

## **The key selling points of “9 Realities of Caring for an Elderly Parent” include:**

- \* Ms. Shaffer’s true story is by turns gripping and hilariously funny, tender and no-holds-barred and will resonate with the 43.5 million American adults providing care for loved ones today.
- \* “9 Realities” gives caregivers an honest, straightforward account of what they can expect and how to handle their parent’s end-of-life issues.
- \* It also provides detailed, actionable advice on topics such as how to set up an accounting system for all care-related expenses, how to purge a parent’s house of a lifetime of belongings while still preserving memories, the best way to handle interactions with medical professionals and family, and insight as to why grief counseling is exceptionally important to the adult orphan entering a new disorienting stage of life.

## Key Talking Points

1. What were the thoughts that led you to share your experience of caring for your elderly mother?

I could not escape the nagging feeling that I wished someone had sat me on a stool to share with me the realities of what goes into caring for an elderly person. There was a lot to manage even before my mother fell into a decline. The constant worry I had of when the next fall was going to lead to a head injury or a broken hip really made me aware of how fragile seniors can be. It never occurred to me I would be dealing with home repair issues typical for old houses, plus shuttling back and forth to doctor appointments, and more importantly, spending years sleuthing through 85 boxes in the garage to figure out where her assets were. I finally felt compelled to demystify what goes on behind the scenes of elder care so other Baby Boomers will know upfront what lies ahead.

2. What was the hardest part of crafting this memoir?

My greatest fear was that I would forget my mother's voice and the Mom-isms she would frequently utter. The pain came flooding through, but there were also really funny memories that made me laugh so hard, my grief broke for an instance. Writing the death and dying scenes were cathartic, and excruciating. I cried for several hours as my fingers scampered across the keyboard to keep up with the words rushing out of my head. Doing research was also time consuming since I write about getting legal documents in order. I needed to be precise in my language before I was comfortable getting legal eyes on the final read to make sure I got it right.

3. Did you leave anything out during the edit that you regret losing?

There were several pieces that were cut after trimming 15,000 words. Thinking back I can't even remember what they were, but there is one scene I advocated for keeping because it is such a frightening reminder of how vulnerable seniors are when left alone. I still have no explanation for how an emergency 9-1-1 call was placed to our home at pre-dawn. The real-life scene continues with the police showing up ready to break down the door because I was afraid they were post-Halloween imposters. At the time, my bedbound mother was in a coherent state, but quite weak, her muscles atrophied. When I discovered the call came from within the house, inside my locked den, from a secondary number that was rarely used, we all expected to find a burglar inside. With guns un-holstered, it played out like every scary babysitter movie I ever saw as a teen. I shudder to think of the many ways it all could have gone terribly wrong.

4. What were some of the most surprising realities you learned, aside from home repair?

I learned that seniors are on rosters of rotating doctors that require nearly weekly appointments for some kind of check up. Whether it is for a hearing appointment, or bone density test, or blood work, or eye doctors, it is constant running, much like what I imagine moms do for kids with after school extra-curricular activities. I learned that a bed bound person requires diapering, something I hadn't done since I was a babysitter for kids in our neighborhood thirty years earlier. I learned that without long-term health insurance, the night nurse duties fall to you. I also learned that not everyone wants to visit your elderly parent when they are sick because it is too painful—for the visitor. Some people expressed to me that they just wanted to

remember my mom the way she was before her decline. But, hearing is the last sense we lose before death, so patients know who has come to visit.

5. What is the biggest problem that elders face, in your opinion?

Elders who cannot see very well, or hear very well, or are unsteady in their balance are particularly vulnerable, but they can still feel fiercely independent, as my mom did. Ninety percent of elders in surveys through AARP research will say they want to remain in their own home, but if they do not see well enough to cook, or hear well enough to answer the door or telephone, it can be very isolating. It is also very taxing to maintain upkeep on a decades old home. A senior needs regular contact with someone who is laying eyes on the scene inside to determine what the senior is eating, and what kind of condition they are living in, and what kind of personal care they need. A senior who no longer drives is even more reliant on a steady stream of supporters.

6. How would one be able to determine if their parent is still safe in their own home?

There are specific warning signs in a checklist from the Aging Solutions website with the top ten questions you need to know the answers to if you want your senior to be safe at home. Chief among them does your elderly parent turn on the stove and walk away? My mom would take naps while pots sizzled and hissed melting upon burners hours later. Does your elderly parent know how to exit the house and return? Does she know how to make an emergency phone call? Is your elderly parent able to prepare meals; my mother was spoon-feeding herself from a jar of Ragu and calling that dinner. Does your parent look clean or is she wearing a threadbare robe

with coffee splatters and Ragu drippings all up and down the front? Is the house overrun with ants or critters? These are things you will not know if you are long distance, or not within those walls. There is a lot my mom was trying to hide from anyone who wanted to visit, so she would wait on the bench outside for her friends.

## 7. Who should be caring for our elderly?

My first thought when I drove up to my dilapidated childhood home after being away for years was, “Why aren’t the neighbors doing more to help?” I could not believe that they would allow our front yard to look like an overgrown savannah with weeds and peeling paint that made the curb appeal less than appealing. After my first few months on the job, I realized quickly that this is a job for an insider. After the first time my mother fell in front of me, landing her in the emergency room, I knew that she would not have lived through it had she been alone in her home that Saturday night. The next day I inspected the entire house for tripping hazards, like looped rugs to catch lazy toes, and sharp edges of marble coffee tables. These were just bloody foreheads in the making as far as I was concerned. Since AARP projects that by the time Baby Boomers are in need of elder care, we will outnumber the caregivers available. Sad, but true, the job of caring for an elderly parent, or an elderly spouse, will likely fall to a family member.

## 8. What are the first steps to take as the adult child coming home to care for an elderly parent?

Step 1: Check to see what legal documents are still not in order. The starter kit of four includes: an Advanced Health Care Directive, a Power of Attorney for Finances, a Will, and a Trust.

Step 2: Determine how safe the home is by looking for tripping hazards, sharp corners on tables in case an elderly parent falls down, and analyze the meal prep pattern and medicine routine. Is the elder able to see well enough to self-medicate or will she accidentally overdose because she can no longer read labels.

Step 3: Know where the assets are held. Many seniors hide money in the house. I wish that all of our assets had been in one place, with a tidy little bow around them. I would have avoided the scavenger hunt I endured for years gaining access to many different safe deposit boxes, and poring through two hundred empty cartons of checkbook boxes after the first one I un-lidded had fifty dollars tucked away.

9. How does a caregiver find support and relief? What did you do?

I was absolutely exhausted all of the time. Before my mother's decline, I tried to enlist help from one of the popular services advertising senior companionship. The problem I kept running into is no agency would be willing to administer insulin shots for my mother's diabetes. I had no relief because of this. I could not afford a nurse to come and administer twice-daily shots.

I had no idea how the stress was impacting my body. During the last part of my mother's decline into dementia, I was constantly worried and anxious. I was still teaching seventh graders in the daytime when our caregiver would stay at home, until I returned after school and then took over night nurse duties because we still could not afford round the clock care. People kept telling me I was wearing my shoulders as earrings. I didn't understand what they meant until they would physically push my shoulders down into a relaxed position. It felt so unnatural. Meeting my husband provided a tremendous amount of support. Fortunately, he came along when my mom was

still buoyant and healthy. Without him, I never would have made it through the gut-wrenching end.

10. How did you share the role of caregiving with your siblings?

I wish our family had even roles and worked out a schedule with alternating days of caregiving. I found that once my siblings got comfortable with the fact that I was there, they knew they didn't have to be. Some families are able to really pull together in a crisis. My siblings were limited in what they could do, and fortunately, I suppose, they entrusted the job to me.

11. What is the best way to keep relatives in the loop during a parent's decline?

When my mother was healthy but needed my help, I kept a transparent checkbook accessible to anyone at anytime whenever they had an interest in the outgo and income. After my mother's decline and after Hospice entered the picture, I place a personal phone call to each sibling right away whenever it seemed as if things were taking another turn for the worse. After her demise, I emailed when I needed to convey multiple details about funeral arrangements and burial plans. I also used email to convey the series of steps for emptying the house before putting it on the market. For big plans that include dates, times, locations and checklists, it is important to put them in writing so everyone is on the same page and there is little chance for miscommunication. It is also important to use the "Reply All" button so that all of the siblings are involved as these conversations take place.

12. What are some strategies you learned about organizing financial paperwork?

This was one of the most daunting tasks because there was paperwork filed all over the house from the previous thirteen years since my father's death. Statements were opened and then bundled into rubber bands by month and shoved into shoeboxes that lined bookshelves, and drawers, and underbellies of beds. I realized early on that the paper trail would lead to the money. My first step was to find any statement that was part of the current tax year and begin an alphabetical filing system with the most recent month appearing at the front. The previous year's statements were archived into banker's boxes until I had the time to do some serious sleuthing about institutions that may have changed hands over time since there were many unfamiliar holdings. I uncovered many life-changing details from this system. For one thing, my mother's home insurance was forcefully terminated for failure to pay two years earlier. This led to a lot of change for us. The point is, do not throw away any papers until you know what they mean to your parent's financial health.

13. What made you think you could do this job instead of putting your mother in assisted care?

I had no idea what I was saying yes to. Looking back, no one says yes to Firefighting, or Nursing, or the ARMY without asking a few questions up front about what a typical day at work is like. I would have still said yes, but I would have known better what the job entailed. Organizing and planning has always been my strength, even from an early age when elementary teachers would allow me to help them after school.

I have also gained experience from tackling classrooms and donation centers that were dump-sites until I overhauled them by purging, and re-imagining a thoughtful staging space. I also knew my mother's words were ringing in my ears from a lifetime of hearing, "If you put



me in a home, that will be the surest way to get rid of me.” I wanted to fulfill her wish that she remain in her own home. I also believed that my father would have wanted to know his beloved wife of fifty-four years wasn’t going to have to go it alone.

14. Looking back, how did you manage day to day, not knowing how long the decline would last?

The scariest part was wondering if she would outlast her money. I was so grateful to have the support of an incredible Hospice team and then my mom’s health took an upswing, which meant Hospice was preparing a temporary exit. This was my greatest fear because I had no idea how to care for a bed bound mother whose entire life’s goal was to die in her own home. My focus became to make sure did not die alone. I became overanxious about following through on every idea I had to make her more comfortable. I never procrastinated because I never knew if today would be her last day. It got to the point where I was afraid to turn my back to go down the hall for fear she would be gone when I returned moments later.

15. Your mother, in essence, became your child. What kind of mother would you be?

I would have been a very nervous mother. Maybe this is how most first-time mothers are with newborns. From the beginning, my sense of urgency revolved around her falling and breaking a hip. Then my anxiety ramped up when warning signs began to appear for onset dementia; I did not know how I would be able to care for someone with Alzheimer’s. Then, trying to protect her from her horrible hallucinations that left her petrified made me cry because there was nothing I could do to help. In the end, I comforted her with reminders that she is home, she is safe, I am here. It’s all I kept repeating to try

and soothe her. I am so grateful I did it. It was my privilege. But, I don't think I will ever again have the kind of energy required to give to someone else in that same way.

16. What are you most grateful for after spending the last five years of your mother's life together?

I am so grateful I came home. We needed to mend a rift. I am so grateful I got to see all the qualities my father always said made him fall in love with her. I discovered her sense of humor and wish I was half as funny. Had I not come home, I never would have met the man who became my husband, whom she affectionately termed her "Son-in-Love". Those years of our pairing were what built our bond as the Three Musketeers. I am so grateful I got my wish that she not die alone. I am so grateful I have no regrets.

17. What would you say to a busy adult who is faced with the same prospect of moving back home?

Get ready for the single hardest job you have ever known. It will be what Hospice nurses will liken to post-traumatic stress syndrome for war-torn soldiers who see the worst of the battle from the front lines. When you are the on-site caregiver, it is a completely different experience than being the relative who pops in from afar on occasion. Be prepared to take the brunt of family members' emotions because death and money bring out the worst in family dynamics, even for families that are not fractured to begin with like mine. If you are part of the "sandwich generation" wherein you are simultaneously raising children at home while caring for an elderly parent, be prepared for marital strain, which is true for those of us who weren't also taking care of children at home. Get organized. Preparation prevents regret. This will be your greatest privilege.

18. You talk about what it feels like to be an adult orphan. What did you take away from your experience in grief counseling?

I thought I was doing fine. It had been several months and I seemed to be compartmentalizing my life just fine. I was managing my work. I was waiting to cry until after school when I could go home to pet the cat and fall asleep in my skirt until I would miss dinner once again. Grief is something we think we can bury. Mine washed over me when I least expected it out in public. I finally decided to attend a session for daughters who had lost their mothers sponsored by Hospice. I learned that people are here for the time that we need them. I learned that even the best marriages are susceptible to strife when caring for an elderly parent until the very end. I learned that my parents had already taught me everything I needed to navigate my way through this world without their voice in my ear. I learned that I can plow through any job, even when I am reduced to tears because figuring out where to begin seems nearly impossible.

19. You are not in contact with your siblings. What do you suppose they will think of the book?

I hope they see the broad strokes and shading that finally fills in the whole picture. There is a lot that goes on behind the scenes that no one can imagine unless they are in the thick of it. I hope they enjoy the memories I have painted of our mother so if they are worried that time might diminish the sound of her voice, or her Mom-isms, that they have this book as a record to keep her near to them.

20. What is your advice to those who are still grieving the loss of their parent?

It takes the time it takes to heal a broken and grieving heart. There is

no shame in taking years to feel better. Hospice nurses reminded me often that being the on-site caregiver meant that it would take a minimum of two years to begin feeling like your old self again. There is such a thing as shell shock. We are not built to look on while the person we love, who fixed everything for us when we were a child lies helpless in front of us, worried about their own mortality. It is difficult to lose both parents because the new term adult orphan is a disorienting phrase. We are so accustomed to that voice guiding us, giving advice or opinions, whether we like it or want it or not, that when it is gone, there is a void that cannot be filled. Grief is real. Take the time it takes to self-soothe. Include grief counseling. You need it more than you think.

## 21. In a nutshell, what are the 9 Realities?

You've answered the call to come home and care for your elderly parent until the very end. These 9 realities will answer your next question, "Now what?"

Reality 1- The House is a Wreck, Inside and Out. Being there is most important for the adult child to assess the safety of the home, and the wellness of the parent.

Reality 2- Fiercely Independent but Can't Cook, Drive, or Bathe. There is a lot a senior can do to put up pretenses that everything is fine. There are criteria for making sure your elder is not suffering from neglect.

Reality 3- Getting Your Physical Home and Your Financial House in Order. Purging vs. preserving memories, and how to set up a filing system for finances that are in desperate need of organizing. These are motivating pages that have readers squaring away their own homes today.

Reality 4- Managing Health—Both Medical and Financial— Is a Second Full-Time Job. Knowing what medication your parent takes, along with dosages, is critical for every doctor appointment. How to create a prescription chart for doctors and ease of renewals is covered in this chapter.

Reality 5- When Your Home and Your Parent Begin Falling Apart, Get Prepared. Warning signs that your parent is at the beginning of the end can no longer be ignored. And such is life, when everything is going downhill, the decades old home is also in decline. Know where your assets are held. Expenses are coming.

Reality 6- A Birth Allows Us Nine Months to Prepare; Death Has No Timeline; Act with Urgency in All You Do. A death march will take its toll on the caregiver. While you nervously watch your parent wrestle against an illness, this begins your gut-wrenching experience, as if everything leading up wasn't hard enough.

Reality 7- The Critical Role Bowel Movements and Bed Sores Will Play in the End. Going home....it's all she longed for. Straddling two worlds as patients get ready to cross over leaves them busily preparing before they feel ready to be un-entwined from this life. The secret of what she saw on the other side was never revealed. But I now know what death looks like in the final weeks, days, and hours.

Reality 8- A Preplanned Funeral Is a Gift to Your Family; Binders, and Lots of Them, Are an Executor Trustee's Gift. The funeral playbook and how to establish a binder system for Communications, Estate Assets, and Legal Documents will make this your indispensable guide.

Reality 9- Do Everything You Can To Self-Sooth, but Include Grief

Counseling; You Need It More Than You Think. Compartmentalizing grief seems the easier route. When the crying jag ends, we think we're over the loss. This is not true for the frontline caregiver for whom it will take years to process the experience.

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