IN THE MEANTIME, PLEASE DON'T HARM YOURSELF

By Paula Spencer Scott

*Surviving Alzheimer's* (2nd Edition) 2018, pp 63-65

The TV personality and Alzheimer's activist wants you to do one thing today: Move yourself up to the top of your to-do list.

*The oversize kitchen of her airy Beverly Hills home shrinks to cozy coffee-klatch familiarity as Leeza Gibbons leafs through a family photo album. She laughs about a leopard-print bikini that was a favorite of her beautiful mother – “a cross between Jackie Onassis, Cher and June Cleaver” – who had insisted on packing it for her move to a care facility, “just in case.” And Gibbons tears up as she recounts the day that “sassy, sexy” and beloved woman no longer recognized her.*

*Hearing her authentic Alzheimer's tales, it's easy to forget that Gibbons is a media personality with a star on the Hollywood Walk of Fame, a face you first met in your own kitchen, on the TV screen when she was an “Entertainment Tonight” co-host and, later, host of her own talk show, “Leeza.”*

*“Don't hide it. Make it count,” Gloria Jean Dyson Gibbons had urged her journalist daughter upon learning that she the same disease that had killed her own mother. So Leeza, co-host of the daily syndicated TV news show “America Now” and “My Generation” on PBS (for which she won an Emmy in 2013) and the 2015 “Celebrity Apprentice” winner, did. She created the nonprofit Leeza Gibbons Memory Foundation in 2002. Its centerpiece: Leeza's Care Connection, community support and education centers for caregivers. In addition to hosting fundraisers such as the Dare2Care gala, she wrote *Take Your Own Oxygen First: Protecting Your Health and Happiness While Caring for a Loved One with Memory Loss*.*

*TV host Larry King describes the Alzheimer's activist caregiver advocate in terms anyone dealing with the disease would do well to emulate: “For Leeza, there is only one way to move, and that is forward.”*

**Mom first began showing symptoms of the disease when she was in her late 50s.** One day she confessed to my dad that she'd paid the same household bill three times. After that, we all started noticing things about her behavior that just “weren't Mom.”

**She started using profanity after never having cursed a day in her life.** She repeated herself. She made paranoid, outlandish accusations to my dad, saying that he'd never loved her and was going to kill her. (He adored her.)

**We thought maybe it was alcoholism, though she was just a social drinker.** We were in a state of denial. Maybe it was a combination of Dad covering up for her behavior and our not really understanding what was wrong. I guess none of us wanted to believe that our wonderful mother might have such a terrible illness.

**I wish I had known what a marathon this is.** Battling Alzheimer's disease is an endurance race, the likes of which I could never have imagined. My mom was diagnosed young, at 63. She died young, at 72. In between, as Nancy Reagan used to say, it really was the “longest goodbye.”

**This thief of life, thief of memories, isn't content to take just the diagnosed individual – it wants the whole family.** It can suck you into a deep, dark hole unless you take steps to bolster yourself physically, spiritually and emotionally. I was distressed to learn that stress-related disorders can take ten years off a caregiver's life, and that caregivers often experience so many stress-related challenges that they get sick and die before the one they're caring for.

**Compassion fatigue is a very real syndrome, and it can take down the best.** At Leeza's Care Connection, we say you should “take your oxygen first,” meaning: Nourish yourself before you take care of anyone else. Keep your body strong. Give your soul some strength, too. Take a break. Forgive yourself, forgive others. Do those things first.

**The ultimate love and selfless act is to first love yourself enough to care for yourself.** Think of it as an investment that will allow you to love and support the person who's sick. When I felt my reserves were depleting, I'd remind myself to stop achieving and start receiving.

**The caregiving challenge became hardest for my father, as my mother's disease progressed.** I worried about Dad when Mom could no longer express her appreciation or her love but

*continued on page 18*

## BOOKSHELF

**Alzheimer's Disease and Dementia: What Everyone Needs to Know** by Steven R. Sabat, 2018. Sabat is known for his research on the remaining cognitive and social strengths of people living with dementia. In this book he covers biological aspects of Alzheimer's, as well as the subjective experience of living with Alzheimer's; and he reminds readers of the "respect and empathy owed to those living with dementia."

**The Art of Dying Well: A Practical Guide to a Good End of Life**, by Katy Butler, 2019. The Art of Dying Well is a well-organized and easy-to-read guidebook to, "living, aging, and dying with meaning and even joy." Based on Butler's experience with her parents, as well as interviews with medical experts, the book is simultaneously spiritual and practical.

**The Book of Joy: Lasting Happiness in a Changing World** by Dalai Lama, Desmond Tutu and Douglas Carlton Abrams, 2016. To celebrate his 80th birthday, Tutu visited the Dalai Lama in India. From the visit came this dialogue on where and how to find joy. Sometimes joy is hiding in the most unlikely places.

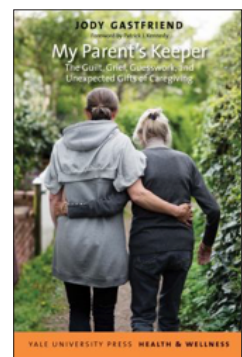
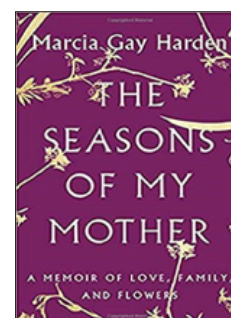
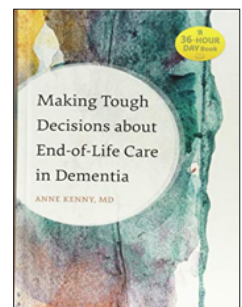
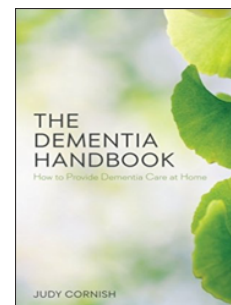
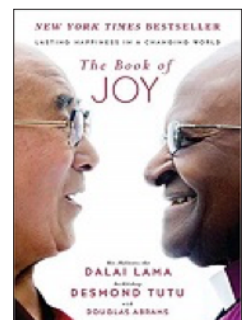
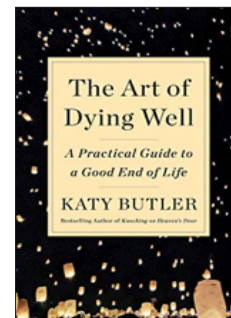
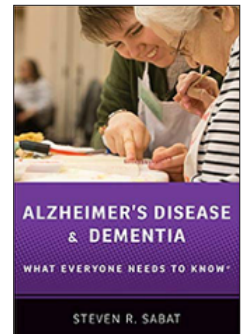
**The Dementia Handbook: How to Provide Dementia Care at Home**, by Judy Cornish, 2017. The author has identified a pattern in the abilities and disabilities of people living with dementia. Based on her findings, she developed methods for caregivers to ease emotional distress, aimed at resolving behavioral complications.

**Dementia Reimagined: Building a Life of Joy and Dignity from Beginning to End**, by Tia Powell, 2019. Powell, a physician and bioethicist, focuses much of Dementia Reimagined on the disturbing history of how cruelly people with dementia have been viewed and treated. She weaves in personal stories, including her own feelings of vulnerability due to her family history, along with research topics and policy considerations. Towards the books end, Powell discusses some practical caregiving strategies and her goal of making life with dementia a little more joyful.

**Making Tough Decisions about End-of-Life Care in Dementia (A 36-Hour Day Book)** by Anne Kenny, 2018. The author, a palliative care physician, describes how to navigate the difficult journey of late-stage dementia. Dr. Kenny offers practical advice based on her personal experience caring for a mother with dementia and her professional knowledge of dementia and end-of-life care.

**My Parent's Keeper: The Guilt, Grief, Guesswork, and Unexpected Gifts of Caregiving** by Jody Gastfriend, 2018. This book offers guidance for a broad range of caregiving situations when family caregivers assume their new role. It is a blend of stories and practical advice.

**The Seasons of My Mother: A Memoir of Love, Family, and Flowers**, by Marcia Gay Harden, 2018. We have seen her on the screen but now readers get a glimpse into her mother's life with Alzheimer's disease. It has been described as, "powerful and stirring."



# BOOKS: WHERE THE ELDERLY FIND HAPPINESS

By Kim Blanton



Aging is not, as the cliché goes, for the faint of heart. If a woman makes it to 65, she can expect to live at least 20 more years. Three new books written by or about older adults provide a wonderful roadmap to aging with grace, introspection, gratitude, and humor.

## **“Coming of Age: My Journey to the Eighties” by Madeleine May Kunin**

The former Vermont governor and ambassador to Switzerland has authored books about politics, feminism, and women as leaders. In her new memoir, she has blossomed into an essayist and poet. Kunin, who is 85, muses about defying “death’s black raven” on her shoulder. The color red is one way to achieve this. She bought a Barcelona Red Prius (easier to find in the parking lot), and then she and her late husband, John, purchased two oversized red armchairs. “I wanted to bring life inside—not leave it outdoors. And the red chairs did exactly that,” she says.

In her poem, “I Loved You When You Did the Dishes,” she writes tenderly of John—first as a robust partner, then as a dependent, and always as “the man of my dreams.” Old age has given her permission to let down her guard, which she did not do as a public figure. Now she discloses private matters like thinning skin and her pain when, as a young legislator in the 1970s, male colleagues didn’t take her seriously. But she invariably looks back on her life with humor. Kunin tells one

anecdote about ducking into a men’s bathroom to avoid the long line for the women’s room. A man who recognized her immediately said, “I never thought I’d meet the governor here.”

## **“Women Rowing North: Navigating Life’s Currents and Flourishing as We Age” by Mary Pipher**

Early in her book, Pipher borrows a novelist’s words: “Old age transfigures or fossilizes.” Pipher, who is a psychologist, urges women to aim for transformation or “willing ourselves into a good new place.” The most important thing, she says, is to keep moving along, upriver – memory loss, muscle loss, and stereotypes be damned! Each chapter is a roadmap to that good place: Understanding Ourselves. Making Intentional Choices. Building a Good Day. Creating Community. Anchoring in Gratitude. In the chapter Crafting Resplendent Narratives, she advises readers dealing with difficult situations to “honor our pain and move toward something joyful.”

Pipher admires a woman named Willow, caregiver to her husband with Parkinson’s. Willow wakes up every morning looking for ways to make him laugh. But I often found myself skipping past these anecdotes about other women in the book to get to the next batch of 71-year-old Pipher’s insights. “I argue that neither our genetics nor our external circumstances determine our happiness,” she writes. “Rather, happiness depends on how we deal with what we are given.”

*continued on page 18*



## BOOKS *(continued from page 17)*

Every January, the writer refreshes her own narrative about her life when she and her daughter-in-law escape to a retreat. Her book ends with the comforting thought that we are accompanied on our journey into old age by spouses, family, friends, and grandchildren.

### **“Happiness is a Choice” by John Leland**

Okay, elderly men find happiness too. To research his book, Leland, a New York Times reporter, whiled away hours and hours in the company of six men and women in their 80s and 90s. Fred Jones, an 87-year-old World War II veteran, has had more than his share of hardships, but age has given him a kind of happiness that the young, with their eyes on the future, can't grasp: Happiness, he says, “is not the dance you're going to tonight. If you're not happy at the present time, then you're not happy.” Leland explains how seniors use selective memory to overcome the inordinate losses they experience – the deaths of spouses, siblings, and friends. John Sorensen,

also profiled in the book, had a 60-year relationship with his former partner but can remember only a single argument in all their time together.

The only couple in the book are Helen Moses and Howie Zeimer, who fell in love in the nursing home. Leland struggles to understand why Helen's love grows as Zeimer becomes increasingly disabled and dependent on her. “The less capable Howie was, the more she could do for him ... the more she got in return,” Leland writes. The biggest lesson for readers from his time with these people is about “what it means to be human. Old age is the last thing we'll ever do, and it might teach us about how to live now.”

*Reprint permission granted by the Squared Away writer Kim Blanton and the Center for Retirement Research at Boston College. Squared Away is a personal finance, retirement and research blog at the Center for Retirement Research at Boston College.*

## LEEZA GIBBONS *(continued from page 15)*

instead lashed out with anger at almost everything. I worried about Dad when Mom would turn around in the kitchen with a spatula in her hand and start swinging at him. I worried about Dad every night when he would go to his room and close the door, knowing we were losing him along with my mother. They were married for 55 years, but ten of them were stolen by Alzheimer's disease.

If you tore a page from my diary from this period, it would be shocking. Every day I felt frustrated by some new change or behavior. I'd lose my temper. I'd make mistakes. I'd feel overwhelmed. I was snapping at my kids, getting distracted by everything. I began to wonder what on earth had happened to the old me and if she was ever going to return.

Nobody is a natural-born Florence Nightingale or Mother Teresa all the time. I know I wasn't. I'd look at other people and think they had so much wisdom and patience, and then there was me. I was so not those things! But I learned that no one takes their first step on this path with all the answers. Heck, I didn't even know most of the questions.

Here's the thing: Being a caregiver allows you to either come face-to-face with the truth that we are all perfectly imperfect, facing vulnerabilities that are better handled with support – OR you can use your situation as a reason to prove that life isn't fair, that no one understands, and that you have to do everything yourself.

Guilt can become a constant companion. I've never met a caregiver who didn't feel some of it. So recognize it and let it go. When I was with my mom, I felt guilty that I wasn't going to see her enough. When I was away from her, I felt guilty for not being there. If I was out laughing and enjoying my life, I'd feel guilty because I knew Mom couldn't enjoy her life. If my sister was spending time with Mom, I'd feel guilty. I'd even feel guilt because I was healthy and she was sick!

It helped me to repeat to myself a little mantra I made up: “I love my mother. I'm doing the best I can.”

*Reprinted with permission from Paula Spencer Scott, author of Surviving Alzheimer's (Expanded 2nd Edition, 2018)*

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