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On Eagle's Wings: A Caregiver's Story

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Increased attention is being focused on the *Sandwich Generation*, a rapidly growing subset of the adult population usually in their 40's to 60's who are the primary caregiver for children under the age of 18, as well as an aging parent(s). The pull between the two generations is one of the greatest struggles facing mid-life adults 'sandwiched' between caring for their developing children and their aging parents. The delicacies of balancing logistical and emotional resources among the generations can be overwhelming for sandwich generation caregivers. The resulting stress on caregivers is related to higher absenteeism from work, levels of depression, chronic fatigue, and increased rates of job burnout. As life expectancies continue to increase and parenthood continues to be delayed, more adult children will find themselves slung precariously in the middle of caregiving for people at opposite ends of the lifespan. What follows is a personal account describing the day-to-day challenges, grief, and role-reversals that are common among sandwich generation caregivers. This work aims to provide the reader insight into the unique lived experiences and delicate nature of caring for loved ones at opposing ends of the life-cycle.

KEYWORDS: Sandwich Generation, caregiving, aging parents, anticipatory grief, death and dying, family therapy, family life cycle

A Caregiver's Story

In the fall of 2015, my husband and I made a major life decision to move from our home of nearly twenty years and relocate our family to the front range of the Rocky Mountains. We were moving away from our extended family and friends in the Southeast while in the throes of mid-life and all the typical life-cycle issues that go along with it; rearing our three young children, debating career choices, and tending to a 15-year marriage. What I did not know as we drove the 2000 miles towards a new life, was that within two short months I would be facing what so many adults in mid-life also contend with, the additional role of being the primary caregiver for an aging parent.

With boxes still to be unpacked and my children not quite settled into their new schools and friendships, it was unexpectedly necessary to move my father to Colorado from his home in South Carolina. With the blink of an eye, I had joined the roughly 41 million Americans in the Sandwich Generation, a rapidly growing subset of the adult population usually in their 40's to 60's who are the primary caregiver for children under the age of 18, as well as an aging parent (Stepler, 2015). As life expectancies continue to increase and parenthood continues to be delayed, more adult children will find themselves slung precariously in the middle of caregiving for people at opposite ends of the lifespan.

Upon my father's arrival in Colorado, I made the decision to put a stop on all efforts to finish getting settled into our new home. Instead, I chose to romp around town with my dad in tow getting to know all the best coffee shops, book stores, and French bakeries, the things he and I love best. I delayed pursuing new friendships so I could be fully present in this unique time with my father. He and I have always had a close bond, which has become especially deepened during my adult life. Yet we had not spent time like this before: just the two of us, for weeks on end, spending

all our hours alone together. My children were in school, I had not yet enrolled in graduate school, and I savor the wisdom I had to put my focus on time with him. He lived in our spare bedroom, and he and I cooked dinners together, ran errands, shuffled kids to after school practices and games, he became the sixth member of our household.

As much as he and I laughed and joked, our conversations were often heavy. We were both grappling with his recent diagnosis of Progressive Supranuclear Palsy (PSP), a rare and untreatable brain disease affecting speech, balance, and executive functioning. His condition was changing before my eyes, and in addition to helping my family adjust to our new surroundings, I was careening into the new and unexpected territory of grieving the loss of the father I had known. The literature on grief calls this type of grieving *anticipatory grief* (Holly & Mast, 2010; Meichsner & Wilz, 2018) which is common among caregivers of loved ones with diseases like Alzheimer's or other terminal illnesses such as cancer. Anticipatory grief, also referred to as pre-death grief, occurs while the person you love is still alive, but their personality and character are wasting away. Proper terminology aside, I called what I was experiencing a *living-loss*. A death before death.

I consciously dedicated myself to him while he lived in our home, with an awareness of the uniqueness of this time together. I considered this period a gift. Even so, the reality of maintaining this level of care long-term was starting to formulate in my mind. My husband and I were beginning to feel the strain of having a constant houseguest and were becoming more agitated by the disruption to our daily patterns. My children were experiencing what it means to share their mother's attention, which they tolerated with mercurial understanding. Over time I stopped taking my dad on errands because as his walking slowed, there was no appropriate way to hurry him along. When my children doddle I grab their hands pulling them along, but I could not do this with my father. I felt awkward leaving him at my house unattended too long for his own safety, but also to protect him from any sense of loneliness as he grieved the changes occurring in his life. Consequently, my errands were rushed, and I did not exercise regularly or see friends, all in the name of coddling him through this new life phase.

And I must explain that this is not a man to be coddled. I am the third of my father's four children, and he was an involved and expansive figure in our lives. He was dashing handsome, a French professor, a musician, and outdoor adventurer, and a lover of antiques and poetry. He was strong and could build anything from a lawnmower engine to a house. His students called him Dr. K., his grandchildren call him Poppy, and because we are from the South, I call him "Daddy." His nick-name among friends is Bahama-Bill from years of sailing around the islands of the Bahamas. There was salt in his veins, and he lived his life fully and intentionally. He had a quick temper, could be notoriously nit-picky and was a perfectionist to an almost crippling degree. His temper mellowed in his older years, and he savored getting to spend time teaching all the things he had taught us kids to the next generation, his grandchildren.

The Canary in the Coal Mine

One afternoon, while he was still living with us, I escaped to my room to have some down-time and read. What followed was one of the most poignant moments of my time with him that fall. I was reading Dr. Atul Gawande's *Being Mortal* (2014), a valuable contribution to literature on modern medicine's influences on the way our society approaches aging and dying. At one point, Gawande, a surgeon, follows a geriatrician who describes how elderly patients often slowly lose the ability to tend to basic grooming and hygiene needs but rarely alert outsiders to this decline.

The geriatrician assesses his patient's bare feet to get a full picture of their ability to care for themselves. Long toenails signify not only the obvious, that geriatric patients can no longer bend over to reach their feet, but they likely cannot put socks, shoes, or pants on without great difficulty either. Long toenails are the canary in the coal mine, indicating a decline in the ability for self-care such as personal hygiene and grooming for older adults.

Without even finishing the page I was reading, I ran downstairs to inspect my father's feet. But once I arrived by his side, I had no idea how to ask him, the man who had taught me to drive a car, sail a boat, and build a campfire, if he could still cut his own toenails. I knelt down beside his chair, put my hand on his hand and softly said I wanted to ask him a funny question: who cuts your toenails? Fran, his wife. But he had not seen her in over two months. May I look at your toenails, I asked tentatively. I reached down and slipped off his shoes and socks.

Oh, Daddy...look at your beautiful feet.

There I was holding my father's still youthful, soft, tanned feet in my hands. I had always thought his feet were beautiful and was overwhelmed by their seemingly unchanged handsomeness when so many other aspects of his appearance had morphed into something I had difficulty accepting.

May I cut your nails for you?

As I approached him with nail clippers in hand, I realized I had no idea how to cut an adult's toenails. My children are young enough that I still oversee many aspects of their grooming, including cutting their nails. How though, was I to do this so my dad did not feel ashamed or embarrassed. How do I do this and let him keep his dignity? I did not have answers, so I followed my instincts, sitting on the floor beneath him, resting his beautiful feet with over grown toenails in my lap. As I trimmed his nails, I felt the unwanted prick of tears, threatening to spill down my cheeks. I was humbled by the changing of the guard. I was honored to perform this simple yet meaningful task.

I asked him if he could still get his socks and shoes on easily. He said it was not "easy." How do you handle getting your pants on? *With great difficulty*, was his only reply.

I had the sense, sitting with my father's feet in my lap, that there was so much he was keeping secret. That day I did not press him about other difficulties he may be disguising from me, privileging his sense of dignity over truths.

Role Confusion: Reversals and Dualities

My father has now been living in Colorado for three years, most of which he has spent in an assisted living facility 10 minutes from my home called Mountain View Senior Living*. As his disease progressed, his care needs became more significant than what my husband and I could safely offer him in our home, and we made the difficult decision to move him into a facility nearby. I have the name of his assisted living facility programmed into my phone and without fail, each time I see *Mountain View* on my caller ID, a feeling of urgency mixed with dread runs through my body. Worse still are the middle of the night phone calls to the house. I did not consider that as a caregiver for a declining parent I would be on eternal night watch, similar to my daughter going away to sleep away camp for the first time, but very, very different. When the phone rings in the middle of the night my body goes from a state of deep slumber to Olympic long-jumper in an amount of time too small to measure. With a kid at sleep away camp, when the phone rings in the middle of the night, you imagine your child throwing up or terribly homesick. With a 3am phone

call from Mountain View, you think only one thing; this will be the phone call that I learn my father has died.

The phone calls have been about falls my father has had in the middle of the night, resulting in bumps and bruises, minor skin lacerations, and occasionally something more serious. It is a standard procedure for assisted living facilities to notify the family when a resident has fallen, even if there is no significant injury. The most recent call was at 4:30am, and though my father was not injured, I could not calm my mind and lull myself back to sleep. My heart was racing, and my limbs were full of nervous energy. The same thought keeps circling in my mind; after three years of caretaking, I still have not gotten used to the parent-child role reversal.

My notion of caretaking for an aging parent before being in this role involved buying groceries, paying bills, or driving a parent to a doctor appointment. Those *are* parts of caretaking, but they are logistical elements of care, not the emotional roller coaster ride of becoming the *parent of your parent*. I did not dream of having to confront my father about his behavior at mealtimes in the dining room or how he treats the staff at Mountain View. Getting a phone call from the director of Mountain View about his disruptive and disrespectful behavior towards the care staff feels like getting called to the principal's office. Actually, having the follow-up conversation with my father regarding his actions and attempting to influence his future behavior by discussing the consequences, which include eviction, is a stomach-turning task. The role reversal becomes the most delicate dance adult caregivers have to navigate. There is a keen awareness that in fact, this is not a role reversal, but a *dual role*. You are your parent's adult child, wanting shelter from the storm on their shore. Yet also sensing that you must find the strength to become the lighthouse for you both. I often feel overwhelmed by the precarious position of parenting my father while simultaneously remaining his child.

The Dark Secret

The dark secret is that I want to be the child. No dual role. Often when I am with my father I will ask him, am I doing this right? Do you feel my love, do you sense my hesitation to correct your misbehavior? I feel myself almost pleading with him for validation, to say that he senses my best efforts to move through this phase of our relationship with grace. But he does not know how to be in this new version of our relationship either. He also would say No Dual Role if he could. Neither of us is comfortable with this new dynamic. Just as I want to be his daughter, asking for advice and seeking comfort in his presence, he wants to continue being the father who has been my teacher with wisdom to share for over 40 years.

The understanding that I was to be both daughter and guardian became clear to me during the second holiday season my father was in Colorado. He had gotten the flu and been hospitalized and was recovering in a rehabilitation center which was a dismal place with dank carpet and bedspreads in tiny rooms with wall-mounted TVs. I visited every day during the holidays but was unable to take my husband or children as the rehab center had a Norovirus outbreak limiting visitation. I was his only visitor for almost three weeks, and he felt the isolation. The holiday season made the visits particularly dreary...so much festivity and life outside, so much stillness and staleness inside. With few remaining holidays for him, there was a sense of injustice in the air about missing this one. He was weak and drowsy, so we spent a lot of our time without talking. I was sitting in a small circle of lamplight in his dark room when I accidentally knocked his Day-Timer off the nightstand. There is not much to record in a weekly calendar when your health is failing, and you rarely leave the assisted living facility in which you live. Yet as I picked his pocket-sized

calendar up from the floor, I saw tiny, barely legible scribble on many of the pages. Looking more closely, I saw that it was my name recorded on so many of those pages.

Heather called today.

Heather visit today.

Heather in class tonight.

Heather will call today.

Heather brought kids to visit.

The weight of my importance in his life moved through me like lead...heavy and thick. It was too much responsibility to be that significant in my father's life. How could it be that I had become his whole world? I selfishly wanted to be the child in this story, the one who gets to depend on my parent's stability to feel safe. The more pages I flipped through, the more the tears welled up, and I felt my chest heaving under the weight of this discovery. I did not cry in front of him that evening. I waited until I got in my snow-covered car in the parking lot, thankful for the anonymity provided by the dark night sky as I sat crying in the cold driver's seat. The tears ran and ran, fueled by guilt about my selfishness. But also, by the honor of being the person to support my father at the end of his life. Honor and guilt are odd bedfellows and make a shaky platform on which to stand. I was starting to understand that I have to make room for both, honor and burden, accepting the shakiness below my feet.

Grief Wins the Tug-of-War

Many difficult months followed his bout with the flu, and I fell into a constant state of grief. I was losing him by inches. He and I talked about end-of-life issues such as the reality of a feeding tube as his disease robbed him of the ability to swallow, and the details of his wishes for his funeral service. We were dealing with challenging topics, and it was increasingly more difficult to have these conversations with him and then run home to parent my children in the patient way they were accustomed to. I was not emotionally or physically able to be the parent I prided myself in being. The children and I talked often about death and dying, and about what was making me feel so sad and move so slowly.

On the one hand, they understood why I was behaving so differently. On the other hand, my children are young and expect their mother to be fully present with them and shelter them from this frightening and confusing discussion about death. The pull between the two generations is one of the greatest struggles facing mid-life adults 'sandwiched' between caring for their developing children and their aging parents (Boyczuk & Fletcher, 2016). For whom is it "okay" to forsake attention when deciding whether to miss your child's solo in the school play or attend a parent's necessary doctor appointment. There is no satisfactory answer to this question, and caregivers suffer greatly under the stress with higher absenteeism from work, levels of depression, chronic fatigue, and job burnout (Steiner & Fletcher, 2017; Evans et al., 2016). Researchers interested in this stage of the life-cycle make a case for further study of sandwich generation caretakers and their unique lived experiences. As I walk a time-management tight-rope attempting to give the people I am responsible for the attention they deserve, I agree that understanding the delicacies involved in sandwich generation caregiving needs more attention.

In my home, my children feel frustrated when I have to *leave again* because Poppy needs something. They want me to stay and make the gingersnap cookies I had promised we would bake. My father has never asked that I see him more often, but I imagine he wishes I could see him daily. I am not the only member of my family feeling the tension with the increased responsibilities. My

husband struggles finding ways to contribute, already juggling a demanding career and being an involved father. I see it in the children too as they experience guilt when they resist visiting their grandfather. They love him, *and* they want a break from taking care of him. I understand completely.

In the late spring, my dad and I had a lengthy discussion with a social worker about some of his legal documents, including his living will and my position as his health care power of attorney. He was quiet during the conversation, and I felt like I had to lead him gingerly through it. When the social worker left, I let silence hover in the room. In the stillness, I felt the weight of my emotions *and my father's* pressing down on my shoulders. How surreal it must feel to him to be sitting in this room with a stranger, the social worker, and his daughter, discussing the end of his life? I only knew what I felt in that moment, and in an instant, I decided I would be my father's child, and let my feelings flow through the room into his ears and into his heart. Young children lead with an unembarrassed vulnerability, and in this instant, I felt that was how I would move forward on this difficult topic.

With a shaky voice, I told him how hard this conversation is for me. That this is all hard for me. *I know I can't even begin to understand what it feels like for you. I imagine what it is like for you, but I wish that you could tell me how you feel. I wish you still had the words to express yourself. I would sit patiently and listen attentively. I miss our conversations, and I know if you were your old-self, we could talk frankly about your death. I love you, Daddy. I wish your disease did not take so much away from you. I wish I could see you more often and not be rushed when I do see you. I wish I weren't juggling so many responsibilities. I wish we were still sailing on your boat together. I wish you were still giving my kids piggyback rides. I wish we could still talk about books, and music, and hiking the Appalachian Trail.*

I did not parent him by protecting him from the sadness and bulkiness of my feelings. I was his daughter and let him be the one to hold my fears and sadness. And just as I decided to be childlike in my vulnerability, he chose to be my shelter and reached out with an unsteady hand to wipe the tears from my face and managed to say, "don't cry." With his diminished speech, his two small words were magnified in their meaning. At that moment, I felt we were both grateful to let him comfort me, let him be the parent a little while longer.

Processing a Deluge of Emotion

I see a wonderful therapist regularly and with great wisdom she suggested that each time I leave my father, I take a moment to sit in my car and put the emotions I am feeling in a "box." The intention of this practice is to be present in my emotional experiences as a caregiver and give validation to whatever feelings I am experiencing that day. This type of emotional processing is precisely what Meichsner and Wilz (2018) outline as beneficial for caregivers to positively cope with anticipatory grieving.

The box that came to mind is antique, small, and steamer-trunk-like with leather and metal embellishments. Now when I leave my father, I pause for just a few moments to place my feelings in this imaginary, yet sacred, box. Before the idea of the box, I would often get in my car and speed off to the next obligation without even acknowledging the pit in my stomach. I buried the daily heartache of watching this man I love so dearly fade from my life. There were days I pulled up in the carpool line having quickly done a mirror check before my kids got in the car to see if it looked like I had been crying.

Now when I leave my father, I sit with my tears, letting them pool in my lap. When I am ready, still sitting in the parking lot of Mountain View Senior Living, I gather up the tears pouring them in my treasure chest of experiences; a mounting collection of sadness, tenderness, and small gifts of connection.

Talking about Death and Dying

One day recently my youngest daughter, who is ten years old, and I spent a sunny afternoon visiting my dad. It was an ordinary visit, time to say hello and be together. At the end of our visit, it was dinner time at Mountain View, so we wheeled him to his usual table in the dining hall. My daughter instinctively got out the special clip used to attach a cloth napkin around his neck, like a bib, to catch the dribbles of his puree-dinner. As I watched her tenderly care for her grandfather a wave of sorrow ran through my body. There are small gifts woven into many aspects of tending to someone in this way. This intergenerational exchange was a bittersweet gift. While it was a valuable experience for my daughter to care for her grandfather, the image of my father in a bib, no longer able to eat solid food, was a sight my mind and heart could not reconcile. We each gave my dad and kiss on his unshaven cheeks and waved goodbye as he hunched over the table, slurping his meal. There he sat, a thin ghost-like figure reminding me vaguely of the father I used to know.

As my daughter and I walked to the car, she put her still small hand in mine and asked, "Are you okay, mommy?" Seeing my daughter's compassion for her grandfather, and the reminders of his deteriorating condition was too much that day, and I felt humbled by my sadness. My daughter felt it also and with tears, she looked at me and said, "I feel sad about Poppy too." And so, it was on a beautifully sunny Sunday afternoon that she and I stood holding each other tightly, in the parking lot, sharing in our sorrow. Sometimes I laugh ironically to myself at the amount of emotion that has spilled all over that paved parking lot at Mountain View Senior Living.

Once we were in the car, she cried freely, as children tend to do, and explained that she does not have any friends to talk with about her sadness. She recounted emphatically that her 4th-grade friends do not know what to say to her when she feels sad about Poppy. "Mommy, my friends do not understand what this feels like. Well, actually, one friend said she did because her dog died last year and she still misses him. That made me feel a little better, that she could understand."

I commiserated with my daughter about how similarly I feel with my peers. It is challenging to find social support on a topic that invokes fear in so many adults. Many people "check in" with me on my dad's health, but do not inquire about my emotional experience as it relates to him. For many people in my life, allowing me the space to talk about what it is like to watch my slowly dying father is too intimate, and for them, only a frightening abstract conversation. As a sandwich generation caregiver, very few of my peers have lost a parent. In fact, the majority of my friends' parents are still enjoying the freedoms and joys of retirement. As Atul Gawande's stories plainly illustrate, most of contemporary western society does not have the language, or even the emotional availability, to discuss death. My daughter and I discussed how difficult it is for other people to understand the constant nature of our sadness, how it persists most days without a "fix." She and I both felt comforted by our shared experiences related to my father's decline, and as a parent, I was grateful for this profoundly connecting time with my young daughter.

The Dream

In the first few weeks of my dad's arrival at our home three years ago, I had a dream that is as vivid to me now as it was the night I had it. That night I awoke shaken and unsettled from the prophetic nature of the dream. The dream takes place high on a plateau, like the ones found in the Utah desert, hundreds of feet high with expansive panoramic views of the dramatic landscape. In my dream, there is not another living thing present, just my father and I walking silently towards the edge of the plateau. It is a cloudless day, a bluebird sky, and the air is warm with a heavy breeze. I feel resolute, yet calm, as I walk a few steps in front of my father. I feel his presence behind me, though I have a sense of being on a solitary march. When we get to the cliff's edge, I stop. Just beyond our feet, the sand and dirt drop away falling dramatically down to the dry desert below.

Standing at the very edge, I turn to him.

Come on.

Those are my only words. *Come on.* I say it gently and with invitation in my voice, but also with resignation for the task at hand. No anger, no resentment, no fear. The wind is whipping my hair, and the warmth of the sun on my skin feels comforting. There is a sense of clarity in the air. At that moment, without hesitation, I leap off the edge of the cliff and unfold majestically, silently, and with utter beauty into an eagle. My wings are made of sheer strength and span with immensity into flight over the valley below. And that is where the dream ends. I do not know if my father climbs onto my back and we soar over the valley; if we succeed in our flight together. I do not know for how long, or how far, or how gracefully I carry him. I am left to guess at the ending of the dream, hoping that I soar, carrying my father on eagle's wings.

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